



**VOICES FROM THE FIELD: REMOBILIZING HIV/AIDS PHILANTHROPY FOR THE 21<sup>ST</sup> CENTURY**



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## FUNDERS CONCERNED ABOUT AIDS

Organized in 1987, Funders Concerned About AIDS (FCAA) mobilizes philanthropic leadership and resources, domestically and internationally, to eradicate the HIV/AIDS pandemic and to address its social and economic consequences. FCAA assists philanthropy in being aggressive, creative and strategic in HIV/AIDS and related grantmaking areas by helping funders to:

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- Broaden their understanding and appreciation of HIV/AIDS issues;
- Focus on populations that are currently underserved by existing HIV/AIDS programs, as well as by other health, welfare, education and social services;
- View HIV/AIDS within its larger health, political and socio-economic contexts and strategically integrate HIV/AIDS funding into broader philanthropic agendas;
- Support high quality, effective and non-duplicative HIV/AIDS services; and
- Collaborate with other private grantmakers, corporate philanthropy, government officials and policy makers here and abroad, the United Nations and non-governmental organizations (NGOs).
- Ongoing work in the public policy arena on issues ranging from public/private collaboration to the relationship between public policy and philanthropic efforts to address the pandemic;
- Participation in the Centers for Disease Control and Prevention's Business Responds to AIDS/Labor Responds to AIDS (BRTA/LRTA) program, and the Global Business Council on HIV/AIDS (GBC), including corporate philanthropy-related publications, research, technical assistance, presentations, meetings and collaborative ventures; and
- Media outreach to promote informative, comprehensive and meaningful coverage of philanthropy's response to and role in fighting the HIV/AIDS pandemic.

FCAA develops extensive programming and offers an array of services and products—free of charge—to enable the philanthropic sector to understand, anticipate and respond effectively to HIV/AIDS, both domestically in the United States and globally. These offerings include:

- Our website, publications, original research, referral resources and other materials;
- Briefings, presentations, meetings and events on HIV/AIDS and HIV/AIDS grantmaking;
- Technical assistance to the philanthropic sector, including responses to requests for information and materials, one-on-one consultation and referrals to other funders and resources;

FCAA has a core constituency of over 2,100 individuals representing private foundations, corporate grantmakers, community and family foundations, United Ways, other charitable organizations, key government and public policy officials, United Nations officials and media contacts. Hundreds of additional grantmakers and others access FCAA's work annually through the programs listed above.

FCAA is a non-profit 501(c)(3) organization and is an official Affinity Group affiliated with the Council on Foundations. FCAA is not a grantmaking organization, nor do we provide direct assistance to HIV/AIDS organizations or others in identifying or seeking potential grants from private funders.

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# Voices from the Field: Remobilizing HIV/AIDS Philanthropy for the 21st Century

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This report was researched and prepared for **Funders Concerned About AIDS** by **BTW Consultants - informing change**.

BTW Consultants - informing change is a Berkeley, California-based consulting firm specializing in evaluation, planning and organizational development in the philanthropic and nonprofit sectors.

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- Irene Crowe
- Beth Darmstadter
- Kim Hamilton
- Len McNally

## **COVER ARTIST**

FCAA would like to thank Becky Trotter for the use of the artwork, "Pull Up A Chair," which appears on the cover of this publication. Thanks are also due to Chris Hogan and Visual AIDS for connecting FCAA with Ms. Trotter.

Becky Trotter is a nationally exhibited and accomplished artist, motivational speaker and writer, and a long-term survivor of AIDS. The cover artwork is from an exhibition of 17 acrylic paintings of empty chairs, each one a tribute to the life of a friend who has died from AIDS. The diverse selection of individual chairs in the exhibition captures the genuine essence, style and eclectic personality of each person represented.

Visual AIDS strives to increase public awareness of AIDS through the visual arts, creating programs of exhibitions, events and publications, and working in partnership with artists, galleries, museums and AIDS organizations. Visual AIDS is responsible for national projects such as Day Without Art, Night Without Light and The Ribbon Project. Visual AIDS raises money to provide direct services to artists living with AIDS. If you are interested in any artwork catalogued by Visual AIDS, please contact them at (212) 627-9855.

# Introduction

**AS WE ENTER** the third decade of the HIV/AIDS pandemic, it is clear that our understanding of this disease—utterly unknown twenty years ago—is in a state of transition and increasing complexity. The abundant and pervasive health, social and economic consequences of HIV/AIDS are now more clearly understood than ever before. HIV/AIDS is entangled with many of society’s most challenging problems—from poverty, racism and access to health care to sexuality, substance abuse and global relations.

In the United States and Western Europe, public and private sector investments in research, advocacy and education have yielded noticeable progress in HIV/AIDS prevention and treatment in the last five years. Continued advances can be expected as long as this support endures. Yet even with this progress, HIV/AIDS remains a serious problem in industrialized countries—particularly among racial, ethnic and sexual minority communities—and one that demands increasingly creative and sustainable solutions.

In other parts of the world, there is scant good news as the HIV/AIDS pandemic rages out of control. In Africa and perhaps soon parts of Asia, AIDS is and will continue to be one of the most devastating pandemics in human history. Governments and communities alike are responding to the multiple impacts of HIV/AIDS in areas as diverse as public health, economic development and national security. Perhaps no observation is more telling than that uttered recently by the President of Botswana, Festus Mogae. He said that if his country does not take action to combat HIV/AIDS, it means “blank extinction,” adding that,

“the implications are too horrendous to contemplate.”<sup>1</sup>

The philanthropic sector, with support from Funders Concerned About AIDS (FCAA), has worked hard to play a constructive role in helping to create and sustain an enlightened response to the HIV/AIDS pandemic. As FCAA research and publications have shown, private, corporate, community and family foundations, and other charitable entities have supported innovative and effective HIV/AIDS initiatives. In doing so, grant-makers have demonstrated a willingness to step forward as leaders and act with independence, flexibility and compassion. Organized philanthropy of all kinds has provided critical strategic vision and leadership that other sectors, for a variety of reasons, either could not or would not provide.

Our 1999 publication, *Philanthropy and AIDS: Assessing the Past, Shaping the Future*, documented that funders who had been early and strong supporters of HIV/AIDS initiatives were showing some signs of retreat from HIV/AIDS-related concerns, at least domestically. The

<sup>1</sup> Nessman, AP/Nando Times, March 14, 2001.

FCAA/Gallup survey of philanthropy, on which the 1999 report was based, also documented that far too few funders were supporting the fight against HIV/AIDS internationally. The strength of these trends was not always clear. The reasons were not well understood. Still, even a hint of a decline in philanthropic support for HIV/AIDS was troubling given the expanding scope of the HIV/AIDS pandemic occurring simultaneously to a period of unprecedented growth in overall philanthropic giving. As hoped, that report received national attention and stimulated important discussion about the state of HIV/AIDS philanthropy.

In order to further this vital dialogue, FCAA embarked on a qualitative research project in 2000 called the Funder Remobilization Project (FRP). Our goal for this work was to understand more clearly the current state of HIV/AIDS grantmaking, trends in the field and the underlying challenges and opportunities grantmakers face now and will face in the future. In achieving this greater understanding of the forces at play in HIV/AIDS philanthropy, our other goal was to assist grantmakers and other inter-

ested parties in remobilizing the philanthropic response to HIV/AIDS. This report is the fruit of that effort.

While there are significant challenges to philanthropic support for HIV/AIDS initiatives, this assessment leads us to believe that the opportunities for innovative and meaningful HIV/AIDS grantmaking by private foundations of all kinds as well as corporate funders far outweigh the challenges. It is becoming clearer that many HIV/AIDS grants are being and can be successfully mainstreamed and integrated within broader grant portfolios in programmatically sound, innovative and necessary ways.

We hope you find this publication informative, provocative and useful. As the HIV/AIDS pandemic evolves, so must philanthropy's response. Only in this way can we respond effectively to a very dynamic national and global crisis and continue to build upon our successes on behalf of individuals living with or at significant risk for HIV/AIDS.

Paul A. Di Donato, Executive Director

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# Executive Summary

**FUNDERS CONCERNED** About AIDS (FCAA) is the leading educator and advocate within the philanthropic community on HIV/AIDS. In research conducted by FCAA through the Gallup Organization in 1999, there were clear, troubling signs of weakness and disengagement in the domestic philanthropic response to HIV/AIDS.<sup>2</sup> The same research documented a developing, yet small and somewhat unorganized, philanthropic commitment to the enormous international HIV/AIDS crisis.

In response to this research and a pandemic that is evolving both domestically and internationally, FCAA embarked on additional qualitative research involving leading HIV/AIDS funders. This study, called the Funder Remobilization Project (FRP), was designed to gather information that will enable FCAA to better understand and further the philanthropic response to HIV/AIDS well into the 21st century. The research involved conducting in-depth interviews with 35 of the nation's leading HIV/AIDS funders to answer several primary research questions.

## KEY FINDINGS

### How are funders maintaining long-term support of HIV/AIDS?

**Grantmakers are re-aligning HIV/AIDS funding with their missions and strategic goals by making the connection between HIV/AIDS and other community needs.**

- The populations most affected by HIV/AIDS domestically and the issues confronting them—poverty, access to health care and substance abuse, for example—often align well with many foundations' longstanding commitments to community development and problem solving.
- Most of the funders interviewed are integrating HIV/AIDS grantmaking

into broader, longstanding grantmaking areas such as health, chronic care, youth development and public policy.

- According to the funders interviewed, this strategy of “integration” can lead to increased resource availability and the potential for more sustained support.
- Grantmakers interviewed expressed concern that this strategy of integration could result in the opposite effect as well—a net loss for HIV/AIDS and could lead to increased competition for limited philanthropic resources between HIV/AIDS and other issues.

<sup>2</sup> Funders Concerned About AIDS, *Philanthropy and AIDS: Assessing the Past, Shaping the Future*, 1999.

**Complex and evolving HIV/AIDS epidemiological trends often motivate funders to stay involved in HIV/AIDS grantmaking.**

- Leading HIV/AIDS grantmakers understand the complexity of the domestic and international pandemic and often use this understanding to justify their involvement, directly and indirectly, in the HIV/AIDS pandemic.
- The increasingly disproportionate impact of the HIV/AIDS pandemic on communities traditionally disenfranchised from mainstream health, social and economic life is enabling most

leading funders to stay involved in HIV/AIDS because it relates to their broader commitment to serve underserved communities.

**Collaborative funding mechanisms often keep grantmakers involved in HIV/AIDS.**

- Collaborative funding pools continue to provide a vehicle for ongoing philanthropic support of HIV/AIDS. In some cases, the mechanism itself takes on a life of its own, keeping funders who might have withdrawn support involved in the issue.

**What obstacles and challenges remain for HIV/AIDS-related philanthropy, domestically and internationally, particularly as the pandemic evolves?**

**Traditional roles for philanthropy have positive and negative consequences on HIV/AIDS-related grantmaking.**

- Funders tend to be “first-in” supporters of emerging issues. As HIV/AIDS enters its third decade with a robust public sector response in the United States, the ability for philanthropy to be “first-in” is limited because the issue is no longer seen as “new” or a “crisis”. However, internationally the issue is viewed as a burgeoning crisis with a limited government/public sector response. This clears the way for philanthropy to play to its strength of issuing “first-in” funding.
- Grantmakers often look to fill gaps and identify “niches” where they can have a unique impact and leverage resources. As the pandemic evolves domestically, funders interviewed acknowledged that it might be more difficult to identify

these opportunities, yet at the same time there are still a multitude of opportunities for philanthropy to be even more strategic and effective.

**The perception of HIV/AIDS domestically has changed from being a “crisis” to an “important problem”.**

- HIV/AIDS domestically is no longer seen as a crisis by most of the funders interviewed. Nevertheless, HIV/AIDS is still viewed as one of the most important problems facing communities today.
- This change in perception has enabled many funders to integrate HIV/AIDS support into broader, often more long-standing areas of grantmaking. The downside is that it may also be contributing to some decreases in HIV/AIDS funding.

## How has U.S.-based philanthropy addressed the burgeoning global pandemic? How, if at all, has the global pandemic affected domestic HIV/AIDS philanthropy?

### **The devastating international HIV/AIDS pandemic is receiving increased attention from the philanthropic community, yet few U.S.-based grantmakers fund international HIV/AIDS efforts.**

- Growth in HIV/AIDS philanthropy in recent years has occurred primarily on the international front through several major initiatives by large foundations.
- The increased attention given to the international HIV/AIDS pandemic has had an impact on the domestic response. In some cases it has overshadowed the U.S. problem and provided funders with justification for decreasing or withdrawing their support. In other cases it has kept attention on HIV/AIDS in general, enabling some to maintain or renew domestic efforts.
- The scope of the global pandemic is so great that many grantmakers are at a loss for how to apply their limited resources to the problem in a meaningful and effective way. This effect is particularly true for smaller foundations and for grantmakers that have never funded outside of the United States.

- The growth in the international HIV/AIDS pandemic is of great concern to grantmakers yet, for many, they cannot fund HIV/AIDS efforts in other countries because of perceived or actual restrictions in their funding guidelines.
- Many funders were unaware that there are many U.S.-based agencies doing work internationally that would be eligible for domestic grantmaking.

### **International HIV/AIDS funding raises questions of how to be most effective.**

- Grantmakers are concerned about the mechanics of international grantmaking and how to work with local governments, local organizations, international institutions, other national governments and other grantmakers to develop and implement effective grantmaking strategies.
- Grantmakers questioned how to balance their need for accountability in funding with the larger need for local empowerment and control of international HIV/AIDS efforts.

**CONCLUSION**

As a philanthropic leader in HIV/AIDS, how can FCAA continue to mobilize and support an ongoing, robust and strategic philanthropic response?

As this research documents, philanthropy continues to play a critical role in the domestic and international response to the HIV/AIDS pandemic. The leading HIV/AIDS funders continue to view HIV/AIDS as a very important community issue in the United States that is related to many of the other health, social and economic concerns that they are trying to address through their grantmaking. It is this approach of “integration” that is enabling many funders to maintain, institutionalize and perhaps even increase support of HIV/AIDS programs and services. Internationally, philanthropy as a field appears to be slowly increasing its role. Leading large funders are paving the way (some in dramatic ways), yet there are many opportunities for grantmakers, large and small, to make an impact in the international pandemic.

This study has provided valuable information and answers to many key questions, particularly that philanthropy can and must continue to play an essential and ongoing role in bringing an end to the HIV/AIDS pandemic. The research identifies many opportunities for philanthropy to continue to play to its strengths and at the same time have a meaningful and strategic impact on the pandemic domestically and internationally. While many challenges remain, this research and the work of FCAA have helped to make these challenges more clearly understood. Through this understanding, what were once only challenges and insurmountable problems can become opportunities for philanthropy to do one of the things it does best—strategically invest in sustainable community problem-solving.

# Purpose of This Study

**FUNDERS CONCERNED** About AIDS (FCAA) is the chief advocate within the philanthropic community on HIV/AIDS issues. In that role, FCAA has been troubled by data that suggest a diminishing philanthropic response to HIV/AIDS domestically. This phenomenon is documented in the 1999 FCAA publication, *Philanthropy and AIDS: Assessing the Past, Shaping the Future*, as well as a recent publication by the Northern California Grantmakers AIDS Task Force.<sup>3</sup> As we begin the 21st century with no cure for HIV/AIDS, increasing numbers of people living with the disease domestically and an exploding pandemic in resource-poor nations of the developing world, there are many ongoing and new challenges and opportunities facing philanthropy in the third decade of HIV/AIDS.

In the fall of 2000, FCAA embarked on a research project called the Funder Remobilization Project (FRP). The project was designed to develop a clearer understanding of the current state of philanthropy in order to motivate and activate an ongoing robust philanthropic response. The research was intended to provide the field with systematic, qualitative information about the current context for HIV/AIDS grantmaking by private, corporate, community and family foundations, in addition to critical insight into the key factors that are compelling current HIV/AIDS funders to either retreat from, or stay the course in, HIV/AIDS philanthropy.

Previous research by FCAA answered many important questions, but presented new ones as well. The FRP study was designed to address some of these questions, such as:

- How are funders maintaining long-term support of HIV/AIDS?
- What obstacles and challenges remain for HIV/AIDS-related philanthropy,

domestically and internationally, particularly as the pandemic evolves?

- How has U.S.-based philanthropy addressed the burgeoning global pandemic? How, if at all, has the global pandemic affected domestic HIV/AIDS philanthropy?
- As a philanthropic leader in HIV/AIDS, how can FCAA continue to mobilize and support an ongoing, robust and strategic philanthropic response?

The answers to these and other related questions are intended to help funders fully mobilize around HIV/AIDS in ways that are both appropriate for the roles of private foundations and corporate philanthropy and that are responsive to the growth and changes in the HIV/AIDS pandemic domestically and around the globe. It is FCAA's hope that this report will help stimulate increased participation in HIV/AIDS by philanthropy with the ultimate goal of eradicating the disease from our lives.

<sup>3</sup> Northern California AIDS Task Force, *Challenge & Change: The Legacy and Future of Foundation Funding of HIV/AIDS in California*, 2000.

# Information Gathering

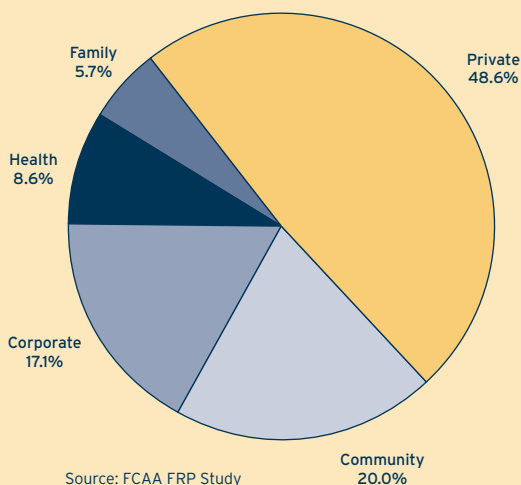
**METHODS** In the spring of 2000, FCAA engaged BTW Consultants, a consulting firm specializing in evaluation, planning and organizational development in the philanthropic and nonprofit sectors, to develop and conduct a qualitative research study that would address the research questions of the FRP. FCAA chose a qualitative study in order to obtain illustrative information that would answer the most important why and how questions related to the philanthropic response to HIV/AIDS.

The study was designed to include domestic as well as international HIV/AIDS funders. A list of approximately 65 grantmaking organizations was identified as potential respondents because they were known to be leading HIV/AIDS funders and had some connection to FCAA. BTW attempted to contact all of the potential respondents, and based on a self-selection process, BTW conducted a total of 35 in-depth, confidential telephone discussions lasting 45 to 60 minutes in length. Interview respondents included program officers in charge of HIV/AIDS grantmaking and private, corporate and community foundation executives including presidents and chief executive officers.

The interview questions included general impressions about the HIV/AIDS pandemic, philanthropy's response to the pandemic and roles for a HIV/AIDS-focused affinity group. A series of questions explored the process and motivation for HIV/AIDS grantmaking within the organization, significant factors that have affected the organization's HIV/AIDS philanthropy and lessons learned from HIV/AIDS grantmaking. Other questions probed about how broader health, social and economic trends are affecting the organization's HIV/AIDS funding.

The respondent pool includes a robust portrait of the leading HIV/AIDS grantmakers across the U.S. This sample of grantmakers includes many of the long-standing and most experienced philanthropic advocates on HIV/AIDS issues. While not statistically generalizable, the experience and opinions reported in this qualitative study provide notable insight into the current status of HIV/AIDS philanthropy. In addition, these key funders offer important lessons learned that apply across the sector. This study is meaningful because it offers rare insight into the behavior and the underlying thinking of many of the leading HIV/AIDS funders in the field.

**Types of Foundations Interviewed**



## RESPONDENTS

The organizations interviewed include a broad cross-section of U.S. grantmakers. They represent the spectrum of types of foundations.

- 48.6% private foundations (n=17)
- 20.0% community foundations (n=7)
- 17.1% corporate foundations (n=6)
- 8.6% health specific foundations (n=3)
- 5.7% family foundations (n=2)

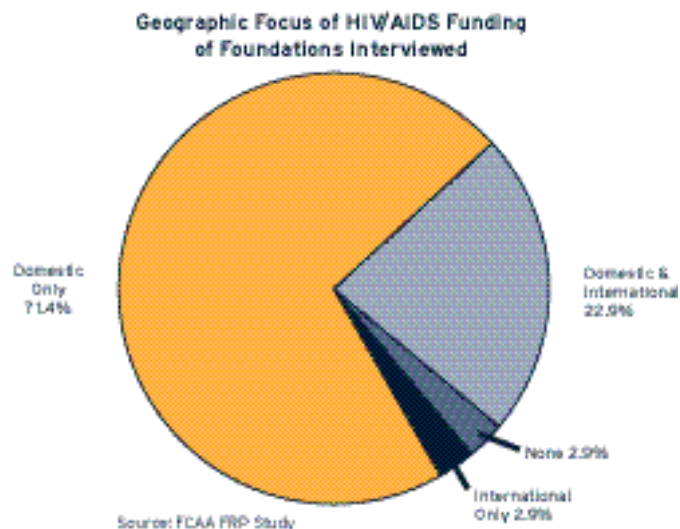
Responding foundations are geographically distributed across the United States.

- 51.4% in the East (n=18)
- 20.0% in the South and Midwest (n=7)
- 28.6% in the West (n=10)

The 35 foundations interviewed account for a total of \$2.3 billion in annual grantmaking. The size of foundations interviewed as measured by annual budget size is diverse, with the annual grantmaking per foundation ranging from \$817,000 to \$800 million and averaging \$68 million annually.

The study design includes funders of HIV/AIDS in the U.S.—domestic funders—and grantmaking organizations based in the U.S. that either provide resources to organizations in other countries or to U.S.-based organizations that work overseas—international funders. The study included 25 organizations that only fund HIV/AIDS domestically, eight organizations that fund both domestically and internationally, and one organization that only funds HIV/AIDS internationally. One organization interviewed is not currently funding HIV/AIDS.

The respondents overall represent an experienced group of private and corporate HIV/AIDS funders. Two-thirds (68%) of the organizations funding HIV/AIDS have been doing so for 11 or more years. The organizational support for HIV/AIDS reported by respondents ranges from \$10,000 to \$10 million annually. In sum, the organizations interviewed in this study alone provided \$36.4 million in HIV/AIDS funding in their last completed fiscal year.



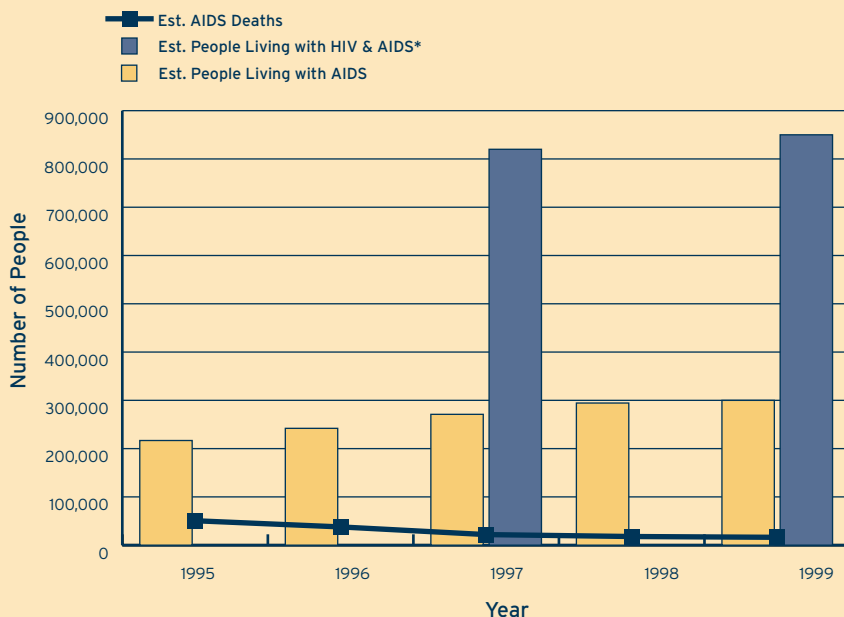
# The Context for HIV/AIDS Philanthropy in the 21st Century

**THE HIV/AIDS PANDEMIC** In order to understand the context of the findings of this study, it is useful to reflect on the current state of the HIV/AIDS pandemic. There are striking differences between the HIV/AIDS pandemic in the U.S. and what is occurring internationally, primarily in developing countries.

To understand the dynamic nature of the pandemic, it is first important to note the distinction between HIV and AIDS. HIV (human immunodeficiency virus) is the virus that causes AIDS. Once infected with HIV, individuals may live twelve or more years before they develop the symptoms of the disease called AIDS. Acquired Immune Deficiency Syndrome (AIDS) is a clinical diagnosis that is made up of one or many pre-determined symptoms or illnesses.

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**People Living with AIDS, Living with HIV/AIDS and AIDS Deaths in the United States**



Source: Centers for Disease Control and Prevention  
\*Data available only for 1997 and 1999.

## HIV/AIDS IN THE UNITED STATES

**The number of deaths from AIDS in the U.S. has declined in the past five years.**

- AIDS deaths in the U.S. decreased from over 50,000 in 1995 to just over 16,000 in 1999.<sup>4</sup>
- The decrease in AIDS deaths is attributed in large part to effective drug regimens that are dramatically increasing the lifespan of people living with HIV/AIDS.
- There are growing concerns that the number of AIDS deaths may again be on the rise in the United States. For example, in Wisconsin, the number of AIDS-related deaths rose 11% from 1999 to 2000.<sup>5</sup>

**The total number of people living with HIV and AIDS in the United States is increasing.**

- By mid-2000, over 850,000 people were estimated to be living with HIV or AIDS in the United States, the highest level ever since these numbers have been reported.<sup>6</sup>
- This increase is due to the relative stability in the number of new HIV infections, coupled with a decrease in the number of AIDS deaths due to the availability of new drug therapies initiated in the early 1990s.
- The life expectancy of Americans diagnosed with AIDS is on the rise. Half of all adults and adolescents diagnosed with HIV/AIDS in 1984 lived 11 months or longer, while by 1995, half lived 46 months or longer.<sup>7</sup>
- HIV/AIDS is not just an urban pandemic. Over 5% of all AIDS cases that have occurred to date in the U.S. have been in rural areas of the country, and this proportion is on the rise.<sup>8</sup>

**The number of new HIV infections domestically has remained constant and may be increasing.**

- Since the HIV/AIDS pandemic began, effective prevention has decreased the number of new HIV infections from more than 150,000 annually in the early 1980s to approximately 40,000 in 2000. The number of new HIV infections has stalled at the current level, with no appreciable decreases for much of the past decade.<sup>9</sup>
- There are many factors contributing to the stalled decline in HIV/AIDS cases, such as issue fatigue among those most-at-risk, increased effectiveness of treatments leading to complacency among high-risk individuals and the need for new prevention approaches targeting

communities experiencing stalled or increasing HIV infection rates.

- Recently, HIV/AIDS-associated stigma has also been identified as an important factor contributing to level or increasing HIV infection rates. Stigma leads people to deny that they are at risk for HIV infection, to avoid testing and to delay treatment. An indicator of continued HIV/AIDS stigma is that 19% of respondents to a 2000 Centers for Disease Control and Prevention study believe that “people who got AIDS through sex or drug use have gotten what they deserve.”<sup>10</sup>

**HIV/AIDS treatment is complex and challenging.**

- People living with HIV/AIDS need ongoing support to avoid unsafe sex and drug behaviors and to adhere to the complex drug regimens that are keeping them alive. A recent survey documented that HIV-positive individuals are having difficulty complying with their drug regimens and are anxious to take fewer and more effective drugs.<sup>11</sup> There are also reports of increasing failure rates of current HIV/AIDS drug treatments.<sup>12</sup>
- Treatment options for people living with HIV/AIDS appear to be declining because the HIV virus is mutating at an increasing pace. According to a study in nine cities in the U.S. and Canada, 14% of individuals infected with HIV from 1999 through 2000 have strains of the virus that are resistant to one or more of the current drugs, compared to just 3.5% of HIV-positive individuals diagnosed from 1995 through 1998.<sup>13</sup> A recent study in the United Kingdom shows a more dramatic trend, reporting that a quarter of individuals newly-diagnosed with HIV are believed to be carrying drug resistant strains of the virus.<sup>14</sup>

4 CDC, *HIV/AIDS Surveillance Report*, Vol. 12, No. 1.

5 *Kaiser Daily HIV/AIDS Report*, January 30, 2001.

6 Centers for Disease Control and Prevention.

7 Rostler, Reuters Health, March 13, 2001.

8 Rural Center for AIDS/STD Prevention website: [www.indiana.edu/~AIDS/factsheets8.html](http://www.indiana.edu/~AIDS/factsheets8.html).

9 CDC, *HIV Prevention Strategic Plan Through 2005*, January 2001.

10 CDC, *Morbidity and Mortality Weekly Report*, Vol. 49, No. 47, December 1, 2000.

11 CDC, *Prevention News*, March 16, 2001.

12 *Kaiser Daily HIV/AIDS Report*, March 15, 2001.

13 *New York Times*, February 8, 2001.

14 *PlanetOut News*, April 13, 2001.

**Men who have sex with men continue to account for the largest group of people with AIDS.**

- 53% of all AIDS cases in the U.S. through June 2000 are among men who have sex with men.<sup>15</sup>
- There are indications that HIV infection rates among men who have sex with men may be increasing in major urban settings. From 1997 to 2000, San Francisco reported an alarming 104% increase in the number of new HIV infections among men who have

sex with men.<sup>16</sup> In addition, a recent study in Southern California reported that more than half of syphilis cases in the first half of 2000 were among men who had sex with men, an increase from 26% a year earlier.<sup>17</sup>

**Communities of color, particularly African Americans, continue to be disproportionately affected by HIV and AIDS.**

- Representing only an estimated 12% of the total United States population, African Americans comprise almost 47% of all AIDS cases reported in 1999 in this country.<sup>18</sup>

• 30% of young gay and bisexual African American men are infected with HIV. This is the highest HIV infection rate among any group in that age range,<sup>19</sup> and mirrors the staggering seroprevalence rates in African countries that are hardest hit by the pandemic.

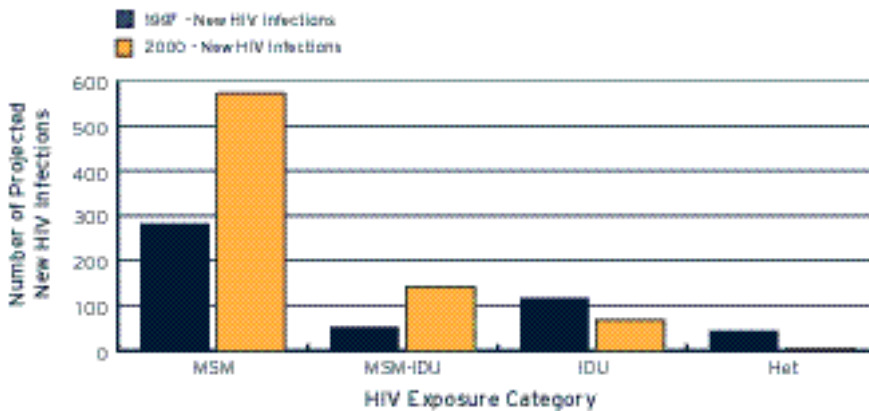
• In 1999, Hispanics represented 13% of the U.S. population, yet accounted for 19% of the total number of new AIDS cases in the United States that year.<sup>20</sup>

• Incarcerated individuals in the U.S.—disproportionately people of color—have higher rates of HIV/AIDS than the nation's non-incarcerated population. At the end of 1997, 2.1% of male prisoners and 3.5% of female prisoners were known to be HIV-positive, and the rate of confirmed AIDS cases was 5½ times higher in prisons that year than in the general population.<sup>21</sup>

**Individuals continue to engage in risky behaviors.**

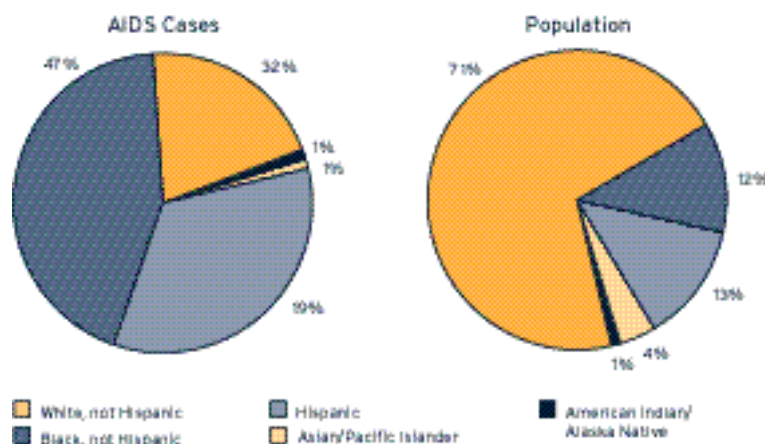
- Young gay and bisexual men are engaging in behaviors that put them at heightened risk for HIV-infection. Forty-six percent of gay and bisexual

Changes in Estimated Number of New HIV Infections in San Francisco - 1997 to 2000



Source: The San Francisco Department of Public Health and AIDS Research Institute/UCSF Response to the Updated Estimates of HIV Infection in San Francisco, 2000.

AIDS Cases Reported in 1999 and Estimated 1999 Population, by Race/Ethnicity, United States



Source: Centers for Disease Control and Prevention

men in their 20s in six major cities reported having unprotected anal intercourse in the preceding six months.<sup>22</sup>

- An estimated one in three people in the United States who are infected with HIV do not know that they are HIV-positive.<sup>23</sup>

**HIV infections are on the rise among young people, particularly young gay and bisexual men.**

- Fifty percent of new HIV infections are among young people under the age of 25.<sup>24</sup>
- 12% of gay and bisexual men between the ages of 23 and 29 are HIV-positive.<sup>25</sup>

**The proportion of women with HIV/AIDS is growing.**

- Twenty-four percent of new AIDS cases in the U.S are now among women, up from 6.7% nearly two decades ago.<sup>26</sup>
- Women of color are disproportionately infected with HIV. Less than a quarter of women in the United States are

African American or Hispanic, yet women in these populations account for 81% of AIDS cases reported among women between July 1999 and June 2000.<sup>27</sup>

**Injection drug using behavior continues to contribute to a significant proportion of HIV and AIDS cases in the United States.**

- Injection drug use-associated AIDS cases accounted for 30% of the total new AIDS cases reported in 1999.<sup>28</sup>
- Since the pandemic began, 58% of all AIDS cases among women have been attributed to injection drug use or sex with a partner who injects, compared with 31% among men.<sup>29</sup>

**INTERNATIONAL HIV/AIDS PANDEMIC**

**The international HIV/AIDS pandemic is a rapidly expanding crisis.**

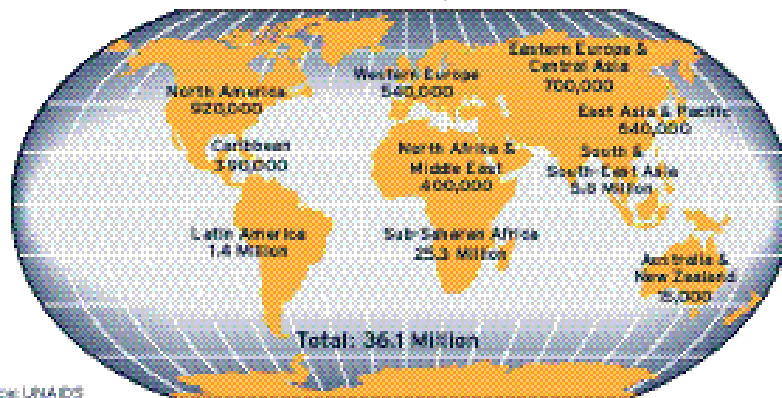
- The Joint United Nations Programme on HIV/AIDS estimates that at the end of 2000, a total of 36.1 million people across the globe were living with HIV/AIDS. This includes 34.7 million adults and 1.4 million children younger than 15 years of age.<sup>30</sup>
- There were 5.3 million new HIV infections around the world in 2000 —approximately 15,000 new infections each day.<sup>31</sup>
- Through the year 2000, 21.8 million people with AIDS have died—17.5 million adults and 4.3 million children under the age of 15. Three million people died from AIDS in the year 2000.<sup>32</sup>
- At the end of 1999, there were already an estimated 13.2 million AIDS orphans worldwide.<sup>33</sup>

IDU-Associated* AIDS Cases and Rate per 100,000, by Race/Ethnicity Reported in 1999, United States		
Race/Ethnicity	Cases	Rate
White/ Not Hispanic	3,416	2.0
Black/ Not Hispanic	7,170	22.0
Hispanic	3,124	9.0
Asian/ Pacific Islander	36	0.3
American Indian/ Alaska Native	56	3.0
<b>Total</b>	<b>13,802</b>	<b>5.0</b>

\*Includes injection drug users (IDU), MSM-IDU, heterosexual partners of IDUs, and children whose mothers are IDUs or sex partners of IDUs.  
Source: Centers for Disease Control and Prevention.

15 CDC, *HIV/AIDS Surveillance Report*, Vol. 12, No. 1.  
 16 *The San Francisco Department of Public Health and AIDS Research Institute/UCSF Response to the Updated Estimates of HIV Infection in San Francisco*, 2000.  
 17 The Associated Press, *New York Times*, February 23, 2001.  
 18 CDC, Fact Sheet—HIV/AIDS Among African Americans: [www.cdc.gov/hiv/pubs/facts/afam.htm](http://www.cdc.gov/hiv/pubs/facts/afam.htm).  
 19 *New York Times*, February 6, 2001.  
 20 CDC, Fact Sheet—HIV/AIDS Among Hispanics in the United States: [www.cdc.gov/hiv/pubs/facts/hispanic.htm](http://www.cdc.gov/hiv/pubs/facts/hispanic.htm).  
 21 *CRIA Update*, Vol 9, No. 3, Summer 2000.  
 22 *New York Times*, February 6, 2001.  
 23 American Association for World Health, *AIDS: All Men—Make a Difference! Resource Booklet*, December 1, 2000.  
 24 Ibid.  
 25 *New York Times*, February 6, 2001.  
 26 CDC, *HIV/STD/TB Prevention News Update*, April 5, 2001.  
 27 Ibid.  
 28 CDC, Fact Sheet—Drug-Associated HIV Transmission Continues in the United States: [www.cdc.gov/hiv/pubs/facts/idu.htm](http://www.cdc.gov/hiv/pubs/facts/idu.htm).  
 29 Ibid.  
 30 UNAIDS, *AIDS Epidemic Update*, December 2000.  
 31 Ibid.  
 32 Ibid.  
 33 UNAIDS, *Report on the Global HIV/AIDS Epidemic*, June 2000.

Adults and Children Estimated to be Living with HIV/AIDS as of end 2000



**HIV/AIDS is found everywhere in the world.**

**Africa**

- Sub-Saharan Africa continues to experience the greatest impact from the pandemic, with 25.3 million people infected with HIV—70% of the world’s HIV-infections.<sup>34</sup>

At least one in five adults in seven southern African countries are living with HIV/AIDS.

Country	Percent of Population Living with HIV/AIDS
Botswana	36%
Swaziland	25%
Zimbabwe	25%
Lesotho	24%
Zambia	20%
South Africa	20%
Namibia	20%

Source: UNAIDS

- During 2000, about 3.8 million people became infected with HIV in Sub-Saharan Africa, and 2.4 million people there died from AIDS.<sup>35</sup>

- Eighty percent of children with AIDS worldwide live in Africa.<sup>36</sup>

**Asia & the Pacific**

- South and South-East Asia are also deeply affected by the pandemic, being home to 5.8 million people infected

with HIV—16% of the world’s HIV-infections. An additional 640,000 people in East Asia & the Pacific are living with HIV/AIDS.<sup>37</sup>

- In South and South-East Asia, 780,000 adults, mostly men, became infected with HIV in 2000. In East Asia and the Pacific, there were 130,000 new HIV infections last year.<sup>38</sup>

- The HIV/AIDS pandemic is being driven by unsafe injection drug use, especially in some provinces of China, Malaysia, Nepal, and Vietnam. Recent reports suggest that a similar situation is emerging in Indonesia, especially in Jakarta.<sup>39</sup>

- Three countries in this region, Cambodia, Myanmar and Thailand, have HIV/AIDS infection rates above 1% among 15 to 49 year olds. These rates are rising, for the most part, through unsafe sexual behaviors.<sup>40</sup>

- In India, at the beginning of the year 2000, there were 3.7 million people living with HIV/AIDS. Forecasts estimate that this number will escalate to 35 million by 2005.<sup>41</sup> India is second only to South Africa in the number of HIV-positive individuals living in the country. Health officials in that country fear that India is “sitting on a ticking time bomb” and is “falling far behind Africa” in HIV/AIDS prevention and treatment.<sup>42</sup>

34 UNAIDS, *AIDS Epidemic Update*, December 2000.  
 35 Ibid.  
 36 Ibid.  
 37 Ibid.  
 38 Ibid.  
 39 UNAIDS, Press Kit: World AIDS Day, December 2000.  
 40 Ibid.  
 41 National Public Radio, *All Things Considered*, March 14, 2001.  
 42 *Kaiser Daily HIV/AIDS Report*, March 15, 2001.  
 43 UNAIDS, *Report on the Global HIV/AIDS Epidemic*, June 2000.  
 44 Joint UN/UNAIDS Press Release, February 20, 2001.

- Rates of HIV/AIDS within the general population of a number of Asian countries mask the fact that the rates are exceptionally high in some geographic regions. For example, in some Indian states, as many as 2% of the population are infected with HIV.<sup>43</sup>

#### Eastern Europe

- Some of the most dramatic trends in HIV infections are in Eastern Europe and the former Soviet Union. The number of HIV infections jumped from 420,000 at the end of 1999, to 700,000 by the end of the year 2000.<sup>44</sup>

#### Latin America

- In Latin America, an estimated 1.4 million people are infected with HIV. An estimated 150,000 adults and children became infected in 2000.<sup>45</sup>
- The Caribbean has the second highest rate of HIV infection in the world, after Sub-Saharan Africa.<sup>46</sup>

#### The international pandemic is devastating the infrastructure of developing nations.

- In the six countries of southern Africa, AIDS is expected to claim the lives of between 8% and 25% of today's practicing doctors by the year 2005.<sup>47</sup>
- In South Africa, the HIV-infection rate is 60% to 70% in the military, compared to 20% in the general South African adult population.<sup>48</sup>
- In the Central African Republic, nearly as many teachers died as retired between 1996 and 1998. Of those who died, 85% were HIV-positive.<sup>49</sup>

*The HIV/AIDS pandemic is "the most formidable development challenge of our time."*

*Kofi Annan  
United Nations Secretary-General*

#### The growing HIV/AIDS pandemic threatens international security.

- Leading international researchers and intelligence experts report that AIDS is "poised to lead poorer countries into a spiral of economic ruin that could result in rebellions and violent conflict, ... undermin[ing] economies and governmental revenue, ... drastically increase[ing] class polarization."<sup>50</sup>
- HIV/AIDS may reduce gross domestic products of Sub-Saharan African nations by 20% by 2020, exacerbating the conditions that have made Africa extraordinarily vulnerable to violent conflict in the past.<sup>51</sup>
- Soldiers in Rwanda and the Republic of Congo returning from combat to their rural homes may increase the spread of HIV/AIDS as they forgo the use of condoms in an effort to have children to replenish the population.<sup>52</sup>

*"The impact caused by AIDS has reverberated through every sector of the society, from health, to agriculture, education and the private sector, and is draining economies of the vital resources and contributions of a whole generation. For the private sector, the implications of AIDS are felt both at the micro and macro level. The impact on the workforce is felt in greater absenteeism, high turnover and reduced productivity. At the macro level, AIDS affects the environment in which businesses operate, including markets, investment, services and education."*

*Peter Piot, Executive Director, UNAIDS  
James Wolfensohn, President, World Bank  
The Business Response to HIV/AIDS:  
Impact and Lessons Learned, 2000*

45 Joint UN/UNAIDS Press Release, February 20, 2001.

46 Ibid.

47 UNAIDS, *Report on the Global HIV/AIDS Epidemic*, June 2000.

48 Ibid.

49 Ibid.

50 Zwillich, Reuters Health, May 9, 2001.

51 Ibid.

52 Ibid.

## GENERAL PHILANTHROPIC GIVING

A second area of critical context for current HIV/AIDS philanthropy is the landscape of general philanthropic giving in recent years. This context is important because it provides a framework to compare trends in HIV/AIDS philanthropy to developments in the field overall. This brief summary of general philanthropic giving trends includes domestic and international grantmaking by U.S. philanthropy—private, corporate, community and family foundations.

### Philanthropic giving has been on a steep increase in recent years.

- Foundation giving more than doubled from 1994 to 1999, growing from \$11.3 billion in 1994 to an estimated \$22.8 billion in 1999.<sup>53</sup>



Source: The Foundation Center, *Foundation Yearbook*, 2000.  
\*Figures estimated for 1999. All figures based on unadjusted dollars.



Source: *International Grantmaking II*, 2000.  
\*Based on a sample of grants from 75 *Foundation Goes Study* for the years indicated.

- The 17.2% growth from 1998 to 1999 followed a record 21.7% increase from 1997 to 1998.
- This period of immense growth is attributed in large part to three factors:
  1. Consistent gains in U.S. investment markets;
  2. Remarkably large new gifts into foundations; and,
  3. A significant increase in the number of foundations overall.
- According to an Associated Press survey, charitable giving by individuals, corporations and foundations in the U.S. in 1999 exceeded \$190 billion, the highest level ever reported.<sup>54</sup>
- Corporate contributions, while on the rise, represent a decreasing proportion of their organizations' annual pre-tax net income. According to the Conference Board survey of 156 United States companies, corporate contributions in 1998 as a percentage of the corporation's pretax income were at their lowest levels since 1994.

### International giving by U.S. Foundations—including both grants to organizations overseas and to U.S.-based international organizations—has been rising with the growth in overall giving, but at a slower pace.

- International giving grew from approximately \$1 billion in 1994 to \$1.6 billion in 1998, a 51% gain.<sup>55</sup>
- International giving as a proportion of overall giving fell slightly over the same time period, from 11.5% of all philanthropic giving in 1994 to 11% in 1998. While the decline is small, it punctuates the end of a period of consistent growth in the 1980s.<sup>56</sup>

- One third (33%) of international grant dollars awarded in 1999 were directed towards overseas recipients; two-thirds (67%) were awarded to U.S.-based recipients.<sup>57</sup>
- HIV/AIDS is among the program areas experiencing new growth in international grantmaking in recent years. Additional growth areas include other diseases, children's health, disaster relief and humanitarian aid, climate change and pollution control, forest protection, impact of globalization and the humanities.<sup>58</sup>
- More than two out of three grantmakers surveyed by the Foundation Center indicated that, among other things, "U.S. donors appear more interested in funding internationally," and "More grantmakers are interested in funding directly overseas."<sup>59</sup>

One final important contextual piece of information is HIV/AIDS-specific philanthropy. FCAA's 1999 publication<sup>60</sup> and other data sources indicated a downward trend in overall HIV/AIDS-specific philanthropy at a time of increases in general philanthropic giving. As of 2000 - 2001, this trend appears to have slowed, stopped and, in some cases, reversed.

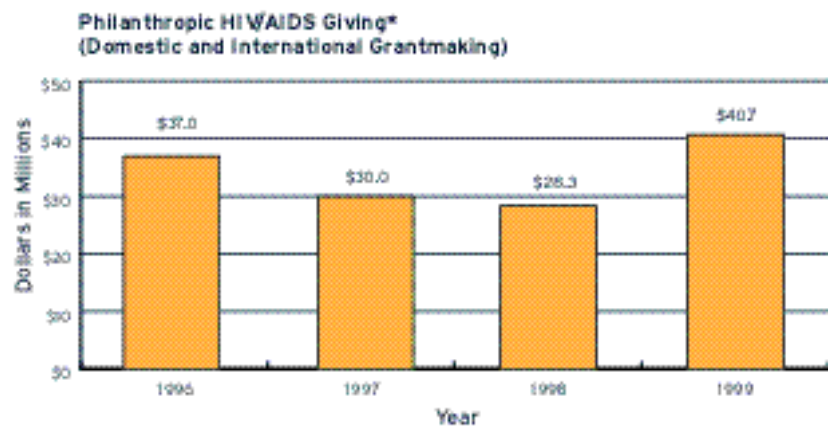
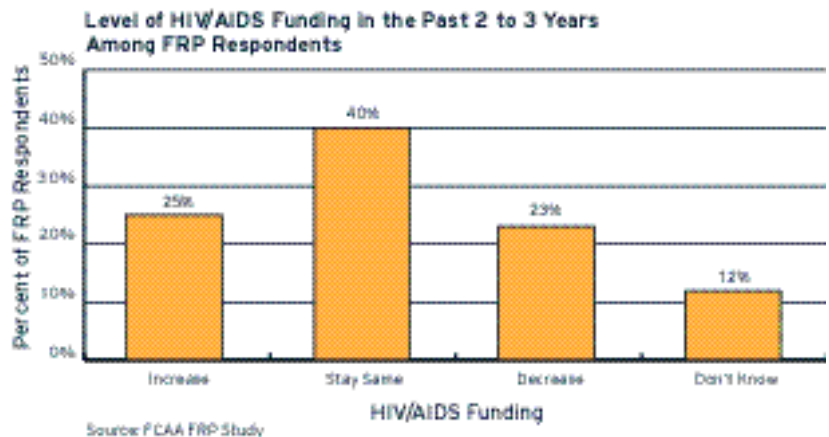
**Several data sources indicate that HIV/AIDS-specific philanthropy appears to be stable and even increasing in the international arena.**

The FRP interviews with 35 leading HIV/AIDS funders suggest relatively level HIV/AIDS funding in recent years. Forty percent of the domestic funders included in the study reported that their HIV/AIDS funding stayed the same in the last two to three years, while almost equal numbers reported either an increase (25%) or a decrease (23%) in HIV/AIDS

funding during the same time period. As described later in this report, funders are maintaining support for HIV/AIDS through grantmaking in categories that are often not HIV/AIDS-specific. Thus, capturing all HIV/AIDS grantmaking is increasingly difficult because it is often hidden within other categories.

According to Foundation Center statistics from a sample of grants of \$10,000 or larger awarded by leading U.S. independent, corporate, community and operating foundations, HIV/AIDS-specific giving both domestically and internationally clearly declined from 1996 through 1998, from \$37 million to \$28.3 million. However, in 1999—the most recent year for which figures are available—HIV/AIDS grantmaking grew to \$40.7 million. This increase is likely due to major international initiatives.

53 The Foundation Center, *Foundation Yearbook*, 2000.  
 54 *Philanthropy News Network Online*, December 11, 2000.  
 55 Based on a sample of grants from *The Foundation Grants Index* for the years indicated. *The Foundation Center, International Grantmaking II: An Update on U.S. Foundation Trends*, 2000.  
 56 *Ibid.*  
 57 The Foundation Center, *Foundation Giving Trends: Update on Funding Priorities*, 2001.  
 58 The Foundation Center, *International Grantmaking II: An Update on U.S. Foundation Trends*, 2000.  
 59 *Ibid.*  
 60 Funders Concerned About AIDS, *Philanthropy and AIDS: Assessing the Past, Shaping the Future*, 1999.



Specifically, the Foundation Center reports that this includes a \$5.5 million international grant from the Bill and Melinda Gates Foundation. Domestic philanthropic support for HIV/AIDS, therefore, probably experienced only a modest increase, if any at all, from 1998 to 1999.

Philanthropic giving to HIV/AIDS on the international front appears to be at its highest level ever. In 2000 and 2001, several large U.S.-based funders have made major commitments in the international arena. In particular, in January 2001, the Bill and Melinda Gates Foundation awarded a multi-year \$100 million challenge grant to the International AIDS Vaccine Initiative (IAVI), a global non-profit organization working to speed the development and distribution of an AIDS vaccine. This followed previous Gates Foundation grants of \$1.5 million and \$25 million, among others, for other international HIV/AIDS projects.

Taken together, these data suggest that although HIV/AIDS funding appeared to be stagnating, and in some cases even declining, by the mid- to late-1990s, it is now showing signs of renewed growth, particularly in the international arena. If many other funders are following the example of the FRP respondents by making HIV/AIDS grants in non-HIV/AIDS-specific categories, then HIV/AIDS grantmaking may be more stable than previously thought. Furthermore, philanthropy is increasing its attention on the international HIV/AIDS pandemic. While this news is optimistic, these trends need to continue in order to successfully combat HIV/AIDS.

#### **NEW UNITED NATIONS INITIATIVES ON GLOBAL AIDS MAY RESULT IN ENHANCEMENT OF INTERNATIONAL HIV/AIDS PHILANTHROPY.**

In 2001, the United Nations is launching an unprecedented effort to focus international attention and resources to fighting HIV/AIDS globally. A highlight of this effort is the United Nations General Assembly Special Session (UNGASS) on HIV/AIDS. As part of this initiative, Secretary-General Kofi Annan has also called for the strengthening of existing and creation of new multi-sector initiatives and collaborations. Although such efforts can and should have many goals, one important end result of such public/private partnerships includes efforts for private foundations, corporations, governments and United Nations agencies to work together to enhance the overall resources dedicated to AIDS globally. The initial target is \$7 to \$10 billion for HIV/AIDS in low and middle-resourced countries, an estimated four to five fold increase in the amount of all resources going to such countries now from all sources to fight HIV/AIDS.

In particular, the Secretary-General has called for the creation of a global AIDS fund to combat HIV/AIDS and other diseases. Endorsed by the World Bank, the International Monetary Fund and the Group of Seven largest industrialized countries, the fund is being created to finance HIV/AIDS, tuberculosis and malaria prevention and treatment efforts around the globe. The vast majority of the fund is anticipated to be provided by governments of industrialized countries. Annan, however, has also called on foundations and corporations to provide funding for the global AIDS fund.

While some private funders may choose to contribute to a special fund directly, others would be more inclined to support international HIV/AIDS initiatives through direct grants to NGOs already working on HIV/AIDS in their respective countries. In either case, the mechanism is less important than the overall push for a real war on HIV/AIDS globally with the funds from all sources, including philanthropy, to make it successful.

*“So let’s be in no doubt. The world has the resources to defeat this epidemic, if it really wants to.”*

*Kofi Annan*

*United Nations Secretary-General  
Address to the Annual Conference of the  
Council on Foundations, April 30, 2001*

## CONTEXT SUMMARY

While the HIV/AIDS pandemic has slowed domestically, it continues to take an unacceptable toll, particularly on communities of color, gay men, women, injection drug users and young people. Early signs of weakening, particularly in HIV/AIDS prevention, threaten the gains of recent years. Internationally, the pandemic is burgeoning and devastating an increasing number of developing countries at almost every level of society. At the same time, philanthropy has grown exponentially. It appears that the downward trend in HIV/AIDS specific philanthropy may be slowing, stopping and in the case of the international pandemic, reversing.

# FRP Research Findings: Challenges & Opportunities Moving Forward in HIV/AIDS Philanthropy

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**THIS SECTION OF THE REPORT** contains the findings from the FRP research that respond to the key questions posed by the study. Findings are described along with illustrative quotes from the interviews and secondary data. Each finding includes a discussion of the opportunities and challenges for the field of philanthropy as it moves forward into the 21st century.

As described earlier, the FRP research and other secondary data indicate that many funders are maintaining their commitment to HIV/AIDS. The FRP study is designed to look more closely at how grantmaking organizations are doing this.

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## Q HOW ARE FUNDERS MAINTAINING LONG-TERM SUPPORT OF HIV/AIDS?

**Grantmakers are re-aligning HIV/AIDS funding with their missions and strategic goals by making the connection between HIV/AIDS and other community needs.**

Many leading HIV/AIDS funders are maintaining their support of HIV/AIDS programs and services through grantmaking categories that align with the organization's long-term programmatic goals and mission. Most of the funders interviewed in this study are continuing to

make HIV/AIDS-related grants. The difference between their current and past HIV/AIDS grantmaking, however, is that they are moving away from funding HIV/AIDS as an exceptional category that is separate from the organization's other longstanding, more general areas of grantmaking. For the purpose of this study, we call this strategy "integration."

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*"We don't see ourselves as an HIV funder, but we do fund types of institutions that include HIV services."*

*Private Foundation*

*“We stopped looking at diseases from a categorical approach and began looking at more systems approaches. The real issue is how to deal with those generic kinds of problems, like lack of community-based home health care, regardless of the particular disease.”*

*Private Foundation*

Integration is funding HIV/AIDS programs through existing programmatic priorities that have continually addressed longstanding community issues, such as health, minority populations or youth development. It also includes funding HIV/AIDS by addressing the systemic issues that are risk factors for HIV/AIDS or that present significant obstacles to successful HIV/AIDS prevention and treatment. For example, one private foundation reported that it has moved away from funding disease-specific health issues to more crosscutting efforts, such as access to health care. As a result, while some foundations are funding HIV-specific programs and organizations, others are supporting programs that have an indirect, yet still important impact on the HIV/AIDS pandemic. A family foundation included in this study funds programs targeting gay and lesbian youth who are at high risk for suicide. The foundation acknowledges the indirect impact this grant and program has on HIV/AIDS because of the connection between high-risk gay and lesbian youth, suicide and HIV/AIDS. Another representative from a private foundation explained that his organization funds HIV/AIDS by ensuring that the unique needs of people living with HIV/AIDS are considered when it funds efforts to address broad, systemic health-related issues.

*“Racism, discrimination—this is the angle that we are coming in at [HIV/AIDS]. The poverty issue gives us a window.”*

*Private Foundation*

A key finding of this study is that **HIV/AIDS funding is occurring under the umbrella of a variety of other program areas.** What makes this finding important is that it responds directly to an unanswered question from prior research—is HIV/AIDS funding occurring and not being captured because it is no longer labeled HIV/AIDS? The FRP interviews clearly document that HIV/AIDS funding is being maintained and in some cases increased, and it is not labeled specifically as HIV/AIDS grantmaking.

*“We tend to include HIV in the population groups that we look at in terms of bigger systems investigations. So in access to care, we will always ask, ‘What about the drug user with HIV?’ for example, and, ‘How are they affected by access to care issues?’. Broader health concerns impact us in that we have moved as a foundation to be more focused on those types of systems of care.”*

*Private Foundation*

Until recently, many of the grantmaking organizations interviewed had a specific HIV/AIDS funding category. Yet the interviews reveal that nearly all FRP respondents now fund HIV/AIDS programs and services in the absence of a specific HIV/AIDS funding category. Instead, they make grants under broader programmatic priority areas such as serving underserved communities or health. In a few instances, funders interviewed still maintain a specific HIV/AIDS category, yet it falls under the auspices of another broader category and therefore is not “publicly” acknowledged specifically as HIV/AIDS. The one exception appears to be with community foundations that have established HIV/AIDS funds or manage donor-designated HIV/AIDS funds.

What this finding reveals and the interviews confirm is that the leading HIV/AIDS grantmakers are making the connection between HIV/AIDS and other systemic community issues such as poverty, substance abuse, racism, homophobia and access to quality medical care. Respondents indicated that HIV/AIDS is one of the few diseases where these relationships are understood. Based on the interviews, this connection is clearly influencing philanthropy's grantmaking behavior and leading to this phenomenon of integration. For example, one respondent from a foundation that has always prioritized issues affecting low-income, minority communities declared that his organization cannot ignore HIV/AIDS if it is going to continue to try and address the needs of these communities.

#### CHALLENGE

Respondents acknowledged several challenges associated with this shift from funding HIV/AIDS as an exception to funding HIV/AIDS as part of an organization's broader interests. First and foremost, when there is no apparent, logical connection between HIV/AIDS and a foundation's mission and priorities, continued support for HIV/AIDS is jeopardized.

*"AIDS has become more integrated into our general grantmaking. But in the past couple of years, that has happened with mixed results."*

*Private Foundation*

Grantmakers interviewed identified several challenges they face as they link HIV/AIDS to broader systemic issues and integrate it into ongoing grantmaking. One concern is that it increases the potential of HIV/AIDS grantmaking to "get lost," resulting in an overall decrease in funding dedicated to the issue. In addition, when HIV/AIDS no longer stands alone, it can lead to a decrease in issue-specific support. One private funder

spoke eloquently about the fact that HIV/AIDS "evokes a great deal of passion," while more general issues such as chronic care are "faceless" and "don't get people out on the streets." Many of the interview respondents addressed how HIV/AIDS has had a personal impact on their lives, families and communities. This "personal" connection has helped philanthropy maintain interest and grantmaking activity. Other issues may not carry with them the same amount of personal connection, without which, respondents acknowledged, it might be harder to generate, maintain or build institutional support.

*"It surely would make sense for [HIV/AIDS] issues to be integrated into a broader agenda. However, what really happens is that there is lip service paid to issues and there is no guarantee that issues will be equitably funded compared with other issues."*

*Private Foundation*

Smaller grantmaking organizations interviewed find it challenging to tackle broad systemic issues because they often do not have the human or financial resources. One respondent from a small, private foundation reported that her organization believes that poverty is one of the root issues related to the spread of the HIV/AIDS pandemic domestically, yet her organization simply does not have the resources to make a meaningful contribution to this issue.

Another issue of concern identified by foundation staff interviewed for this study is that integrating HIV/AIDS with other issues can sometimes require increased justification and documentation in order to make the case that HIV/AIDS is connected to other programmatic and organizational priorities.

This shift presents itself somewhat differently for corporate foundations. In this

#### Examples of Funding Categories in Which HIV/AIDS Philanthropy Occurs

##### Domestic

- Health
- Youth development
- Employment
- Neighborhood revitalization
- Public policy
- Strengthening communities
- Media & public education
- Gay/Lesbian issues
- Harm reduction/needle exchange
- Civil rights

##### International

- Health
- Reproductive health
- Community-based health care
- Harm reduction/needle exchange

sector, strategic grantmaking involves considering the interests of the company, its market, its shareholders and its employees, as well as the needs in the community. As HIV/AIDS is perceived to be less of a crisis and in the face of many other community needs, corporate strategy and employee interest may lead an organization away from supporting HIV/AIDS to addressing other important or crisis issues.

*“You will not see a lot of corporations joining and funding AIDS, other than sponsoring walk-a-thons and special events. It is because the perception is that the epidemic is over, and number two, that more and more corporations are linking their philanthropy to their business. So other than organizations that are directly related to the epidemic, such as pharmaceutical companies, you will not see much. It was hard enough to support HIV/AIDS when this was a very critical issue. Now that that perception has changed, it is even harder.”*

*Corporate Foundation*

## OPPORTUNITY

Integrating HIV/AIDS grantmaking into funding areas that are traditional, long-term areas of grantmaking provides a mechanism for sustained and potentially increased support to fight the pandemic and to do so in increasingly effective ways. When grantmaking organizations are able to make the connection between HIV/AIDS and their mission, priorities or strategic goals, the potential resources available to fund HIV/AIDS may also increase. More and more, HIV/AIDS is understood to be related to many other pressing health, social and economic concerns. According to interview respondents, when foundations periodically reflect on community need, HIV/AIDS surfaces as a problem that needs to be addressed along with these other issues. For example, a respondent from a private

foundation reported that addressing HIV/AIDS in the context of overall health concerns might be a way to work on the issue in a way that is “safer” for individuals and organizations that have traditionally shied away from addressing HIV/AIDS directly because it is sometimes considered too controversial.

*“Health and education are major areas of philanthropic giving, and if they can integrate HIV that would be great. It enormously increases the potential pool of money.”*

*Private Foundation*

Another result of integration can be more focused and relevant HIV/AIDS grantmaking. For example, one foundation that prioritizes employment-related issues moved away from funding HIV/AIDS prevention services broadly. Instead the foundation is focusing its grantmaking on programs that assist people living with HIV/AIDS to return to the workforce. This issue is particularly relevant now that drug therapies are increasing the lifespan and quality of life of many people living with HIV/AIDS in the United States.

*“For many grantmakers, if funding HIV/AIDS was not consistent with their mission and priorities, funding HIV/AIDS was an exception because of the crisis. It needed to be done. As time goes on, you begin to say, ‘If I keep with this, how is this part of our grantmaking based on our mission and priorities?’ This is what happened [here]. We moved past the crisis stage, from funding HIV/AIDS as an exception, to funding the type of programming that can be integrated into our grantmaking priorities ... Making that fit more comfortable enabled us to reaffirm our commitment.”*

*Private Foundation*

### Complex HIV/AIDS epidemiological trends are motivating funders to stay involved in HIV/AIDS grantmaking.

FRP respondents were asked to indicate the factors that positively and negatively influence their HIV/AIDS grantmaking behavior. The top two factors cited that positively influence grantmaking behavior are “infection rates in minority populations” and “the changing socio-demographics of the HIV/AIDS pandemic.” In many cases, respondents indicated that the changing epidemiology of HIV/AIDS is what is enabling them to stay involved, because it relates to their broader commitment to serve underserved communities.

*“We place a priority on populations. We base our funding on where we see the epidemic—the populations that are most affected and where we see the least resources.”*

*Private Foundation*

*The changing socio-demographics of the HIV/AIDS epidemic “has strengthened our focus, particularly in African American and Latino populations, and women, who are affected at increasing proportions.”*

*Community Foundation*

It is clear from the FRP interviews that respondents truly understand the complexity of current issues in HIV/AIDS, both domestically and internationally. On the domestic front, they understand the changing face of HIV/AIDS, with the pandemic increasingly affecting historically marginalized and disenfranchised populations. The number of people living longer with HIV/AIDS raises a host of issues for grantmakers in terms of the effectiveness of HIV/AIDS prevention, access to health care and other social supports, as well as dealing with HIV/AIDS as a chronic illness. For example, the board of directors of one private founda-

tion included in this study is questioning the efficacy of certain HIV/AIDS prevention efforts, such as condom distribution, in light of increases in HIV infection rates among high-risk populations.

Another issue of concern to grantmakers interviewed is the growing perception of diminished public and philanthropic attention to HIV/AIDS. It is this understanding of the domestic pandemic that often enables grantmakers to act more strategically and to support continued involvement in the issue.

*“The issue of prevention [is going] down in the public concern instead of up ... You see fewer people dying. The threat is less and people will take fewer preventive measures in regards to the virus. Partially because of that, and because the federal government has put a lot of money in AIDS research, treatment and prevention, and because it is not as new, the foundation world tends to not pay as much attention.”*

*Health Conversion Foundation*

On the international front, the grantmakers interviewed in this study are deeply concerned about the overwhelming scope of the problem. They expressed doubt that effective solutions to the international pandemic will be the same as domestic strategies and solutions. At the same time, funders are concerned about how to apply the lessons learned in the United States and other industrialized countries that have made progress in reducing the impact of HIV/AIDS to international situations. Lack of progress in global HIV/AIDS prevention and the dire need for a vaccine are also critical issues to grantmakers.

*What I am most concerned about is “the public perception that recent advances have taken care of the problem ... This filters down to grantmakers. As [HIV/AIDS] starts to get into disenfranchised populations, less people will care because they are already the people that general society doesn’t care about.”*

*Private Foundation*

## CHALLENGE

There are no simple solutions to the growing diversity of issues associated with the domestic and international HIV/AIDS pandemics. Grantmakers are keenly aware that their funding needs to be focused and strategic to have the greatest impact in a multi-faceted environment.

There are several implications associated with this situation. It demands increased effort by foundation staff to identify strategic grantmaking opportunities that address the complexity of the HIV/AIDS pandemic. In addition, funders interviewed are concerned that many HIV/AIDS service organizations are not responding to the growing complexity of the HIV/AIDS pandemic. Grantmakers increasingly expect organizations to design and implement programs that link HIV/AIDS to other health, social and economic concerns. Some grantmakers interviewed believe that while philanthropy has been able to shift conceptually from a disease specific focus to a broader, more comprehensive approach, some HIV/AIDS service organizations have not. As a result, a few of the funders interviewed reported that their organizations have resources available for supporting HIV/AIDS efforts that are aligned with other, broader community concerns. However, these funds are often left unspent because the grant requests they receive do not successfully align and integrate HIV/AIDS into broader funding priorities. In addition, grantmakers interviewed indicated that they have difficulty justifying sustained HIV/AIDS funding when service organizations are not addressing the changing needs of the pandemic.

*“One area I am concerned about would be the ability or desire of AIDS organizations to morph themselves to address the changing needs of the HIV/AIDS epidemic ... more dealing with chronic illness that ebbs and flows, such as back to work issues.”*

*Community Foundation*

Some funders spoke candidly about the challenges they experience working with community-based organizations in communities that have been most recently affected by the HIV/AIDS pandemic. More specifically, respondents indicated that some of these organizations do not have the necessary infrastructure to support the important programmatic work they are undertaking. This raises concerns about the ability of these organizations to effectively manage resources and respond to funders' reporting requirements. A few funders indicated that their concerns about organizational effectiveness and stability have sometimes negatively influenced their decision to fund certain organizations. In contrast, organizations that have been working in the pandemic for many years are sometimes viewed as more technically sophisticated and financially stable, yet they may not have the connection to the populations most affected at this time.

## OPPORTUNITY

Many of the communities that are currently most affected by HIV/AIDS are the very same communities that are already prioritized by grantmakers - underserved communities, women, young people and communities of color. The growth of the pandemic within these populations presents an opportunity for grantmakers who have already prioritized these communities to get involved in, or to stay engaged in, HIV/AIDS philan-

thropy. For example, a responding private foundation that has a longstanding interest in low-income and minority communities has been able to sustain support in HIV/AIDS due to the shift of the pandemic to these very same communities.

*“The changing socio-demographics of the HIV/AIDS epidemic has had a positive effect on our grantmaking because all of the work we do is focused on underserved and marginalized populations, and these are the populations impacted most significantly by the epidemic.”*

*Private Foundation*

The growth of HIV/AIDS domestically in under-resourced communities also provides an opportunity for philanthropy to play a role in empowering communities that are traditionally disenfranchised. As a result, grantmaking not only helps implement grassroots solutions to HIV/AIDS, but also helps to establish or build a solid and stable framework in these communities for addressing other pressing health, social and economic concerns, many of which are now inextricably intertwined with HIV/AIDS. One respondent from a private foundation spoke enthusiastically about her experience utilizing this “empowerment” strategy and encouraged other funders to try a similar approach.

*“We fund people who are affected by a problem to address that problem and find solutions to it. Call it empowerment. Call it advocacy. Call it a community responding to their own need ... This is some of the most exciting funding that I am doing. Some of the foundations that are not doing this are missing a great opportunity to see how funding can impact and empower people and see the impact in a public way.”*

*Private Foundation*

Based on the FRP research, it is clear that there are leading grantmakers who clearly understand this multi-faceted disease.

This leadership in the philanthropic community needs to be maintained, nurtured and developed. Several grantmakers indicated during their interviews that the behavior of key funders does influence the behavior of other grantmaking organizations. As the pandemic ages and deepens, funders will look to their peers for guidance in how to respond effectively. It will be important for there to be grantmaking organizations that maintain their role as leaders and role models in order to articulate for their peers the unique role of philanthropy in the fight against HIV/AIDS.

### **Collaborative funding mechanisms often keep grantmakers involved in HIV/AIDS.**

For some funders, collaborative funding mechanisms have proven to be effective grantmaking tools. They can relieve some of the burden of the direct grantmaking process and help to maintain continued funding. Grantmakers report that collaborative mechanisms, if successful, tend to take on a life of their own separate and distinct from the issue itself. Given the increasing focus within philanthropy on collaboration, this approach still is relevant to HIV/AIDS grantmaking. In these cases, the collaborative mechanism itself can be as compelling a reason for continued support as the issue itself.

*“We haven’t had great proposals. That is one reason to do the pool, recognizing early on that a lot of organizations won’t be sophisticated. The AIDS proposals can’t meet the ‘gold standard’ of other [funding] organizations and proposals that come to our board. The pool allows us to get around this because there is a separate advisory committee that reviews the pooled mechanism proposals.”*

*Community Foundation*

## CHALLENGE

Collaborative funding is complicated and can be difficult to maintain. The success of these mechanisms depends largely on the ability of the lead convener to accommodate the interests and cultures of the grant-making institutions of which they are composed. A staff member from a community foundation interviewed for this study commented that although her organization has participated in a local HIV/AIDS pool for several years, the collaborative fund is disbanding because the grantmakers are no longer interested in working together and would rather fund HIV/AIDS individually. Collaborative funding pools can also lead to diminished resource availability if grantmakers only participate in the pooled mechanism and, as a result, decline to give HIV/AIDS-related grants directly. In addition, if the pooled mechanism fails, some grantmakers may choose not to make HIV/AIDS related grants on their own.

## OPPORTUNITY

Collaborative funding pools provide a creative vehicle for ongoing philanthropic support of HIV/AIDS in many different ways. For some funders, it enables them to continue supporting HIV/AIDS after it no longer aligns with their organizational priorities. For example, one private foundation interviewed continues to contribute to a collaborative HIV/AIDS funding pool even though the organization's recent strategic planning process resulted in prioritizing issues that have a weak link to HIV/AIDS. The foundation justifies its enduring support because of the organization's longstanding commitment to the issue and, more importantly, because it did not want to withdraw from the public forum of the funding pool.

*"I've gained an understanding of the effectiveness of pooling resources. You can support really important things that you could not do as an individual [funder]... Participating in the collaborative makes the funding more anonymous and effective and easier for funding controversial issues."*

*Corporate Foundation*

For others, collaborative funding provides a safe shelter to contribute to HIV/AIDS, particularly to support potentially controversial programs. Several organizations interviewed indicated that without the pool, they never would have been able to support needle exchange and harm reduction programs. In these cases, the pooled structure provides a sense of anonymity for funders, as well as the perception of sector-level support for these efforts.

In some communities, collaborative funding is seen as an opportunity to try something new. A prime example is the AIDS Partnership in California. This statewide initiative, founded in July 2000 and jointly supported by the Northern California Grantmakers AIDS Task Force, the California State Office of AIDS and a number of private and corporate funders throughout the state, pilots an innovative public/private funding partnership. AIDS Partnership California is awarding a series of grants to community-based ethnic minority organizations to support HIV prevention services for HIV-positive persons of color. In addition, the collaboration emphasizes organizational capacity building by awarding capacity building grants and sponsoring workshops on strategies for seeking private HIV/AIDS funding.<sup>62</sup>

<sup>62</sup> For further information contact Northern California Grantmakers, 116 New Montgomery Street, Suite 742, San Francisco, CA 94105. Phone: (415) 777-5761. Email: ncg@ncg.org

## What obstacles and challenges remain for HIV/AIDS-related philanthropy, domestically and internationally, particularly as the pandemic evolves?

### Traditional roles for philanthropy have positive and negative consequences on HIV/AIDS-related grantmaking.

Grantmakers who participated in this study universally identified traditional roles for philanthropy. These include being “first-in” funders of emerging issues, providing funding to fill gaps, taking risks by supporting new or unproven approaches, and funding issues only for a limited period of time. Philanthropy often steps in when the public sector has not, as was true of philanthropy and HIV/AIDS early in the pandemic. These roles seem to be generally accepted and understood by respondents even though there is no “rule book” guiding philanthropy in the United States. As the HIV/AIDS pandemic ages, particularly domestically, these traditional roles can be at odds with continued or increased support of HIV/AIDS. They can also provide grantmaking opportunities.

*“Sometimes philanthropy deals with the latest flavor.”*

*Corporate Foundation*

*“It doesn’t have to do with the fact that it is AIDS. It is more a question of, ‘Is it new?’ ‘Is it different?’ ‘Can we make a difference?’ It doesn’t matter what the issue is.”*

*Community Foundation*

### CHALLENGE

As the domestic HIV/AIDS pandemic enters its third decade, the grantmakers interviewed in this study indicated that it is no longer the “hot” new issue that it

once was. Some respondents discussed their sense that HIV/AIDS domestically has already gotten its philanthropic “fair share” and that it is time to move on to other emerging issues and concerns. These reflections were often framed within the context of certain traditional roles for philanthropy. In this case being “first-in” funders and funding issues for a limited period of time. This sentiment appears to be having significant affects on the current philanthropic response to HIV/AIDS. For example, one corporate funder interviewed for this study has supported HIV/AIDS for fifteen years. This funder easily justifies withdrawing support for HIV/AIDS at this time because it has been involved for far longer than is typical for philanthropic institutions. If HIV/AIDS is seen as a “been there, done that” kind of issue, support from the philanthropic community is likely to decline. To the extent that having a short attention span is true for philanthropy in general, not just HIV/AIDS, a decline in funder interest in HIV/AIDS is not unexpected considering the duration of the problem. As a matter of fact, some respondents indicated that they are surprised at how long HIV/AIDS has been able to hold philanthropy’s attention.

*“This is typical of the philanthropic world. What happens is when an issue presents itself and there are an increasing number of people affected, this is when philanthropy pays attention. In general the attention span of philanthropy is not very long.”*

*Healthcare Conversion Foundation*

*“There is the typical fickleness of philanthropy of not staying with things for very long, exacerbated by this not being a singular crisis any more. There is the perception that it is more manageable, with government involvement, more players, so that the typical role of philanthropy, coming in to address an unaddressed need and fill a gap is harder. Foundations do get fickle.”*

*Family Foundation*

Another challenge to sustained HIV/AIDS grantmaking related to the traditional roles of philanthropy is that there are now significant public sector resources available to support HIV/AIDS programs and services. In the United States there is a systematic approach to HIV/AIDS in nearly every community. Early in the pandemic, the role for philanthropy was clear, stepping in before the government response. Now, with a large-scale, systematic public sector response,<sup>63</sup> the role for philanthropy is less clear. While there are still many unmet needs related to HIV/AIDS and unique, effective roles for philanthropy to play, these opportunities are not as apparent as they once were.

*“There is more government money now, so we felt that the decision to pull out was more justifiable.”*

*Corporate Foundation*

## OPPORTUNITY

To the extent that the HIV/AIDS sector, including nonprofits and other community-based organizations, can play to the strengths and traditional roles of philanthropy, there remain an abundance of opportunities for philanthropic support. FRP respondents reported that they continue to fund HIV/AIDS in targeted ways—playing to the notion that grantmakers are niche funders. For example, one private foundation in this study now focuses its

HIV/AIDS grantmaking in non-urban areas because rural HIV/AIDS service providers in this foundation’s geographic funding area recently lost their public sector support. The foundation staff member interviewed understands and agrees with the government’s decision to withdraw funding in these areas, and at the same time indicated that the government’s action affirmed the foundation’s decision to fund rural HIV/AIDS programs and services. The staggering spread of HIV/AIDS internationally also presents many opportunities for philanthropy to offer first-in funding that is creative, risk-taking and in many cases precedes any large-scale public sector intervention.

*“The way we have always looked at our philanthropy is to look at areas where others are not funding, based on demographic need and where we can have the most impact ... We develop and explore a niche where we can make a difference.”*

*Corporate Foundation*

The grantmakers interviewed in the FRP study are also keenly aware that philanthropy can not and should not provide sole support to combating HIV/AIDS. Nevertheless, they see philanthropy as a critical player in this effort. Given the relatively limited resources of the philanthropic sector in comparison to the public sector, grantmakers want to ensure that their resources are strategically allocated to leverage resources from all sectors, particularly the public sector. Several funders interviewed spoke of wanting to focus their HIV/AIDS funding where even their small level of funding can result in measurable changes in the pandemic.

In addition, many grantmakers are traditionally interested in funding new approaches and innovative strategies to address community problems. Grantmakers can be expected to keep on to

<sup>63</sup> For more information about public sector HIV/AIDS funding, see: *The Henry J. Kaiser Family Foundation, Federal HIV/AIDS Spending: A Budget Chartbook Fiscal Year 2000*, Third Edition, October 2000.

responding to the application of groundbreaking methodologies for dealing with the pandemic both domestically and internationally. Domestically, this is particularly relevant as the pandemic devastates communities of color and young people where, to date, there is less of a proven track record of successful interventions. As an example, several foundation staff members interviewed indicated that they were among the initial funders of harm reduction models when this approach was untested. Their support has been instrumental in demonstrating the value in this HIV/AIDS prevention strategy.

*"We fund launching new initiatives, new programs, new models, and the dissemination and replication of those models."*

*Family Foundation*

As grantmakers are aware, the face of HIV/AIDS is dynamic. As the pandemic continues, new populations are affected and new concerns and issues develop that need to be addressed. When these populations and emerging issues are targeted and specific concerns are articulated, grantmakers are then able to identify funding opportunities that are congruent with their desire to address new and emerging issues with significant impact. In other words, what was once old is new again.

*"I still believe there is relevance among philanthropy, but it shouldn't be philanthropy's entire problem when the government should support it. But what philanthropy can do in regards to HIV is still a very important issue."*

*Community Foundation*

### **The perception of HIV/AIDS domestically has changed from being a "crisis" to an "important problem."**

Grantmakers interviewed felt that given the duration of the pandemic and advances made in prevention and treatment, HIV/AIDS domestically is no longer seen as a crisis by the general public, the media or the philanthropic community. Nevertheless, HIV/AIDS is still viewed by most respondents as one of the most important problems facing communities today.

*"I think early on there was the sense of urgency that kind of allowed for people to make exceptions to the rule of no disease-specific funding. Now, because of fatigue and less urgency, and progress made in treatment, it pushes it back to, 'We don't fund specific diseases.' The sense of urgency allowed some to overcome this in the past."*

*Private Foundation*

### **CHALLENGE**

When grantmakers viewed HIV/AIDS as a crisis, some could justify funding in this area simply because it was a crisis. They could make an exception to their stated organizational priorities because the need to respond to this emerging issue was so great and because they are dedicated to responding to crisis issues, whatever their nature. However, as the HIV/AIDS pandemic has come to be viewed by respondents as one of many important problems facing communities, some grantmakers are finding it more difficult to continue to justify funding HIV/AIDS as an exceptional

category. The earlier finding that nearly all respondents are making HIV/AIDS grants from non-HIV/AIDS specific funding categories supports this. The ability of grant-makers to continue funding HIV/AIDS becomes dependent on the fit between HIV/AIDS and the organization's articulated mission and priorities. When there is no fit, continued HIV/AIDS funding is jeopardized.

*"It was hard enough to support HIV/AIDS when this was a very critical issue. Now that that perception has changed, it is even harder."*

*Corporate Foundation*

Defining HIV/AIDS as another of the nation's many important social problems creates competition between HIV/AIDS and those other issues, such as other diseases or other community health, social and economic concerns. When there are limited resources and competition for them, there will always be winners and losers.

*"I am sensing a new dynamic-sensing that there is building tension between breast cancer and HIV/AIDS within [the foundation]. There are more heated exchanges about women's health issues. We have been funding women's health, but not at the level of HIV/AIDS. In the last year there has been a series of conversations within the organization that we have not been funding breast cancer at the same level as HIV/AIDS. I say the facts are right and we have work to do."*

*Corporate Foundation*

## OPPORTUNITY

There is still a relevant role for philanthropy in providing ongoing support to important community problems, even once they move from a crisis state to an endemic problem. Although these issues may not evoke the same level of passion and immediacy as burgeoning crises, ongoing community problems require new, fresh approaches in order to make sure that continued progress is maintained and better solutions continue to be developed. This approach to funding new strategies dovetails with one of the roles philanthropy often sees for itself. And by serving in this role, philanthropy provokes and advocates for new and innovative thinking in communities.

It is important to note that there may be disagreement with the characterization that HIV/AIDS is no longer a crisis. Certain communities are still being devastated by the disease, and recent statistics suggest that HIV/AIDS is still a crisis in certain subpopulations, such as among young gay and bisexual men of color. An appropriate response needs to be developed and implemented in these target populations to stem the growing problem. This presents an excellent opportunity for philanthropy to do one of the things it does best: step in quickly to a crisis situation to support new, effective strategies and to leverage other resources and other sources of leadership on the issue.

## How has U.S.-based philanthropy addressed the burgeoning global pandemic? How, if at all, has the global pandemic affected domestic HIV/AIDS philanthropy?

### The devastating international HIV/AIDS pandemic is receiving increased attention from the philanthropic community, yet few U.S.-based grantmakers fund international HIV/AIDS efforts.

Respondents of all types interviewed in the FRP study are aware of the overwhelming scope and devastation of the pandemic in the developing world. They reported that they believe attention to the HIV/AIDS pandemic globally has increased in the last two years among the general public as well as among philanthropy. The Annual International HIV/AIDS Conference, hosted in Durbin, South Africa in 2000, brought increased attention to the plight of nations around the globe, in particular Africa, but also Asia as well. Recent attention to the pricing and availability of pharmaceutical treatments in developing countries also continues to raise awareness.

*[Because of] “good media coverage in the last year, people are becoming aware of the disastrous social, political and economic impact HIV/AIDS is having in Africa. They are beginning to understand the peace and security issues it might pose.”*

*Private Foundation*

Many domestic funders interviewed in this study indicated that while the growth in the international HIV/AIDS pandemic is of great concern to them, their organization does not or cannot fund HIV/AIDS efforts in other countries. Simultaneously, a few large foundations have recently made significant contributions to help stem the international HIV/AIDS pandemic.

### CHALLENGE

The pool of grantmakers who fund internationally in general—not just HIV/AIDS—is small, totaling 11% of all U.S. foundations. International grantmaking is primarily the realm of a small proportion of funders that have larger capacity in terms of staff and resources. While many FRP interview respondents expressed concerns about the global pandemic, they are often willing to leave actual grantmaking to the larger more experienced international funders.

*“Another huge barrier is that few foundations are responding internationally. Foundations don’t fund internationally. That is a huge barrier to dealing with a major part of the epidemic.”*

*Private Foundation*

The mission of some philanthropic organizations limits the geographic scope of their grantmaking. For foundations that are unable to fund internationally, identifying domestic opportunities that also impact the international HIV/AIDS pandemic can be challenging.

*“The media attention makes it look like everything bad is happening in Africa. It is much more complicated than that.”*

*Private Foundation*

Another challenge to international HIV/AIDS philanthropy is the persistent domestic pandemic. Prioritizing needs at home versus those abroad can be a difficult proposition within an organization, and funding globally can be difficult to explain to foundation or corporate boards or other domestic stakeholders. In some

cases, the international pandemic has overshadowed the domestic pandemic and has enabled some funders to justify a reduction or withdrawal of needed domestic support.

*“Everyone has been exposed to the extent of the global epidemic, so maybe it is hard for people to understand what needs to happen in this country.”*

*Private Foundation*

## OPPORTUNITY

The benefit of recent increased attention to global matters is that it keeps HIV/AIDS on philanthropy’s radar screen. Nearly all of the funders interviewed agree that any attention to HIV/AIDS, whether domestic or international, helps to keep HIV/AIDS at the forefront of issues that warrant attention.

While some funders are overwhelmed by the vast scope of the problem, for others the need is so compelling that it is easier for them to make the case for supporting HIV/AIDS internationally. In some cases, FRP interview respondents indicated that the increased attention on the global HIV/AIDS pandemic is enabling them to keep or renew attention on the U.S. pandemic. For example, one foundation representative interviewed remarked that reports documenting the devastation caused by HIV/AIDS in Africa reminded the organization’s board of directors of the importance of a sustained response, reconfirming their local HIV/AIDS prevention efforts.

*“The demand [internationally] is larger; the need is bigger, and the NGOs are better prepared to work. We are receiving more proposals.”*

*Private Foundation*

Several of the funders interviewed indicated that their organizations recently

expanded the scope of their HIV/AIDS grantmaking to include the unfamiliar territory of international funding. Once investigated, the organizations learned they are not limited in their ability to make international grants and that the process is not as complicated as they initially feared. For example, a private foundation spokesperson interviewed in this study explained that a member of the organization’s board of directors urged the foundation to pursue grantmaking in South Africa, even though the foundation has never funded internationally in the past. Staff then visited South Africa and developed a targeted grantmaking program that dovetails with the foundation’s overall funding priorities. In this case, the enormous scope of the problem overseas compelled the organization to take action, and it found a mechanism to apply its limited resources in a way that it feels is making a meaningful contribution.

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### **International HIV/AIDS funding raises questions of how to be most effective.**

Responding to the international HIV/AIDS pandemic can be a complex and challenging task. Grantmakers are concerned about how to address the problem considering its scope and the available resources. They are also concerned about the mechanics of international grantmaking and how to work with local governments, local organizations, international institutions, other national governments and other grantmakers to develop and implement effective grantmaking strategies. Another area under question is how to balance the need for accountability with the need for local empowerment and control of international HIV/AIDS efforts. One interview respondent from a private foundation asked, “What is the appropriate role for private philanthropy in the international pandemic?” Finally, the question of how

to monitor and evaluate international efforts is still largely unanswered.

*"I am concerned that the responses now have been very quick without thought to the long-term help that we can give people. I am concerned that the approach to the epidemic is not thinking about how countries themselves can respond to the epidemic."*

*Private Foundation*

### CHALLENGE

Many grantmakers indicated that the scope of the global pandemic is so great that they are at a loss for how to apply their limited resources to the problem in a meaningful and effective way. This concern is particularly relevant for smaller foundations that have never funded outside of the United States. Most grantmakers interviewed for this study commented that they look to identify initiatives where the impact of their funding is clear. Lacking experience and sophistication in international grantmaking, some funders are doubtful of their ability to be effective international grantmakers because the impact of their funding may not be clear or measurable.

*"We are at the point where it is difficult to see what contribution we can make. It is not very clear what foundations like us can do at this point."*

*Private Foundation*

*"I think the question is, 'How do we develop philanthropy in Africa and Asia so that Africans and Asians can do their own philanthropy?'"*

*Private Foundation*

### OPPORTUNITY

The international HIV/AIDS pandemic, while complex and daunting, does provide philanthropy with many opportunities for groundbreaking, effective and creative problem solving. The international pandemic presents philanthropy with an opportunity to fulfill many of its traditional roles—creative, risk-taking, gap filling—to provide resources that the United Nations and individual governments can not or will not. Developing new ways to effectively apply funds to address the global HIV/AIDS pandemic is exactly the kind of groundbreaking work that philanthropy has traditionally undertaken. Several FRP interview respondents noted that once their organizations finally made the difficult decision to fund HIV/AIDS overseas, they were able to identify effective programmatic strategies and funding mechanisms, even with relatively limited resources.

## CONCLUSION

As a philanthropic leader in HIV/AIDS, how can FCAA continue to mobilize and support an ongoing, robust and strategic philanthropic response?

As this research documents, philanthropy continues to play a critical role in the domestic and international response to the HIV/AIDS pandemic.

The leading funders in HIV/AIDS continue to view HIV/AIDS as a very important community issue in the United States that is related to many of the other health, social and economic concerns that they are trying to address through their grantmaking. It is this approach of “integration” that is enabling many funders to maintain and perhaps even increase support of HIV/AIDS programs and services. Internationally, philanthropy appears to be slowly increasing its role. Leading funders such as the Gates Foundation are paving the way, yet there are also opportunities for grantmakers with fewer resources to make an impact in the international pandemic.

*“The best role that funders can play is to serve as a catalyst and midwife for important work that needs to be done but that others have difficulty supporting. [Philanthropy needs to] constantly look for what are the gaps that deserve more attention and resources that aren’t existing from larger donors.”*

*Private Foundation*

This study provides answers to many important questions, the most important of which is that philanthropy continues to play an important and ongoing role in bringing an end to the HIV/AIDS pandemic. The research identifies many opportunities for philanthropy to continue to play to its strengths and, at the same time, have a meaningful and strategic impact on the pandemic domestically and internationally. Many challenges remain. However, through this research and the work of FCAA, these challenges are more clearly understood. Through this understanding, challenges can then become opportunities.

# FCAA's Call to Action: A Framework for Ongoing Philanthropic Leadership in HIV/AIDS

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**THE RESEARCH AND ANALYSIS** contained in this report highlights many of the challenges and opportunities for philanthropy as we enter the third decade of the HIV/AIDS pandemic. This research makes it ever more apparent that if we are to win the war against this disease, the field of philanthropy must continue to make meaningful contributions and provide ongoing and, in some instances, new leadership. FCAA is committed to supporting grantmakers in this endeavor in as many ways as we possibly can - by providing information and technical assistance, convening discussions, facilitating dialogues, identifying opportunities and continuing to challenge funders to keep HIV/AIDS at the forefront of their grantmaking, social change and community problem-solving agendas.

FCAA is comprised of most of the leading foundation and corporate grantmakers in HIV/AIDS, some of whom have been involved in guiding this research project and in drafting this section: an action-oriented agenda for the field of HIV/AIDS-related philanthropy. The research, together with the expertise and wisdom of the many experienced grantmakers involved in this process, guided and informed many of these action steps.

It is FCAA's hope that the research and these action steps resonate with your foundation, corporation or giving program and facilitate continued or new engagement in HIV/AIDS. This agenda is offered in the spirit of partnership. FCAA is available to support foundation and corporate grantmakers' HIV/AIDS funding strategies and other leadership activities in the field that dovetail with an organization's mission, funding priorities and resources. In addition, FCAA provides access to up-to-date HIV/AIDS epidemiological data, as well as information about best practices, through its website at [www.fcaaid.org](http://www.fcaaid.org). We hope that you continue to call upon us as a resource and a partner as we move together to bring an end to the HIV/AIDS pandemic.

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## ACTION ITEMS

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### **Stay the course in HIV/AIDS grantmaking.**

HIV/AIDS epidemiological trends, both domestically and internationally, continue to make a strong and compelling case for philanthropic commitment to combating HIV/AIDS. Economic trends related to the impact of HIV/AIDS internationally argue more strongly than ever for enhanced corporate and private philanthropic attention. Grantmakers need to support the full spectrum of programmatic offerings, from direct services, HIV/AIDS prevention and bio-medical research to public policy, community organizing and technical assistance. To this end, FCAA encourages grantmakers to stay abreast of local, national and international HIV/AIDS developments and to form partnerships with health departments, other government entities, United Nations agencies, HIV/AIDS service organizations and other HIV/AIDS grantmakers.

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### **Provide sustained philanthropic leadership in HIV/AIDS.**

Grantmakers who have been leaders in HIV/AIDS philanthropy should be commended for their commitment. We learned from the FRP interviews that it is critical for these funders to continue their efforts—they are leading by example. These grantmakers, along with FCAA and emerging HIV/AIDS funders, must continue to keep this pandemic at the forefront of philanthropic issues/concerns for as many years as it takes to prevail over the disease.

Leadership needs to be sustained from all sectors of philanthropy—from private and family foundations to corporate and community foundations—and it can take many forms in addition to grant-

making. This includes grantmakers serving on nonprofit boards of directors and public sector planning committees, as well as speaking out to counter apathy in the field of philanthropy and in local communities. Corporate funders, specifically, have other options open to them in this arena, such as the ability to work with their colleagues on comprehensive business responses to HIV/AIDS, including developing sound workplace policies and practices and encouraging employee volunteerism in this area.

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### **Examine the relationship between HIV/AIDS and your organization's mission and funding priorities.**

As the HIV/AIDS pandemic evolves, it has become increasingly intertwined with an array of health, social and economic issues that most often affect marginalized populations. Unfortunately, this phenomenon will continue for the foreseeable future. We learned in this study that the mission or funding priorities of most leading HIV/AIDS grantmakers is to address the needs of vulnerable and underserved populations. This has enabled them to reposition HIV/AIDS for ongoing, and often enhanced, support because of the interrelationship between HIV/AIDS, those most vulnerable and underserved, and the issues affecting these communities. FCAA believes that there are many more funders that focus on these populations and the issues that affect them, paving the way for increased investment and involvement by grantmakers who have not previously seen themselves as HIV/AIDS funders.

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### **Integrate HIV/AIDS grantmaking into broader funding categories that allow for ongoing, sustained support.**

One of the most compelling findings from the FRP interviews is that many

leading funders continue to support HIV/AIDS under the auspices of non-HIV/AIDS specific funding categories. For many, HIV/AIDS funding has become a necessary component of a more comprehensive response to health, population and community problem-solving issues. This represents a change for a number of these grantmakers who previously created an exceptional HIV/AIDS funding category in order to respond to the burgeoning HIV/AIDS crisis.

At this time in the HIV/AIDS pandemic, FCAA encourages the field to continue this integration. We acknowledge that there is concern that HIV/AIDS may get lost or suffer inappropriately from increased competition with other issues when it is no longer an exclusive funding category. In addition, we heard from funders interviewed in this study that it now takes greater staff effort to make the case for HIV/AIDS funding because of this complex interrelationship between the disease and other pressing health, social and economic community needs.

However, FCAA learned from the interviews that this strategy of integration might offer an outweighing benefit in that it can allow for increased access to resources, a larger pool of potential funding organizations and a vehicle for ongoing, sustained and innovative support. It will be important for philanthropy to be both thoughtful and intentional in this process. Funders must work proactively with grant seekers, and in some cases entirely new communities, to make sure that funds are still available for HIV/AIDS in programmatic areas that may not overtly appear to be related to HIV/AIDS.

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**Assist organizations involved directly and indirectly in HIV/AIDS to build capacity and effectiveness.**

As the pandemic continues to affect marginalized populations, many of the community-based organizations that serve these communities have had limited access to the resources and support necessary for organizational stability and effectiveness. Grantmakers interested in sustained social change and community problem-solving have an opportunity to make an important contribution through capacity building and organizational development project funding. These include grants for general operating expenses, strategic planning, infrastructure enhancement, capacity building, technology attainment, board leadership development and staff training. Funders can and should also play a positive and creative role in examining whether HIV/AIDS programs and organizations should be refocused, redefined and/or merged with other projects or agencies.

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**Develop collaborative relationships with other public and private funders.**

The FRP study, along with other research, has time and again highlighted the benefits of effective collaboration in solving important community problems. FRP respondents told us that collaborating with other grantmakers, corporations, the public sector and nonprofits, while challenging, is often an effective strategy to maintain ongoing support for HIV/AIDS programs and services. In addition, it often provides a vehicle for creative and risk-taking grantmaking that individual grantmakers may not be capable of on their own. There are several successful collaborative models that can be looked to for guidance. For example, over two dozen local

HIV/AIDS funding collaboratives already exist throughout the U.S involving foundation and corporate funders.

There are also key umbrella programs in which FCAA is involved that can assist corporate HIV/AIDS grantmakers: The Centers for Disease Control and Prevention's Business Responds to AIDS Program and the Global Business Council on HIV/AIDS.

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**Build a sustained philanthropic response to HIV/AIDS that is grounded in philanthropy's traditional roles.**

Too often the traditional roles for philanthropy are cast in a negative light and cited as factors that lead to philanthropic disengagement. However, the opposite can also be true. We learned from the FRP interviews that these traditional roles can and do provide the framework and justification for ongoing, sustained and even increased philanthropic involvement in HIV/AIDS. These roles include:

- **Gap-filling funding** - Domestically, even with a robust public sector response, there are still a variety of niches or gaps for philanthropy to fill. Funders should work with public sector agencies, researchers and community-based organizations to gather information that identifies these gaps locally, regionally and nationally. This is particularly relevant as the domestic pandemic increasingly affects communities of color and, in some cases, is coupled with growing public and media apathy. Internationally, the gaps are even more apparent as the response to HIV/AIDS is newer and less developed, both at the private and public level.
- **First-in funding** - Internationally, there are vast opportunities for philanthropy to provide critical start-up funding.

Domestically, there may be fewer opportunities, yet they do exist.

- **Risk-taking funding** - In all aspects of the HIV/AIDS pandemic there is still the need for private support of strategies and interventions that are seen as risky, untested or controversial. Domestically, there are limits to the use of public sector resources. As the pandemic moves further into communities of color, many of the interventions first used with one culture or community need to be modified or redesigned in order to be appropriate and effective in another. Internationally, the same restrictions on public resources often apply and the availability of government resources is minimal. Philanthropy can play an important role internationally by providing funding for culturally appropriate, indigenously guided programming.
- **Funding in the absence of public sector support** - Domestically there is a large-scale public sector response to HIV/AIDS. However, this response, while broad, is not comprehensive. There are still many opportunities for philanthropy to provide funding for programs excluded from government support, such as needle exchange or non-abstinence-based HIV/AIDS prevention programs for young people. In addition, small grants can often augment public sector support and provide enormous leveraging opportunities.

Internationally, the opportunities are vast. For many resource-poor developing countries, government support is very small or unavailable, and international assistance from the developed world is limited. Philanthropy can play the role it did in the beginning of the domestic pandemic, providing important seed support that later becomes the framework for replication and expansion by the public sector.

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**Examine carefully the perceived limitations to international grantmaking and, if possible, get involved in the global crisis.**

The global HIV/AIDS pandemic is a crisis of enormous proportions. HIV/AIDS overarches all development issues. It contributes to poverty, discrimination, economic underdevelopment and a range of health and social problems. In particular, the staggering impact of the HIV/AIDS pandemic on global business provides a real imperative for corporate philanthropy to get involved in international HIV/AIDS grantmaking.

In the United States, a small proportion of the philanthropic community—approximately 11%—make international grants. We at FCAA believe that a much larger proportion of funders are capable of participating in addressing the global crisis through international grantmaking than are currently doing so. There is no denying that international grantmaking is challenging and complex, and there remain a host of questions about how to best be involved in the international HIV/AIDS pandemic. However, FCAA learned from the interviews that funders of varied sizes have begun to make important contributions in this realm.

Often the perceived limitation to international grantmaking is just that, perceived, and is not actually a restriction. Recent data on the general increase in international grantmaking supports this conclusion. FCAA encourages funders to get involved in the international HIV/AIDS pandemic by learning about the unique role that grantmakers can play and connecting to organizations doing important global work in the United States and especially in highly impacted countries around the world.

While the increased attention to the international pandemic is warranted and long overdue, there is the risk that grantmakers may shift attention and support international efforts at the expense of domestic efforts. Philanthropy must remain focused on the real needs in both the domestic and international pandemic.

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**Engage in public/private partnerships with the United Nations, other multi-lateral organizations and others to enhance strategic international HIV/AIDS grantmaking.**

Philanthropy clearly has an important role to play in enhancing the overall response to global HIV/AIDS, including participating as a key partner in any viable, overall public/private strategy and multi-sector enhanced response to this pandemic.

Grantmakers should explore what existing partnerships in this arena can be enhanced and in which new collaborations and new models they can become involved. It is to no one's benefit for private foundations, corporate funders, U.S. government agencies and United Nations agencies to be engaging in unnecessary duplication of efforts, or in some cases, funding projects at cross-purposes.

Much can be gained from respectful, transparent and meaningful partnerships—whether such new efforts for foundations and corporate giving programs entail contributing to a global AIDS fund or simply enhancing or creating an international grantmaking portfolio that more thoroughly addresses HIV/AIDS and its many connected issues in developing country settings (such as sustainable development, reproductive health and human rights).

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**Think globally about the HIV/AIDS pandemic; act locally.**

There are a growing number of organizations based in the United States doing work internationally. If your organization is truly limited to funding domestic entities only, these organizations may allow for participation in the international HIV/AIDS

pandemic while still making domestic, and even sometimes local grants. Furthermore, rather than providing justification for decreasing attention to the domestic HIV/AIDS pandemic, recent attention on the global HIV/AIDS pandemic can and should be used as a springboard for increasing philanthropic attention on developments and needs in the U.S.

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**WE HOPE** that these action steps for grantmakers are useful to your organization as we work together to bring an end to the HIV/AIDS pandemic and its related human suffering. We encourage funders to stay in touch—with FCAA and with each other—and stay involved.

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## Appendix: HIV/AIDS Resources

The following resources are listed and briefly described to:

- Assist grantmakers in becoming and staying better informed about HIV/AIDS and related issues;
- Help funders learn about the various organizations and entities addressing HIV/AIDS; and
- Suggest the many organizations and entities that can provide fertile ground for collaborations in the fight against the pandemic.

This resource list is by no means exhaustive. Therefore, we encourage private funders and others who may use this list to search for additional materials or organizations, especially at the local level domestically and in specific countries internationally, that may enhance your knowledge base and your work.

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### HIV/AIDS PHILANTHROPY

#### Funders Concerned About AIDS (FCAA)

Phone: (212) 573-5533

Website: [www.fcaids.org](http://www.fcaids.org)

FCAA produces many publications on HIV/AIDS and private grantmaking, all of which are available to order on our publications list through our website or by calling our offices, as well as numerous other forms of programming to mobilize and sustain the philanthropic response to HIV/AIDS.

#### National Guide to Funding in AIDS. New York City: The Foundation Center, 2001.

To order, call: (800) 424-9836

*The National Guide to Funding in AIDS* is the most comprehensive resource available on grantmaking in the field of HIV/AIDS. The volume includes current information on the grantmaking programs of foundations, corporate giving programs and other public charities and is an excellent resource for both funders and grantseekers. The Executive Summary, written by FCAA Executive Director Paul A. Di Donato, provides a description of the changes that have occurred in the HIV/AIDS field, a brief historical overview of HIV/AIDS philanthropy and step-by-step guidelines to assist grantseekers.

**“The Business Response to HIV/AIDS: Impact and Lessons Learned.”** Geneva, Switzerland: Joint United Nations Programme on HIV/AIDS (UNAIDS), the Prince of Wales Business Leaders Forum and The Global Business Council on HIV & AIDS, 2000. To order, call UNAIDS at (41-22) 791-3666 or fax (41-22) 791-4187 or email [unaids@unaids.org](mailto:unaids@unaids.org).

#### Who Funded AIDS: The Role of Funders Concerned About AIDS—Grantmakers as Advocates and Activists. Martha B. Gibbons. Washington, DC: Non-Profit Sector Research Fund, The Aspen Institute, Spring 1999.

This research report discusses the grantmaker's ongoing role in combating HIV/AIDS. To order the publication, contact The Aspen Institute's Publication Office at (410) 820-5338.

**“The Role of Foundations in AIDS Funding.”** Harvard AIDS Review. Fall 1998. This article may be obtained from the Harvard AIDS Review website [www.hsph.harvard.edu/hai/publications/index\\_fall98.html](http://www.hsph.harvard.edu/hai/publications/index_fall98.html). Phone: (617) 432-4400

**2000 Global AIDS Directory.** Global Health Council, 2000. For more information on obtaining a copy, call (202) 833-5900.

**Corporate Responses to AIDS, a Research Report**  
(A UNAIDS-sponsored study conducted by  
The Conference Board, Report Number 1186-  
97-RR). Geneva, Switzerland: Global Business  
Council on HIV/AIDS, 1997.

To order, contact UNAIDS at (41-22) 791-  
4506, or fax (41-22) 791-4898 or  
email [unaids@unaids.org](mailto:unaids@unaids.org).

**Chronicle of Philanthropy**

Website: [www.philanthropy.com](http://www.philanthropy.com)

**Council on Foundations**

Phone: (202) 466-6512

Website: [www.cof.org](http://www.cof.org)

**The Foundation Center**

Phone: (212) 620-4230 or (800) 424-9836

Website: [www.fdncenter.org](http://www.fdncenter.org)

Along with its National Guide to Funding in  
AIDS, the Foundation Center collects and ana-  
lyzes data on a wide range of philanthropic  
issues and areas.

**The Henry J. Kaiser Family Foundation**

Website: [www.kff.org](http://www.kff.org)

This site focuses on health policy, with a heavy  
concentration on HIV issues and reproductive  
health. The Kaiser Daily HIV/AIDS Report  
may also be found here at  
<http://report.kff.org/hiv aids>

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## DOMESTIC HIV/AIDS AND RELATED ISSUES

### HIV/AIDS—General Information

**The Body**

Website: [www.thebody.com](http://www.thebody.com)

A comprehensive HIV/AIDS resource site, The  
Body offers information on giving and getting  
help, as well as treatment information from  
experts, public policy updates, and community  
bulletin boards. It also provides numerous links  
to additional resources.

**Center for AIDS Prevention Studies (CAPS)**

Phone: (415) 597-9100

Website: [www.caps.ucsf.edu](http://www.caps.ucsf.edu)

The Center for AIDS Prevention Studies  
(CAPS) conducts research that will have maxi-  
mum impact on the theory, practice, and policy  
of AIDS prevention. CAPS cores stimulate new  
research projects to keep pace with the ever-  
changing epidemic, provide necessary services

to the organization's existing research projects  
and to the scientists at CAPS, and provide the  
platform for scientific interactions to advance  
and enhance multidisciplinary research in  
AIDS prevention.

### HIV/AIDS—Key U.S. Government Agencies

**Centers for Disease Control and Prevention**

(CDC), National Center for HIV, Sexually  
Transmitted Diseases and Tuberculosis  
Prevention (NCHSTP)

Phone: (404) 639-8000

Website: [www.cdc.gov/nchstp/od/nchstp.html](http://www.cdc.gov/nchstp/od/nchstp.html)

The CDC NCHSTP combats HIV/AIDS by  
integrating prevention science, research and  
practice. Along with supporting a broad range  
of research efforts, the CDC collaborates with  
governmental and non-governmental organiza-  
tions, international and domestic, awarding  
grants to a variety of groups to support preven-  
tion activities based on science. The CDC web-  
site features national and international statistics  
about HIV infection and AIDS cases, both cur-  
rent and projected.

NCHSTP News and Notes is the quarterly publi-  
cation of the NCHSTP. To receive copies, call  
(404) 639-8939.

**Department of Housing and Urban Development**

Phone: (202) 708-1112

Website: [www.hud.gov](http://www.hud.gov)

**Health Resources and Services Administration**

Phone: (301) 443-5798

Website: [www.hrsa.gov](http://www.hrsa.gov)

**National Alliance of State and Territorial AIDS**

Directors (NASTAD)

Phone: (202) 434-8092

Website: [www.nastad.org](http://www.nastad.org)

**National Institutes of Health:**

Phone: (301) 496-4000

Website: [www.nih.gov](http://www.nih.gov)

**Substance Abuse & Mental Health Services  
Administration**

Phone: (301) 443-4111 (Office of Policy &  
Program Coordinator)

(301) 443-3875 (Office of Program Service)

Website: [www.samhsa.gov](http://www.samhsa.gov)

## HIV/AIDS—National Organizations and Advocacy Groups

### AIDS Action Council

**Phone:** (202) 530-8030

**Website:** [www.aidsaction.org](http://www.aidsaction.org)

Dedicated to responsible federal policy for improved HIV/AIDS care and services, vigorous medical research and effective prevention, AIDS Action is a network of 3200 national AIDS service organizations. AIDS Action also convenes National Organizations Responding to AIDS (NORA), the Washington consortium of 175 national organizations concerned about AIDS.

### The AIDS Memorial Quilt

**Phone:** (404) 688-5500

**Website:** [www.aidsquilt.org](http://www.aidsquilt.org)

### American Civil Liberties Union AIDS Project

**Website:** [www.aclu.org/issues/aids/hmaids.html](http://www.aclu.org/issues/aids/hmaids.html)

### LAMBDA GLBT Community Services

**Phone:** (915) 562-GAYS

**Website:** [www.lambda.org](http://www.lambda.org)

### National Association of People With AIDS (NAPWA)

**Phone:** (202) 898-0414

**Website:** [www.napwa.org](http://www.napwa.org)

NAPWA is a national organization that advocates for better health care access and other services for people living with HIV. It does this in a variety of ways from regional HIV community development trainings to Congressional lobbying. NAPWA also produces The Active Voice+, a quarterly newsletter with information on public policy issues related to HIV/AIDS. In addition, NAPWA provides information services, educational resources and technical assistance for consumers and community-based organizations.

### The National Latina/o Lesbian, Gay, Bisexual & Transgender Organization

**Phone:** (202) 408-5380

**Website:** [www.llego.org](http://www.llego.org)

### North American Syringe Exchange Network

**Phone:** (253) 272-4857

**Website:** [www.nasen.org](http://www.nasen.org)

### Project Inform

**Phone:** (415) 558-8669

**Website:** [www.projectinform.org](http://www.projectinform.org)

## HIV/AIDS Among Specific Populations

The following resources provide general HIV/AIDS information and services as well as further information on HIV/AIDS and specific populations.

### People of Color

#### Asian and Pacific Islander American Health Forum (APIAHF)

**Phone:** (415) 954-9988 (CA)

(202) 624-0007 (DC)

**Website:** [www.apiahf.org](http://www.apiahf.org)

The APIAHF maintains the National Asian and Pacific Islander HIV Resource Center, through its Empowerment through Training and Technical Assistance (ETTA) Program, which provides culturally sensitive information regarding HIV/AIDS and prevention programs.

#### National Black Leadership Commission on AIDS (BLCA)

**Phone:** (212) 614-0023

**Website:** [www.blca.org](http://www.blca.org)

BLCA informs, coordinates and organizes the efforts of the African American community to meet the challenge of fighting AIDS in their local communities. It also conducts policy, research and advocacy on HIV and AIDS to insure effective participation of leadership in policy and resource allocation at the national, state and local levels of communities of African descent nationwide.

#### National Council of La Raza (NCLR)

**Phone:** (202) 785-1670

**Website:** [www.nclr.org](http://www.nclr.org)

NCLR is a private, nonprofit and nonpartisan organization established to reduce poverty and discrimination, and improve life opportunities for Hispanic Americans. To further those ends, NCLR also maintains its Center for Health Promotion, which includes the HIV/STD/TB Prevention Project. The Project addresses AIDS and other sexually transmitted diseases as they impact the Latino community.

**National Minority AIDS Council (NMAC)****Phone: (202) 483-6622****Website: [www.nmac.org](http://www.nmac.org)**

NMAC is a national organization dedicated to developing leadership within communities of color to address the challenge of HIV/AIDS. To further this mission, NMAC promotes public policy responsive to the needs of communities of color, provides technical assistance, organizes conferences, provides treatment education and advocacy, and publishes various newsletters, brochures and manuals.

**The National Native American AIDS Prevention Center (NNAAPC)****Phone: (510) 444-2051****Website: [www.nnaapc.org](http://www.nnaapc.org)**

NNAAPC's mission is to stop the spread of HIV and related diseases among American Indians, Alaskan Natives, Native Hawaiians, and to improve the quality of life for members of its community infected and affected by HIV/AIDS. NNAAPC provides prevention, client, and research and evaluation services. NNAAPC also maintains a public policy office in Washington, DC.

**US Conference on AIDS****Website: [www.nmac.org/usca2001/home.htm](http://www.nmac.org/usca2001/home.htm)****Women****Center for Women Policy Studies****Phone: (202) 872-1770****Website: [www.womenpolicy.org](http://www.womenpolicy.org)**

The Center is a policy research and advocacy institution that seeks to incorporate the perspectives of women into public policies that ensure their just and equitable treatment. The Center's current programs include a Women and AIDS Policy component.

**HIV Law Project****Phone: (212) 765-7590****Website: [www.hivlegalnyc.org](http://www.hivlegalnyc.org)**

HIV Law Project serves to protect the legal rights of traditionally underserved HIV-affected populations: low-income women and their families, communities of color, injection drug users, undocumented and recent immigrants, and low-income lesbians and gay men. The organization provides direct and free legal services, conducts large-scale impact litigation and public policy advocacy, and administers advocacy training through the Katrina Haslip Law Technical Assistance Program.

**Youth and Adolescents****AIDS Alliance for Children, Youth, and Families****Phone: (202) 785-3564****Website: [www.aidspolicycenter.org](http://www.aidspolicycenter.org)**

The Alliance is organized to respond to the unique concerns of HIV-positive and at-risk children, youth, women and families. It conducts policy research, education and advocacy on a broad range of HIV/AIDS prevention, care and research issues.

**Incarcerated Community****AIDS in Prison Project****Phone: (212) 673-6633 or (718) 842-0500****Website: [www.aidsinfonyc.org/aip/about.html](http://www.aidsinfonyc.org/aip/about.html)**

The AIDS in Prison Project provides a variety of HIV/AIDS-related services and information to those incarcerated, including prevention and treatment information, discharge planning, inmate support groups and peer counseling, among other things. In addition, the Project conducts public policy and advocacy work as it concerns HIV/AIDS and its impact on prisoners and the penal system.

**HIV/AIDS and the Workplace****Center for Disease Control and Prevention—  
Business Responds to AIDS/Labor Responds to AIDS****Website: [www.brta-lrta.org](http://www.brta-lrta.org)**

BRTA/LRTA is a cooperative effort between the CDC and the business and labor sectors. The organization produces Managers and Labor Leaders' Kits, which offer useful and comprehensive materials to develop programs on manager/labor leader training, employee education, education for employees' families, and community involvement and volunteerism. BRTA/LRTA's programs are comprised of a five branch system which includes a section involving HIV/AIDS related philanthropy, community service and volunteerism activities. To order, contact CDC National AIDS Clearinghouse BRTA Resource Service. The toll-free number is 1-800-458-5231.

**HIV/AIDS Treatment**

The following resources provide further HIV/AIDS treatment information.

**HIV/AIDS Treatment Information Service (ATIS)**

Phone: 1-800-HIV-0440 (general)

1-888-480-3739 (TTY)

Website: [www.hivatis.org](http://www.hivatis.org)

ATIS provides information about federally approved treatment guidelines for HIV and AIDS. ATIS is staffed by bilingual (English and Spanish) health information specialists who answer questions on HIV treatment options using a broad network of federal, national and community-based information resources.

**Treatment Action Group (TAG)**

Phone: (212) 971-9022

Website: [www.thebody.com/tag/tagpage.html](http://www.thebody.com/tag/tagpage.html)

TAG is dedicated to advocating for greater and more efficient research efforts, both public and private, towards finding a cure for AIDS. TAG supports the work of treatment activists, lobbies public and private entities and produces *TAGLine*, a monthly paper of research and policy.

**HIV/AIDS–Housing Issues****AIDS Housing of Washington**

Phone: (206) 448-5242

Website: [www.aidshousing.org](http://www.aidshousing.org)

AIDS Housing of Washington strives to increase the quality and quantity of housing resources for people living with HIV/AIDS through local AIDS housing development and national technical assistance.

**National Hotlines**

For information on national hotlines, visit FCAA's website at [www.fcc aids.org/pub\\_resources.htm](http://www.fcc aids.org/pub_resources.htm)

**GLOBAL HIV/AIDS AND RELATED ISSUES****Global HIV/AIDS–UN Agencies and Key Multilateral and Government Agencies****Joint United Nations Programme on HIV/AIDS (UNAIDS)**

Phone: (+4122) 7913666 (Switzerland)

Website: [www.unaids.org](http://www.unaids.org)

**United Nations Children's Fund (UNICEF)**

Phone: (212) 326-7000

Website: [www.unicef.org](http://www.unicef.org)

**United Nations Development Programme (UNDP)**

Phone: (212) 906-5000

Website: [www.undp.org](http://www.undp.org)

**United Nations Population Fund (UNFPA)**

Phone: (212) 297-5000

Website: [www.unfpa.org](http://www.unfpa.org)

**United Nations Educational, Scientific and Cultural Organization (UNESCO)**

Phone: (212) 963-5995

Website: [www.unesco.org](http://www.unesco.org)

**United Nations Drug Control Program**

Phone: 431 26060 0 (Austria)

Website: [www.undcp.org](http://www.undcp.org)

**United States Agency for International Development (USAID)**

Phone: (202) 712-0000

Website: [www.info.usaid.gov](http://www.info.usaid.gov)

The USAID, primarily through its HIV/AIDS Division, is a global participant in developing and implementing international HIV/AIDS/sexually transmitted infections prevention and control programs. Its work is operationalized by its framework of grants and cooperative agreements with various organizations and the programming of its regional bureaus.

**World Health Organization (WHO)**

Phone: (+00 41 22) 791 21 11

Website: [www.who.org](http://www.who.org)

**World Bank**

Phone: (202) 477-1234

Website: [www.worldbank.org](http://www.worldbank.org)

**Nongovernmental Organizations****2000 International Conference on HIV/AIDS**

Website: [www.aids2000.com](http://www.aids2000.com)

**AIDS Education Global Information Systems (AEGIS)**

Fax: (949) 248-2839 (Sr. Mary Elizabeth)

Website: [www.aegis.com](http://www.aegis.com)

The AEGIS website offers a useful archive of publications.

**Global Business Council on HIV/AIDS****Website:** [www.gbcaids.com](http://www.gbcaids.com)

The Global Business Council on HIV/AIDS (GBC) provides international leadership on HIV/AIDS to businesses around the world and advocates for greater corporate involvement in the global response to HIV/AIDS.

**Global Health Council—Global AIDS Program****Website:** [www.globalhealthcouncil.org/AIDS.html](http://www.globalhealthcouncil.org/AIDS.html)

The Global Health Council's Global AIDS Program website offers useful information on developments in the global AIDS arena, with additional information on conferences, publications, and other related links. AIDSLink is the Council's bimonthly publication on the global response to HIV/AIDS. Subscriptions are available. To order, call (202) 833-5900.

**Global HIV/AIDS & STD Surveillance****Phone:** (+4122) 791 3666 (Switzerland)**Website:** [www.who.int/emc-hiv](http://www.who.int/emc-hiv)**Global Network of People Living with AIDS (GNP+)****Website:** [www.xs4all.nl/~gnp/index.html](http://www.xs4all.nl/~gnp/index.html)

GNP+ is a non-governmental organization forming a global network for and of people living with AIDS. Working in five regions across the globe, the organization sponsors international conferences on HIV/AIDS, lobbies relevant parties on issues affecting the AIDS community, and seeks to bring committed parties together for networking purposes.

**Human Rights Watch****Phone:** (212) 290-4700 (NY)

(202) 612-4321 (DC)

**Website:** [www.hrw.org](http://www.hrw.org)

Human Rights Watch is an NGO dedicated to exposing and curbing human rights violations across the world. Among its work, it seeks to prevent mistreatment of individuals based on HIV status.

**International AIDS Vaccine Initiative (IAVI)****Phone:** (212) 847-1111**Website:** [www.iavi.org](http://www.iavi.org)

IAVI is a global organization working to speed the development and distribution of preventive AIDS vaccines. IAVI's work focuses on three areas: accelerating scientific progress; mobilizing support through advocacy and education; and encouraging industrial participation in AIDS vaccine development.

**International Center for Research on Women (ICRW)****Phone:** (202) 797-0007**Website:** [www.icrw.org](http://www.icrw.org)

ICRW is a non-governmental organization working in collaboration with policy makers, researchers and practitioners to address the economic, social, and health status of women in developing countries. The Women and AIDS Research Program is among their many projects.

**The International Community of Women Living with HIV/AIDS (ICW)****Phone:** 020 7222 1333**Website:** [www.icw.org](http://www.icw.org)

ICW is an international network run for and by HIV+ women. It organizes conferences, performs research and implements various projects on issues of HIV/AIDS as it impacts women.

**International Gay and Lesbian Human Rights Commission****Phone:** (415) 255-8680**Website:** [www.iglhrc.org](http://www.iglhrc.org)**International HIV/AIDS Alliance****Phone:** (44) 171 841 3500**Website:** [www.aidsalliance.org](http://www.aidsalliance.org)

The International HIV/AIDS Alliance is an NGO that supports community action on AIDS in developing countries. The Alliance accomplishes this by mobilizing a broad range of NGOs and community groups, increasing their access to resources at a local level, and enhancing their technical and organizational skills.

**National AIDS Trust (UK)****Phone:** +44 0 1718146767**Website:** [www.nat.org.uk](http://www.nat.org.uk)**OneWorld****Phone:** (202) 638-5770**Website:** [www.oneworld.org](http://www.oneworld.org)

OneWorld's website features an excellent directory of Internet sites belonging to 120 organizations working on HIV/AIDS, human rights, and sustainable development issues.

**Panos Institute****Phone:** (202) 638-5770**Website:** [www.oneworld.org/panos](http://www.oneworld.org/panos)**Program for Appropriate Technology in Health****Phone:** (206) 285-3500**Website:** [www.path.org](http://www.path.org)**World AIDS Day****Website:** [www.aawhworldhealth.org/WAD99/endsilence.html](http://www.aawhworldhealth.org/WAD99/endsilence.html)



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