

Philanthropy and AIDS: Assessing the Past, Shaping the Future

A Report on a
Funders Concerned About AIDS/Gallup Survey

Funders Concerned About AIDS

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Ging M. Louie, *Program Coordinator*
Earl L. Plante, *Administrative Coordinator*
Pauline Reinish, *Staff Assistant*
Irfan Hasan, *NYRAG Intern*

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Len McNally, Chair
Irene Crowe
David Gould
Karen Menichelli
Carmen Price
Peter Teague

Letter from Paul DiDonato and Fred Silverman

Dear Colleague,

Funders Concerned About AIDS (FCAA) was organized in 1987 to mobilize the philanthropic sector to eradicate HIV/AIDS and to address its social and economic consequences. At that time, the broader funding community was not well aware of the HIV/AIDS crisis and limited private resources were available to address the epidemic. FCAA's challenge was basic, yet daunting: to mainstream the disease as a funding priority, to bring accurate and current information to bear on funding decisions, and to provide both technical assistance and leadership within the philanthropic sector on the issue.

Over the past twelve years, while FCAA's mission has remained constant, the work has evolved as the HIV pandemic has changed. FCAA has helped grantmakers to fund the development of a wide range of effective initiatives, from community-based models of care to advocacy and public policy efforts. We have also worked closely with policy makers, government agencies and other nonprofit and philanthropic institutions to help create the vital sector-to-sector linkages needed to respond to HIV/AIDS.

As this report describes, private philanthropy has indeed played a major role in supporting innovative, compassionate and effective responses to HIV/AIDS in the areas of prevention, care, support services, research and public policy. In doing so, funders have demonstrated independence and flexibility that other institutions have lacked, and they have provided critical leadership that other sectors either could not or would not provide.

As we approach the end of the century, it is clear that the HIV/AIDS pandemic is in dramatic transition once again. Domestically, there is significant progress in the prevention and treatment of HIV/AIDS. But this progress is limited and it is not being experienced by all. In the United States, for example, the African American community continues to be disproportionately affected by the virus. And around the world, in developing countries, the pandemic rages out of control.

At a time of continued profound needs, along with new and daunting challenges, we at FCAA began to hear of indications that the philanthropic commitment to HIV/AIDS was waning. Reports from our colleagues — as well as a number of HIV/AIDS organizations — suggested that organized philanthropy, including funders who had been early and strong supporters, were showing signs of retreat from both their support of and leadership on HIV/AIDS-related concerns.

In order to shape and to understand progress, it is necessary to know not only where one is, but also where one has been. FCAA, determined to learn more about the past, present and possible future state of HIV/AIDS philanthropy, contracted with the Gallup Organization to conduct a survey of FCAA audience members to find answers to these and related questions. This survey was then supplemented with other research, including a number of interviews with leaders in the HIV/AIDS service and funding arenas as well as a review of current HIV/AIDS literature.

As this report discusses, the results are troubling. While sizable and sustained grantmaking has indeed resulted in numerous creative responses to HIV/AIDS, there are signs that the core group of funders who have constituted the most significant and sustained supporters of HIV/AIDS are themselves beginning to back away from their support. And, there is no evidence of the formation of a new group of funders poised to take their place. Regarding international HIV/AIDS grantmaking, far too few funders have yet to make grants that even begin to respond to the realities of AIDS in the developing world. However, this potential lessening of support contradicts a pervasive feeling among funders that HIV/AIDS is still an urgent, unsolved problem, both domestically and internationally, that deserves philanthropic support.

Our purpose in presenting this information and related data is to provoke frank and open discussions about the philanthropic sector's appropriate role in addressing the changing HIV pandemic. With new and significant knowledge about philanthropy's prospects for funding HIV/AIDS, FCAA's mandate now is to refocus philanthropy on this issue — to examine critically both where philanthropy has been and highlight where it must go to be an effective partner in the increasingly complex battle against HIV/AIDS. At the end of this report, we provide a number of strategies and also a list of resources that we hope will assist you in this effort.

Everyone involved in the fight against HIV/AIDS now faces a very different and in some cases surprising set of challenges than in the past. The changing face of HIV/AIDS and the faltering philanthropic response only serve to make FCAA's mission that much more critical. We are now doubly committed to maintaining a hardworking and focused staff, board of directors and funder audience that can lead a robust philanthropic assault on the many problems posed by this disease.

We hope you find this publication informative, engaging, and, at times, provocative. Our goal, quite simply, is to both challenge and assist funders to enhance philanthropy's role in HIV/AIDS, to use our resources more effectively and efficiently – ultimately, to bring an end to the HIV/AIDS pandemic as soon as possible. Philanthropy must stay the course. We should not mistake the progress to date for true success – an eradication of HIV/AIDS. While some battles are being won, the war against HIV/AIDS is not yet over.

Sincerely,

Paul Di Donato,
Executive Director

Fred Silverman,
Chair, Board of Directors

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Executive Summary

Funders Concerned About AIDS (FCAA) is the chief advocate within the philanthropic community on HIV/AIDS issues. In that role, FCAA is troubled by clear indications that philanthropy's commitment to HIV/AIDS is beginning to wane. This comes at a time when domestically there are more people living with AIDS than ever before and at a time when the disproportionate impact on minority communities, particularly African Americans, is on the rise. Internationally, little if any progress has been made in stopping the devastation and spread of AIDS.

FCAA's current challenge is to shed light on the current HIV pandemic – to examine where philanthropy has been and where it *must* go to be an effective partner in the fight to end the pandemic and end its many consequences. In order to meet this challenge, FCAA undertook a national Gallup survey of grantmakers active or interested in HIV/AIDS. This document summarizes key findings from that survey along with the results of other primary and secondary research commissioned by FCAA.

Key Findings

What follows is a summary of the key findings that have resulted from these research efforts:

- **The FCAA Gallup survey revealed the existence of a relatively small group of funders who have provided a significant portion of the philanthropic response to HIV/AIDS in the United States. Twenty-seven percent of HIV/AIDS grantmakers surveyed made grants totaling \$50,000 or more in their most current fiscal year. They are described in the report as the “core group” and they possess the following characteristics:**
 - A quarter of the core group has been supporting HIV/AIDS for ten years or more.
 - More than half of the core group funders expect to maintain the same level of funding for HIV/AIDS in the upcoming year as compared with a smaller proportion of those funders who are not members of the core group.
 - Core group funders are more likely to increase HIV/AIDS funding in the future than other funders.
 - Core group funders are more likely to describe HIV/AIDS as an urgent issue for their organization than other funders.
 - HIV/AIDS is a higher funding priority for core group funders than for other funders.
 - Core group funders are more knowledgeable about HIV/AIDS than other funders.
- **The philanthropic response in this core group is weakening.**
 - The number of funders granting \$50,000 or more each year declined 22% over the three-year survey period.
 - HIV/AIDS is not a high priority for 40% of the core group.
 - Eight percent of the core group expect to decrease HIV/AIDS-related funding in the future.

- **The number of all funders committed to HIV/AIDS grantmaking is declining.**
 - The number of funders in the FCAA Gallup survey reporting actual HIV/AIDS grantmaking during the study period declined by 21%.
 - From 1996 to 1997, documented philanthropic funding for HIV/AIDS prevention, treatment and research dropped \$7 million, from \$37 million to \$30 million, a decrease of 19% according to the 1998 Foundation Grants Index.
- **There continues to be a significant sense of urgency in the philanthropic community regarding HIV/AIDS, yet this urgency does not always translate into increased support.**
 - Nearly three-quarters of FCAA Gallup survey respondents who report that HIV/AIDS is an urgent issue for their organization report that their funding is the same as it was last year.
 - Thirteen percent of FCAA Gallup survey respondents who report that HIV/AIDS is an urgent issue for their organization are not currently funding HIV/AIDS at all.
 - More than two-thirds (69%) of grantmaking institutions reporting a reduction in HIV/AIDS funding indicate that HIV/AIDS remains an urgent issue.
- **The FCAA Gallup survey was not able to elicit a single explanation for the current trend in HIV/AIDS funding, but instead suggested many related and sometimes contradictory contributing factors.**
 - Philanthropic giving to HIV/AIDS may not be sufficiently tied to changes in community need. Among those funders reporting an increase in funding for HIV/AIDS, the rise in support is due as much to greater philanthropic resources as it is the result of ongoing or increasing community needs.
 - Some foundations are changing their overall funding strategy for health-related concerns. Some grantmaking institutions report reducing disease-specific funding, including HIV/AIDS, and investing in efforts to improve the overall system of healthcare.
 - Domestically, the AIDS service sector may be a victim of its own success. Some funders report having less interest in supporting large, well established AIDS service organizations than smaller programs because the larger organizations are perceived as less capable of innovation and less responsive to changes in the epidemic.
 - Increased federal support for HIV/AIDS is not responsible for the decline in private funding support. While private funders are well aware of increased federal support for HIV/AIDS, they do not cite that increased support for their own organizational disengagement.
- **There is a great sense of urgency regarding the international HIV/AIDS pandemic, yet few grantmakers are funding in this arena.**
 - According to the FCAA Gallup survey, philanthropy is both aware of and greatly concerned about the international HIV/AIDS crisis.
 - Of all issues related to HIV/AIDS, funders are most dissatisfied with progress in addressing the pandemic internationally.
 - Only a small portion (12%) of the FCAA Gallup survey respondents fund HIV/AIDS internationally.

Conclusion

As the survey and other research suggests, there are significant and troubling changes in the philanthropic response to HIV/AIDS. It appears that a combination of modest domestic progress in addressing the epidemic, general “AIDS fatigue,” the growing endemic nature of the problem, and the sheer explosion of the crisis globally are all contributing to a verifiable and significant diminution in the philanthropic response to HIV/AIDS.

More detailed findings, additional resources and FCAA’s Call to Action are contained in the full body of the report. We encourage you to continue reading for more information.

I. Introduction

From 1996 to 1997, documented philanthropic funding for HIV/AIDS prevention, treatment and research dropped \$7 million, from \$37 million to \$30 million, a decrease of 19%.¹ By contrast, philanthropic giving in 1997 was an estimated \$15.98 billion which represented an overall increase of 15.5% from 1996 to 1997. In 1998, it is estimated that philanthropy granted \$19.46 billion representing a 22% jump over 1997 and the largest single year increase ever recorded.²

At the same time, there were more people living with AIDS in the United States and in the world in 1997 than ever before in the history of the pandemic.

What is the relationship between philanthropic giving to HIV/AIDS and the pandemic itself? How is philanthropy responding to changes in the pandemic? Should philanthropic giving for HIV/AIDS be increasing or decreasing at this time? Should HIV/AIDS grantmaking be different in the next five years than it has been in the past five years? This report is an effort to shed light on these questions and to facilitate a process of thoughtful reflection and debate among grantmakers that will lead to an informed and strategic funding agenda.

Most of philanthropy's initial involvement in HIV/AIDS accomplished what the sector does best – addressing emerging needs, taking risks, helping to build community-based responses and promoting innovation. Historically, the financial contribution of philanthropy has paled in comparison both to the needs within communities and to the public sector's financial contributions. Yet philanthropy played a most critical role at a most critical time by assisting in focusing attention on the pandemic and funding development of prevention, care and treatment models that were later adopted and implemented on a broader scale with public dollars in the U.S. and other countries.

In recent years, FCAA has been concerned about anecdotal evidence of philanthropy withdrawing its support from HIV/AIDS. In order to stimulate and inform a dialogue about the need for and how best to maintain an effective and strategic response to HIV/AIDS, FCAA engaged in an information-gathering and fact-finding effort. The purpose was to answer three central questions: What are the trends in HIV/AIDS-related philanthropy? How should changes in the HIV/AIDS crisis inform and shape philanthropy's response? What is FCAA's role in leading philanthropy into the third decade of HIV/AIDS? These are the main issues addressed in this report.

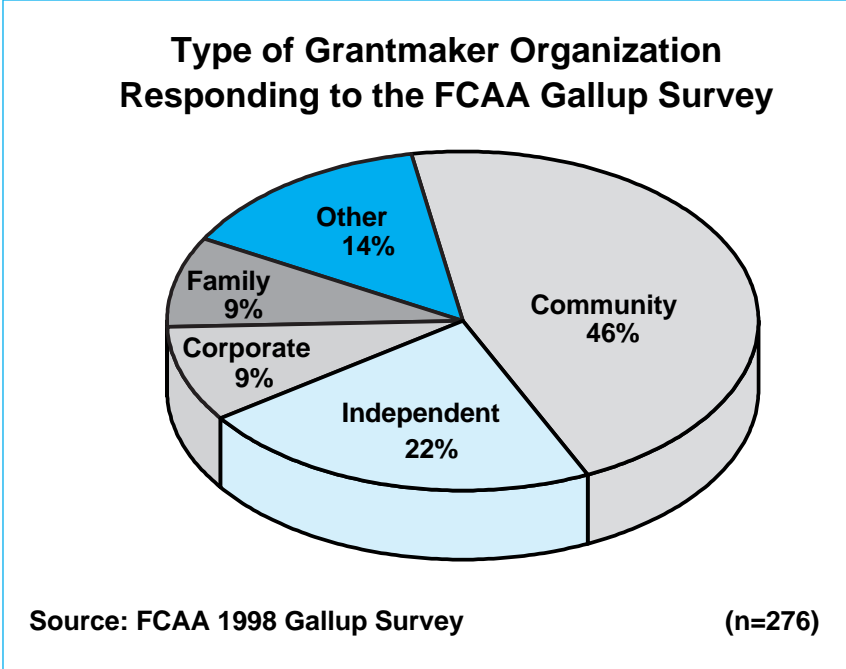
Information Gathering

The process of information gathering began in the summer of 1998 when FCAA commissioned the Gallup Organization to conduct a national survey of philanthropy. FCAA provided the Gallup Organization with a list of 653 individuals in philanthropy who are responsible for making HIV/AIDS-related grants or who have expressed a strong interest in HIV/AIDS issues by either supporting FCAA or receiving regular information from FCAA. From this list, the Gallup Organiza-

¹ 1998 Foundation Grants Index. The Foundation Grants Index includes 86,203 grants of \$10,000 or more, awarded by 1,016 leading foundations and reported to the Foundation Center between June 1997 and July 1998. The funders in the index represent only 2.4 percent of the total number of active, grantmaking foundations, yet their giving accounts for 57.4 percent of total grant dollars awarded by all U.S. independent, corporate, community and grantmaking operating foundations in 1997.

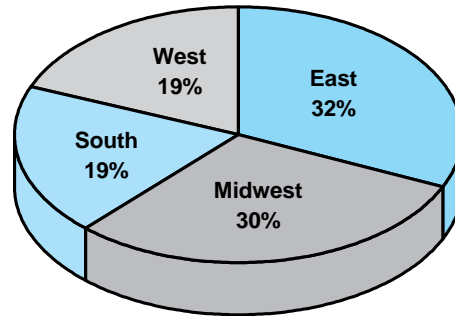
² 1999 Foundation Center (to be published in *Foundation Giving: Yearbook of Facts and Figures on Private, Corporate and Community Foundations*, 1999 Edition.) This same report notes that since 1996 grants have climbed an astounding 41%, or roughly \$5.6 billion.

tion completed a total of 276 interviews with individuals representing the same number of philanthropic organizations. Because the sample included only HIV/AIDS grantmakers or those clearly interested in HIV/AIDS issues, the findings cannot be said to represent the opinions of philanthropy as a whole. A thorough description of the methods used and limitations of the data collected are included in the Technical Appendix to this report.



Nearly half (46%) of the survey respondents represent community foundations, approximately one quarter (22%) are with independent or private foundations, and equal numbers are with family foundations and corporate foundations/corporate giving programs (9% each). The sample includes a geographic spread across the nation: 32% from New England and the Mid-Atlantic states; 30% from the Midwest, 19% from the South; and 19% from the Rocky Mountain and Pacific states. While some of the institutions included in the sample are relatively new to grantmaking, with 24% making grants in health and social issues for 10 years or less, an equal number (26%) are quite established, making grants for 40 years or more.

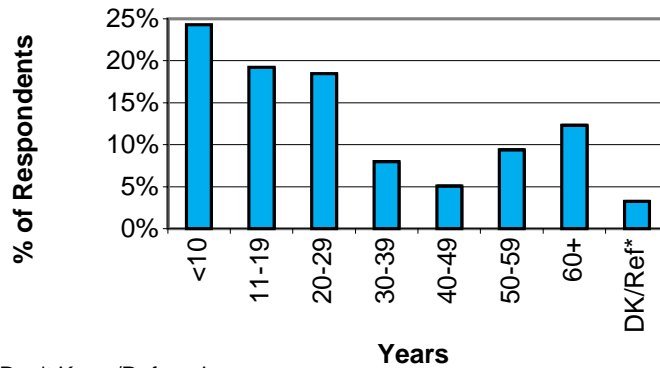
Geographic Distribution of FCAA Gallup Survey Respondents



Source: FCAA 1998 Gallup Survey

(n=276)

Years Grantmaking in Social and Health Issues among FCAA Gallup Survey Respondents



*Don't Know/Refused

Source: FCAA 1998 Gallup Survey

(n=276)

This report summarizes and analyzes some of the key findings from the 1998 survey, placing them in the context of the current state of the pandemic. In order to better understand some of the survey findings, an additional 14 key informant interviews were conducted in early 1999 with a diverse set of select national and international leaders from the philanthropic and HIV/AIDS sectors. Information from these interviews is used to further illustrate survey findings and are not representative of the generalized opinions of philanthropy.

II. The Domestic HIV/AIDS Epidemic

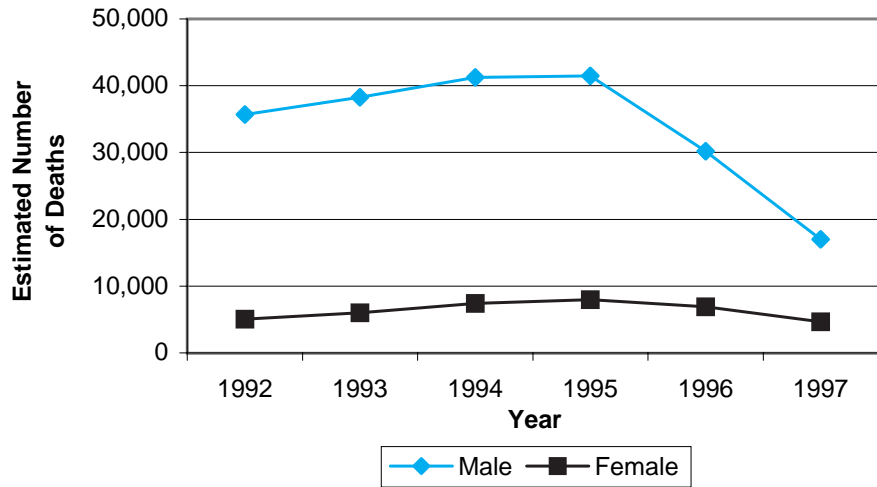
In 1998 an estimated 271,245 people were living with AIDS in the United States, more than at any other time since the epidemic began in 1981.

- Since 1995, deaths due to AIDS have been declining, reversing a decade-long trend of increased mortality. However, since the beginning of the AIDS epidemic in 1981, more than 401,000 people have died.
- The U.S. has seen dramatic reductions in mother-to-child, or perinatal, HIV transmission rates. Between 1992 and 1996, perinatally acquired AIDS cases declined 43% in the U.S. In 1997, this trend continued with a 30% decline.
- In 1997, for the first time since the start of the AIDS crisis, the majority of new AIDS cases occurred among African Americans.
- Hispanic and African American women together represent less than one-fourth of all U.S. women, yet they account for more than three-fourths (76%) of all AIDS cases among women reported to date.
- Men who have sex with men (MSM) continue to be the largest group of people with AIDS in the United States.
- Each year in the United States, between 40,000 and 80,000 persons are infected with HIV, the virus that causes AIDS. Twenty-five percent of all these new HIV infections occur in persons between 13 and 21 years old.

While this portrait suggests the changing face of AIDS, the crisis is evolving in many subtle and complex ways, more than can be described by race, gender and sexual orientation.

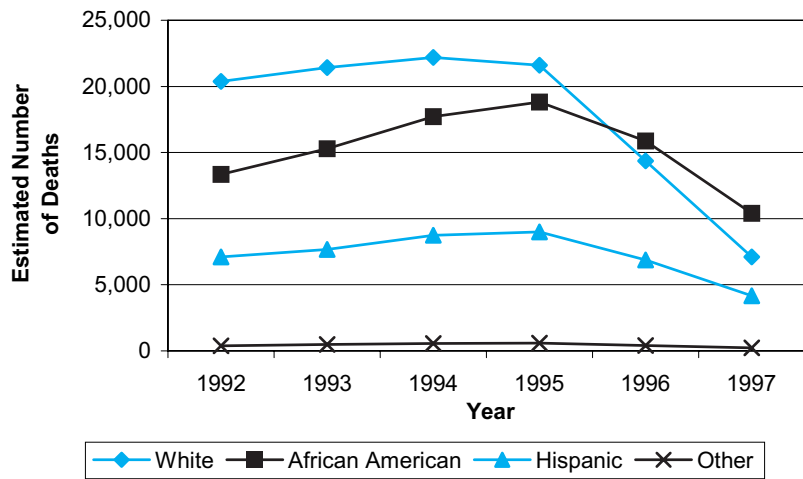
HIV infection is spreading most rapidly among people already struggling with poverty, racism, drug dependence, lack of access to health care, family violence, homophobia, homelessness and incarceration. The progress made in slowing HIV-related illness and death with improved treatments relies on an intricate and often complex web of care and support that enables HIV positive individuals to reduce chaos and increase stability in daily life. Therefore, organizations serving people with HIV and AIDS are increasingly being asked to address multiple health and social problems, including such basic needs as food and housing, before they can even begin to address HIV/AIDS specifically. While government support for many of these services and programs has increased, it has neither kept pace with the demand for services nor minimized the need for creative and innovative solutions to increasingly complex problems.

Estimated Deaths of Adults and Adolescents with AIDS in the United States by Gender and Year of Death



Source: Centers for Disease Control and Prevention

Estimated Deaths of Persons with AIDS in the United States by Race/Ethnicity and Year of Death



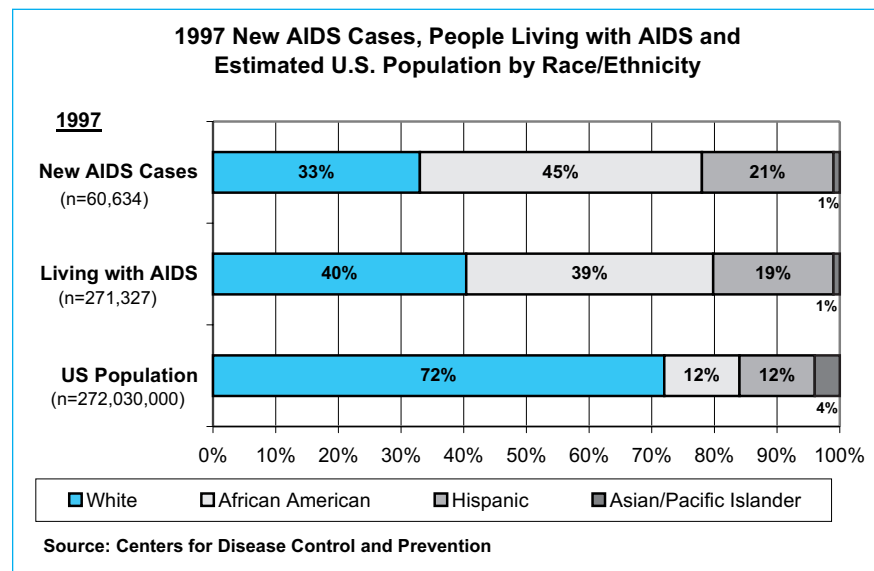
Source: Centers for Disease Control and Prevention

To understand the dynamic nature of the epidemic, it is first important to note the distinction between HIV and AIDS. HIV (Human Immuno-deficiency Virus) is the virus that causes AIDS. Once infected with HIV, individuals may live twelve or more years before they develop full-blown AIDS. Acquired Immune Deficiency Syndrome (AIDS) is a clinical diagnosis that is made up of one or many defined symptoms or illnesses. Because of the often extended time-delay from HIV infection to the onset of AIDS, looking at the number of AIDS cases shows where the epidemic has been because it is evidence of HIV infections that took place many years earlier. Whereas examining the number of HIV cases shows recent infections and where the epidemic is heading.

Communities of color increasingly affected by HIV and AIDS

AIDS continues to disproportionately affect people of color, particularly African Americans. Through June 1998, a total of 240,927 cases of AIDS were reported among African Americans, representing slightly more than one-third (36%) of the 665,357 cases reported by that time. Yet African Americans represent only 13% of the total U.S. population. Researchers estimate that 1 in 50 African American men and 1 in 160 African American women are infected with HIV.

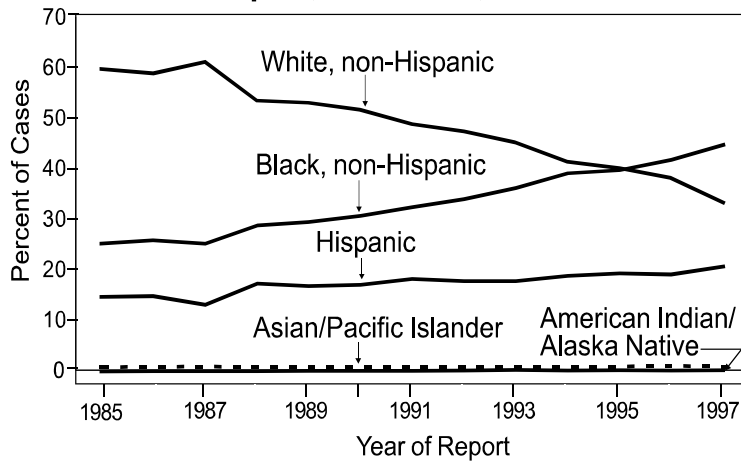
AIDS, too, has disproportionately impacted Hispanics. While comprising only 11% of the nation's population, Hispanics accounted for 18% of AIDS cases (120,484 cases) in the U.S. as of June 1998.



The AIDS epidemic is growing faster in the African American community than in any other racial group in the country. Nearly half (45%) of the new AIDS cases reported in 1997 were among African Americans, followed by a third among whites and a fifth (21%) among Hispanics.

HIV's disproportionate impact on African Americans and Hispanics is expected to continue. A recent Centers for Disease Control and Prevention (CDC) study comparing HIV and AIDS diagnoses in 25 states finds that a larger percentage of HIV than AIDS cases were diagnosed among African Americans. From January 1994 through June 1997, African Americans represented 45% of all AIDS diagnoses, but 57% of all HIV diagnoses. Among young people (ages 13 to 24), 63% of the HIV diagnoses were among African Americans. Hispanics are also increasingly disproportionately impacted. In the same study, while African American HIV cases declined slightly by 3% between 1995 and 1996, HIV diagnoses increased 10% among Hispanics.

Proportion of AIDS Cases by Race/Ethnicity and Year of Report, 1985-1997, United States

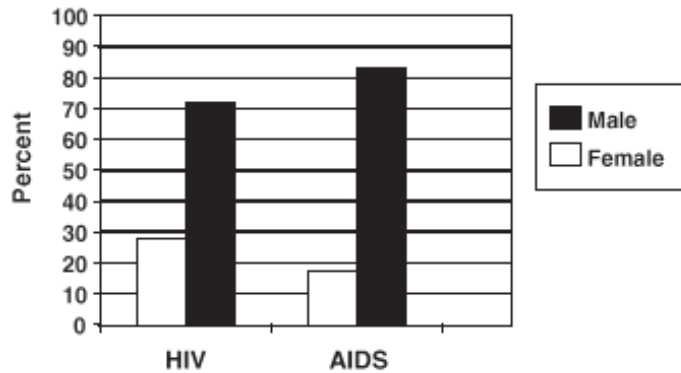


Source: CDC Fact Sheet, Critical Need to Pay Attention to HIV Prevention for African Americans, 1998.

HIV and AIDS cases among women growing

In just over ten years, the proportion of AIDS cases reported among adult and adolescent women nearly tripled, from 7% in 1985 to 22% in 1997. While HIV infections are declining among men, the same study comparing HIV and AIDS cases in 25 states concludes that HIV cases are still increasing among women. Over the three-and-a-half-year period covered in this study, there were fewer HIV infections among men than AIDS cases – indicating a slightly shrinking epidemic. At the same time, new HIV infections outweighed AIDS cases for women. This means that, in the future, we can expect an increasing number of women to be diagnosed with AIDS. Once diagnosed with AIDS, women do not fare as well as men due to the fact that they are disproportionately poorer and have less access to quality healthcare. Overall, women have experienced a smaller decrease in AIDS-related deaths.

Reported Cases of HIV Infection vs. Reported AIDS Cases Among Adults & Adolescents, 25 U.S. States, January 1994-June 1997

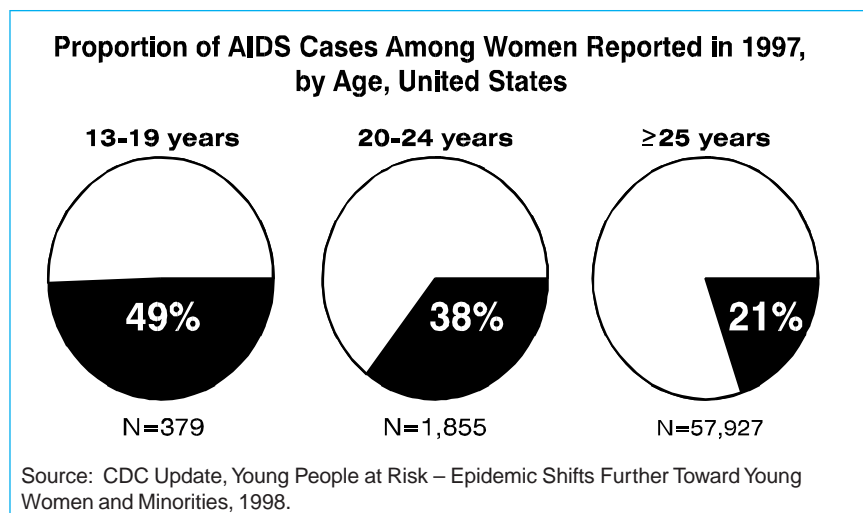


Source: CDC Fact Sheet, Critical Need to Pay Attention to HIV Prevention for Women, 1998.

Over the past decade, the epidemic has increased most dramatically among women of color. Among women and children with AIDS, African Americans have been especially affected, representing 60% of all women reported with AIDS in 1997 and 62% of reported pediatric AIDS cases for 1997.

HIV increasingly affecting youth

Approximately half of all new HIV infections in the United States are among people under age 25, and the majority of young people are infected sexually. Young gay and bisexual men and young women of color seem to be disproportionately affected. Among 13 to 24 year-old males, 52% of all AIDS cases reported in 1997 were among young men who have sex with men. In the recent study of HIV and AIDS diagnoses in 25 states, young people (ages 13 to 24) accounted for a much greater proportion of HIV than AIDS cases, 15% versus 3%. Nearly half (44%) of the HIV infections in that age group were reported among young females, and 63% were among African Americans.



Injection drug use growing risk factor for HIV

Injection drug use (IDU) has accounted for more than one-third of AIDS cases in the United States since the epidemic began. Of the 60,634 new cases of AIDS reported in 1997, 19,463 (32%) were injection drug use-related. Three-fourths (76%) of these cases were among people whose only or most likely risk factor was their own injection drug use. However, 12% were among men who both had sex with other men and were injection drug users, 11% among men and women whose sex partners were IDUs, and 1% among children born to mothers who were either IDUs or sex partners of IDUs.

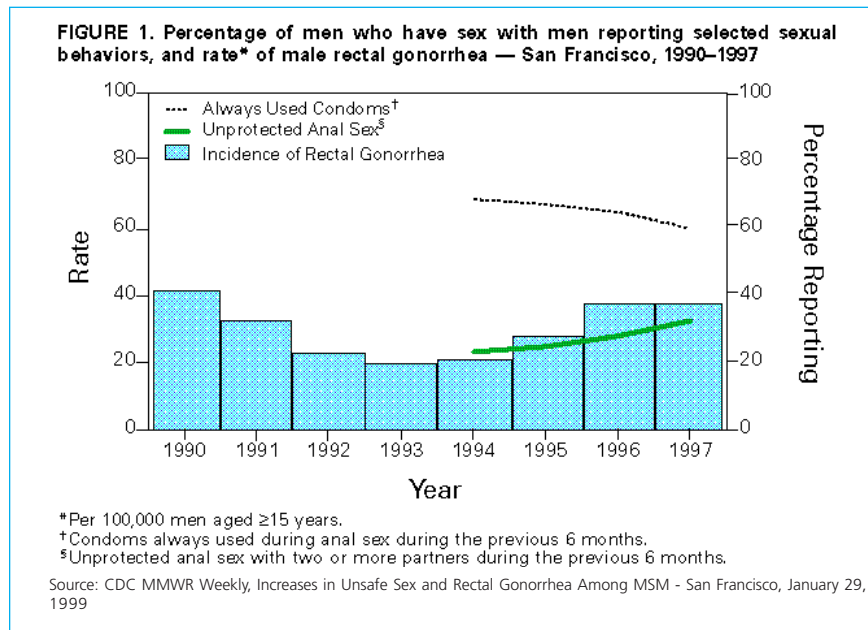
Racial and ethnic minority populations bear the heaviest burden of HIV disease associated with injection drug use. In 1997, more than a third of all AIDS cases among African Americans (38%) and Hispanics (37%) were IDU-associated, compared to 22% among whites. In addition, IDU-associated AIDS has a far greater impact on women than on men. Since 1981, at least 61% of all AIDS cases among women have been attributed to injection drug use or sex with a partner who injects drugs.

Progress in gay and bisexual community threatened

Historically, most people with HIV and AIDS have been men who have sex with men (MSM), including gay, bisexual and other MSM. While MSM have experienced declines in the rates of new HIV infection and AIDS cases, they continue to be the largest number of people with AIDS. In 1997, MSM represented 21,260 new AIDS cases, or 60% of all cases diagnosed in that year. While

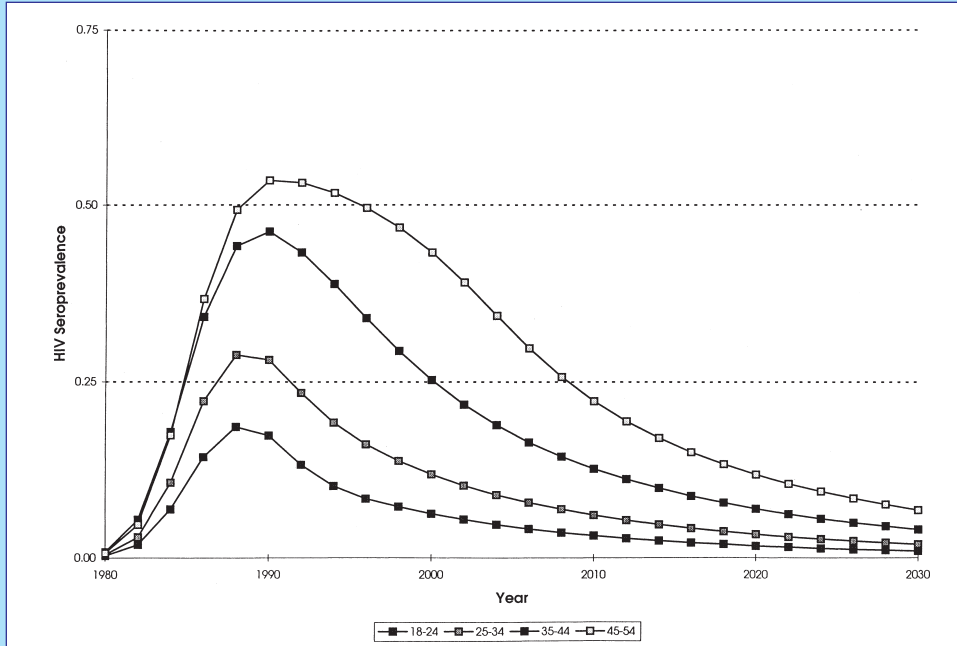
this group is the most affected, MSM overall have experienced the greatest declines in morbidity and mortality.

Recent indicators suggest that progress made with MSM may be temporary. A study of MSM in San Francisco found a slight increase in the proportion of men reporting anal sex from 58% in 1994 to 61% in 1997. Among the men having anal sex, the proportion reporting to use condoms “always” declined from 70% in 1994 to 61% in 1997. At the same time incidence of male rectal gonorrhea – a sexually transmitted disease – almost doubled from 21 to 38 per 100,000. This increase in gonorrhea reversed a three-year decline between 1990 and 1993 and is counter to an overall decline in gonorrhea nationally. These data suggest that MSM may be using condoms less often and increasing sexual behavior that place them at greatest risk for HIV infection.

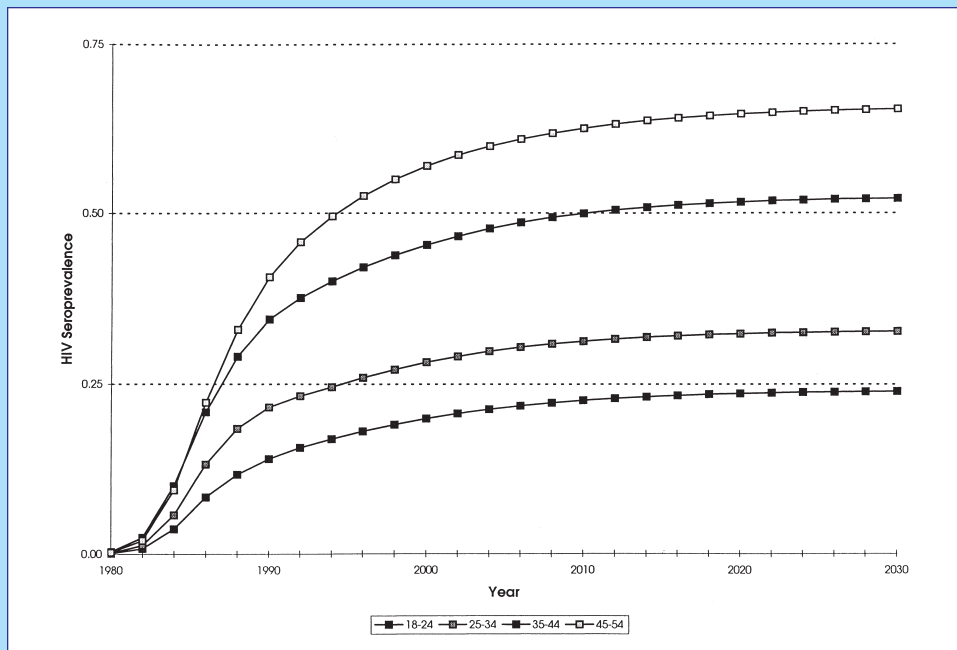


The potential impact of an increase in unsafe sexual behaviors could be devastating. By projecting forward the 1991 safer sex rates among gay men in New York City, Morris and Dean (1994) found that HIV transmission would drop below the epidemic threshold if gay men could maintain those safer sex rates.³ With an increase of only one additional unsafe sexual partner per year, however, the epidemic would explode once again. Clearly the epidemic in the most affected community is in a tenuous position.

³ Morris, M., & Dean, L. (1994). Effect of sexual behavior change on long-term Human Immunodeficiency Virus prevalence among homosexual men. *American Journal of Epidemiology*, 140(3), 217-232.



If safer sex rates reported in 1991 are maintained.



Just one additional unsafe sexual partner per year.

Source: Morris & Dean

III. Philanthropy's Response To The Domestic HIV/AIDS Epidemic

Philanthropy's impact and legacy on HIV/AIDS are substantial. Over the course of the epidemic, a period of only eighteen years, a systematic response to HIV/AIDS in the U.S. has emerged, and philanthropy has played a key role in nearly every element of that response. Today, there is an AIDS service organization in nearly every major city in the U.S. There are prevention and intervention programs that have helped to change the course of the epidemic. There are compassionate treatment services utilizing methods of service delivery that never existed before AIDS. There are laws and policies that protect the human and civil rights of people with HIV – laws and policies that have served as models for other disabilities and conditions. And there is a substantial multifaceted U.S. government effort to provide necessary care and services for people with HIV/AIDS whose central element – the Ryan White CARE Act – utilizes a community-based planning and resource allocation approach that had never been attempted on a national scale with federal funds.

Within the philanthropic sector, HIV/AIDS has had a dramatic impact as well. One of the distinguishing characteristics of philanthropy's response to HIV/AIDS as compared with some other social issues and needs is the way in which funders organized themselves and made long-term commitments to the issue. As early as 1983, HIV/AIDS began receiving sporadic philanthropic support. The New York Community Trust, located in one of the country's early AIDS epicenters, was one of the first community foundations to develop an HIV/AIDS-specific funding initiative and made its first HIV/AIDS grant in 1983. Beginning in 1986 - six years after the first AIDS case was reported, and before there was significant categorical government funding - grantmaking institutions began to provide significant support to AIDS-related programs and services. At that time, the Robert Wood Johnson Foundation weighed in with a \$17.1 million investment – the AIDS Health Services Program – the first large-scale private foray into HIV/AIDS. This leading effort cleared the way for other philanthropic involvement and signaled the beginning of this country's full philanthropic response.

Other support from throughout the sector was soon to follow. For example, in 1988, the Ford Foundation joined together with eight independent and corporate foundations to create the National Community AIDS Partnership (now known as the National AIDS Fund). This national funding pool provided vital leverage for local HIV/AIDS grantmaking and established mechanisms for local control over fund distribution. Corporate funders such as Levi-Strauss and Apple Computer were also early leaders.

Many, though not all, of the foundations and corporations that launched that private funding effort more than a decade ago remain deeply committed to and involved in HIV/AIDS-related funding. The philanthropic response to HIV/AIDS, including the formation of an action-oriented affinity group, Funders Concerned About AIDS, set a new standard for the sector. FCAA brought together grantmakers and non-grantmakers, expanding beyond networking into other activities such as advocating for direct philanthropic leadership, policy and advocacy and systematic collaborative funding efforts.

As we close the second decade of HIV/AIDS, we have had to accept the unfortunate reality that this crisis will be with us for many years. The current therapies, while effective for some in the devel-

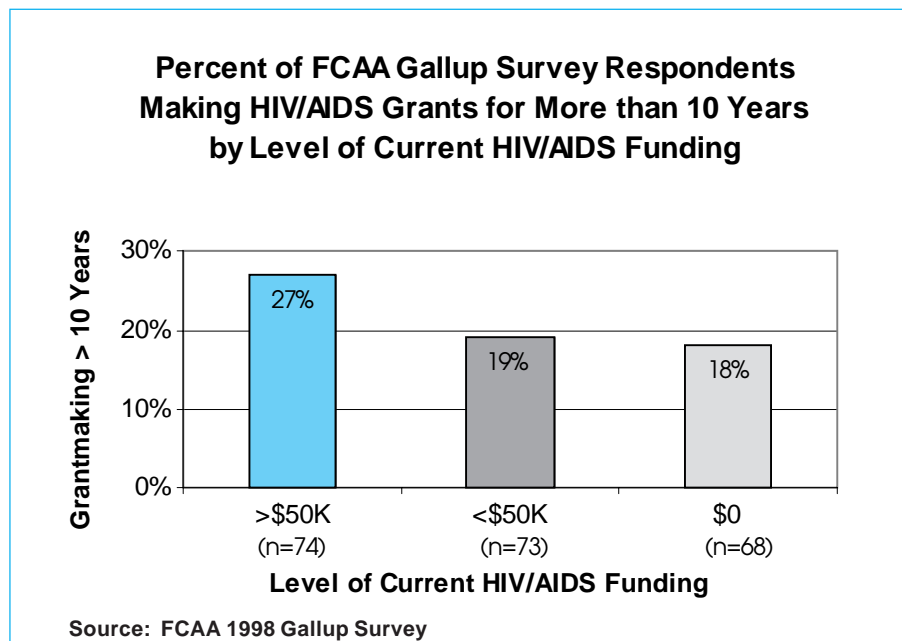
oped world, are not a cure. A vaccine is the only hope for ending the disease here in the United States and the developing world where current treatments are not even an option. Yet, there is no vaccine, and the most optimistic estimates suggest that it will be at least ten years before one is available. HIV prevention strategies are working in some communities, but it is clear that significant improvement in this arena can and must be made. The HIV/AIDS epidemic will be with us well into the next century, evolving and presenting new challenges to philanthropy. Building on the sector's legacy, it is timely and crucial for philanthropy to reflect on its accomplishments and to wisely use the experience of the past to respond aggressively to the future.

The FCAA Gallup survey reveals a core group of funders who have provided long-term significant support to HIV/AIDS

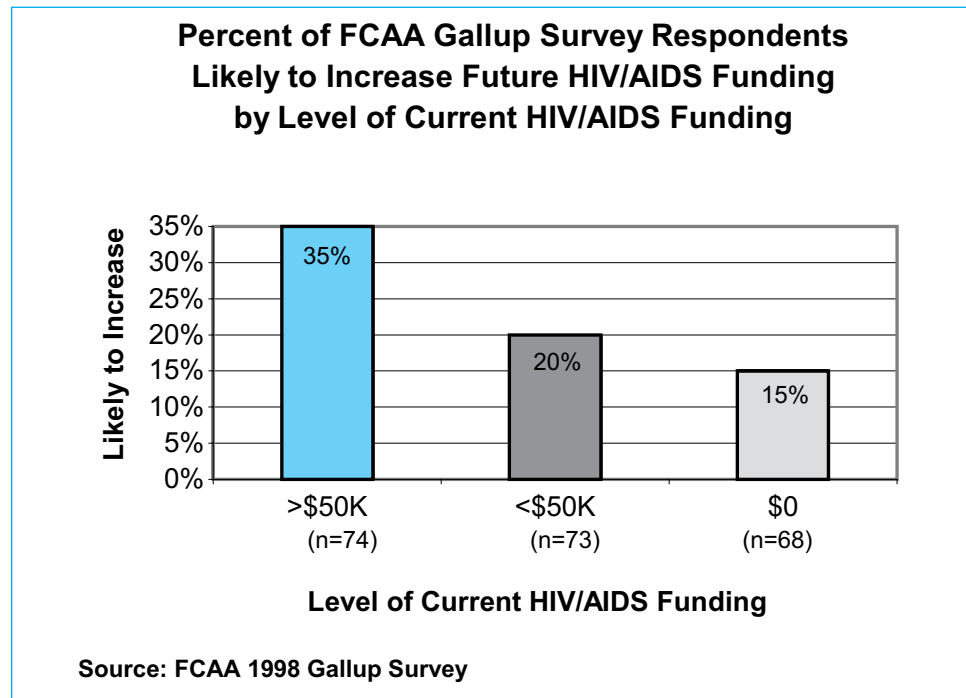
“There is a hardcore group of funders who are staying the course and continuing to be creative and effective in doing their work.” A central finding from the FCAA Gallup survey supports this observation made by an HIV/AIDS grantmaker in a key informant interview.

Based on the FCAA Gallup survey results, it was possible to identify a group of grantmakers – those who fund HIV/AIDS with grants totaling \$50,000 or more in the current fiscal year, 1998 (27% of survey respondents). This group of funders – called the “core group” for analysis purposes – has made a significant investment in HIV/AIDS that, according to the FCAA Gallup survey, relates to other indicators of their commitment to and knowledge about HIV/AIDS. These funders are likely representative of a subset of philanthropy that is and has been the mainstay of HIV/AIDS funding. Members of the core group possess these characteristics:

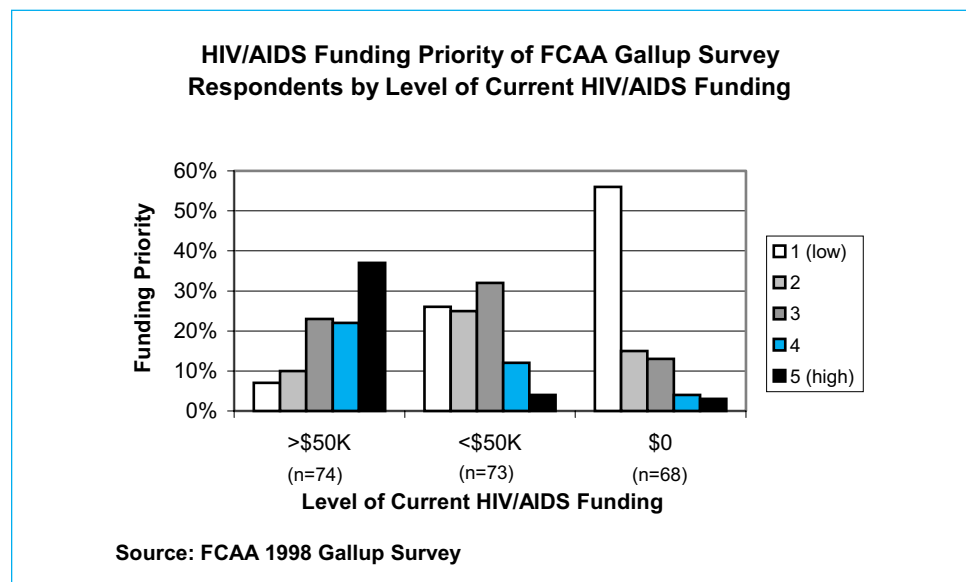
- The core group has been funding HIV/AIDS for longer than other grantmakers. Twenty-seven percent of core group funders have been supporting HIV/AIDS for ten years or more, as compared with only 19% of those grantmaking institutions making grants of less than \$50,000. Ten years is an important benchmark in light of the fact that widespread, major philanthropic funding for HIV/AIDS began in earnest in 1986. It suggests that many of those who launched the philanthropic response to the AIDS crisis are still providing leadership today.



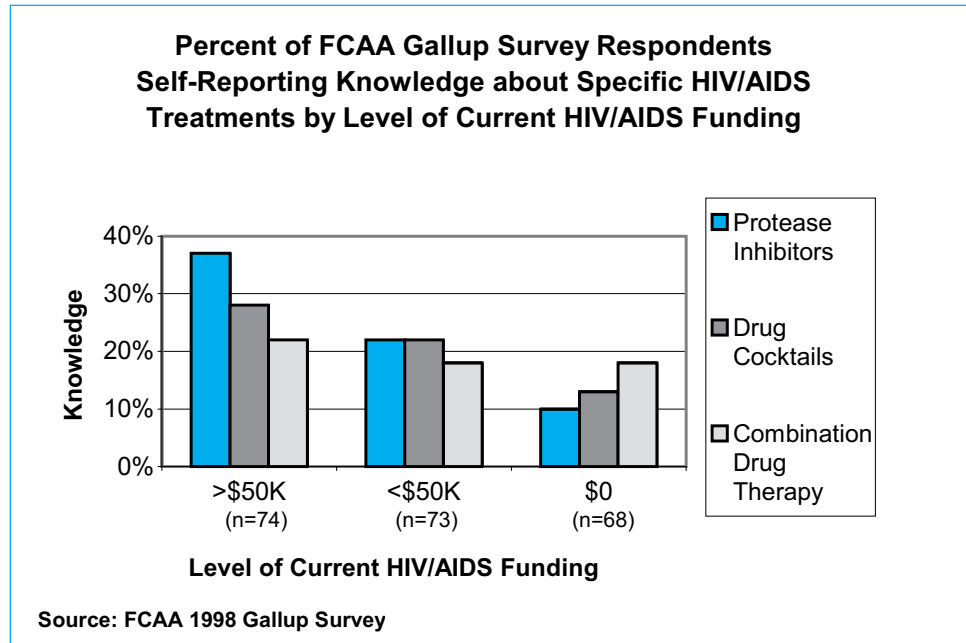
- Core group funders are more likely to increase HIV/AIDS funding in the future. In the FCAA Gallup survey, 35% of core funders are likely to increase future HIV/AIDS funding, compared to only 20% of those giving less than \$50,000.



- Over half (55%) of core group funders expect to maintain the same level of funding for HIV/AIDS in the upcoming year (1999) as in the present year (1998).
- Core group funders are more likely to describe HIV/AIDS as an urgent issue within their organization. Eighty-seven percent of core funders report that HIV/AIDS is an urgent issue for their organization, compared with 64% for those giving less than \$50,000 and 35% for those not giving at all to HIV/AIDS.
- HIV/AIDS is a higher funding priority for core group funders. Thirty-seven percent say it is an “extremely high priority,” and an additional 22% say it is a “high priority.”



- Core group funders are more knowledgeable about HIV/AIDS than other funders. Forty-six percent describe themselves as “very knowledgeable,” compared with 23% of those outside the core.
- The core group also has greater specific knowledge about recent developments in HIV/AIDS treatments than other funders. Thirty-seven percent independently mentioned being aware of protease inhibitors, a treatment for HIV/AIDS, as compared with only 22% of those outside the core group.



The FCAA Gallup survey reveals signs of weakness within the core group of funders.

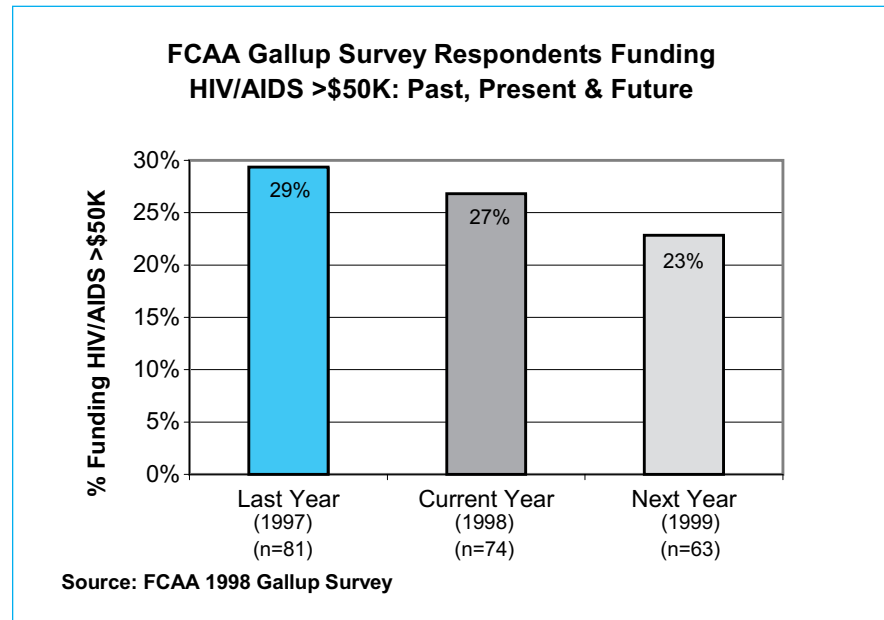
While it is encouraging that there is a group of funders who have been and appear to remain strongly committed to HIV/AIDS, the data from the FCAA Gallup survey points to provocative contradictions and troubling signs of weakness in the mainstay of the philanthropic response.

- Nearly 40% of core group funders say HIV/AIDS is not a high priority. Sixteen percent report it to be a “very low” or “low” funding priority for their organization.
- Eight percent anticipate a decrease in HIV/AIDS-related funding.
- Over half (53%) of core group funders say they are only somewhat familiar with recent advances in the treatment of HIV/AIDS.

These data on the core group are contradictory. On the one hand, it is clear that there is a small group of funders who are knowledgeable, have a long-term commitment and make larger grants. At the same time, one would expect that the vast majority of those most involved in the HIV/AIDS crisis to date would be the most current on HIV-related issues and view HIV/AIDS as a high priority and therefore be increasing support. Most concerning however, is that the core group is shrinking.

After ten years of giving, we felt that if we had to exit a program, this would be the one. It is sort of a "been there, done that" mentality. As the epidemic has become more and more linked to issues of poverty, it is not so clear that it is a "scientific" problem to solve.
 —Private Foundation

The number of FCAA Gallup survey respondents annually giving \$50,000 or more to HIV/AIDS is decreasing from 81 funders in 1997, to 74 in 1998, and 63 active grantmakers anticipated for 1999. This represents a 22% overall decline in the number of HIV/AIDS grantmakers making grants annually of \$50,000 or more to HIV/AIDS from the FCAA Gallup survey sample. In addition, when compared to the total survey sample (n=276), this group represents an even smaller proportion of the total survey sample over the three-year period: 29% in 1997, 27% in 1998 and 23% anticipated for 1999. These data provide further evidence that the mainstay philanthropic response is weakening.

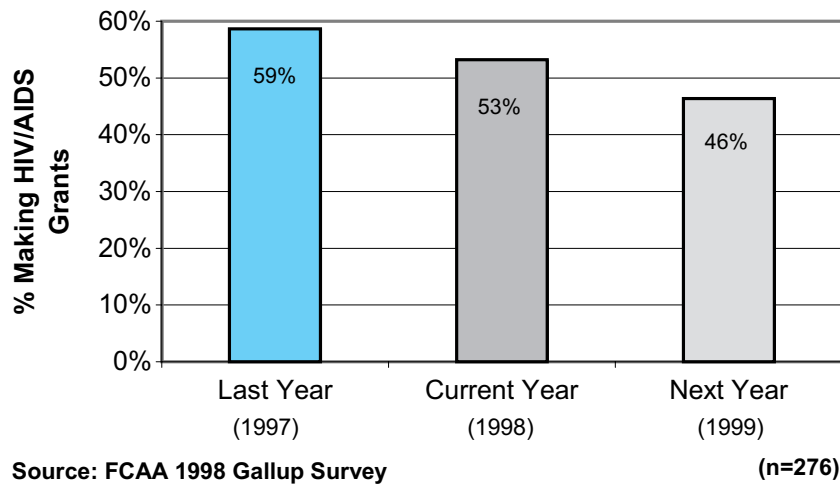


The total number of FCAA Gallup survey respondents committed to HIV/AIDS grantmaking is also declining

The larger pool of grantmakers investing in HIV/AIDS is also getting smaller. Of the 276 respondents to the FCAA Gallup survey, 59% indicate that they awarded an HIV/AIDS-related grant in 1997. Fifty-three percent indicate that they fund HIV/AIDS-related programs and services in 1998, a nine-percent decline in the actual number of funders. More troubling is that only 46% indicate that they intend to make HIV/AIDS-related grants in 1999, an overall decline in the total number of funders of 21% in the three year period in question.

Other data support this finding. The 1998 Foundation Grants Index, which includes a national sample of over 86,000 grants of \$10,000 or more, shows a downward trend for HIV/AIDS-related funding. Support for AIDS prevention, treatment and research fell from \$37 million in 1996 to \$30 million in 1997. Over the same period of time, foundations in this index increased their level of health-related giving from \$1.18 billion to \$1.32 billion. And, as noted previously, this same period also saw an astounding increase of 15.5% in overall philanthropic giving to an estimated \$15.98 billion. Juxtaposed against these increases, the HIV/AIDS decline is even more striking.

HIV/AIDS Grantmaking among FCAA Gallup Survey Respondents: Past, Present & Future



These results are provocative on two levels. First, we are seeing a decline in the number of active HIV/AIDS grantmakers from year to year. If this trend continues, HIV-related grantmaking will engage fewer grantmakers by the year 2000 than has been the case for most of the 1990s. The second cause for concern relates to the sample itself. The survey sample was drawn from the mailing and audience list of FCAA, a list that in theory includes those grantmakers who are thought to be most engaged in or committed to HIV/AIDS-related issues. Nevertheless, upon being asked about their own grantmaking efforts in the field, only 59% indicate that they made a grant in the last year. Nineteen percent are unable to state whether their organization made an HIV/AIDS-related grant in the last year, suggesting that interest in HIV/AIDS, indicated by their association with FCAA, does not necessarily translate into action. This issue is further explored later in the report.

Key informant interviews with philanthropy and HIV/AIDS organization staff offer some evidence that within philanthropy, there may be some sectors where interest and investment are being maintained or even growing and other parts of the sector where they are declining. Anecdotally, corporate funders appear to be most consistent in their funding. One Midwest HIV/AIDS service provider experienced a 10% increase in corporate giving from the previous year, comprising 24% of the agency's total budget. Other AIDS service providers reported receiving more funding from pharmaceutical companies, a trend they believe is related to the recent advancements in HIV/AIDS treatment. At the same time, these same organizations report that insurance-related foundations have been withdrawing support.

Consistent with the FCAA Gallup results overall, key informants are far less positive about support from private foundations. "They are walking away," said the development director of a major HIV/AIDS service provider. A service provider in a smaller city reports that the organization has hired an additional grant writer in order to produce twice as many funding proposals. This was needed just to maintain the status quo because the success rate of the organization's grantseeking from private foundations has decreased to approximately one in five.

It is harder to get private foundation support. They are looking for reasons not to fund us. We are perceived as a wealthy cause...(and) people want to walk away from the epidemic. Our share of private foundation support has shrunk by a couple of hundred thousand dollars in the last couple of years.

—HIV/AIDS Service Organization

We lost half of our funders recently. We dropped from 15 funders in 1997 to 6 funders in 1998. One of our funders is making up the dollar difference this year, but they can't make it up forever.

—HIV/AIDS Funding Collaborative

Major private foundation funders in New York and California, areas first and hardest hit by HIV/AIDS, are pulling back as well. A New York funder noted that foundation support in the area appears to be on the decline. A California AIDS funding collaborative reports a 20% decline in support. Service organizations in other parts of the country are aware of this and fear that if funding on the coasts declines, the rest of the country will experience a similar trend in the near future. As one Midwestern development director put it, “we are waiting for the shoe to start slipping off.” Just as the HIV epidemic spread from the nation’s coasts inland, will philanthropy’s declining investment follow a similar path?

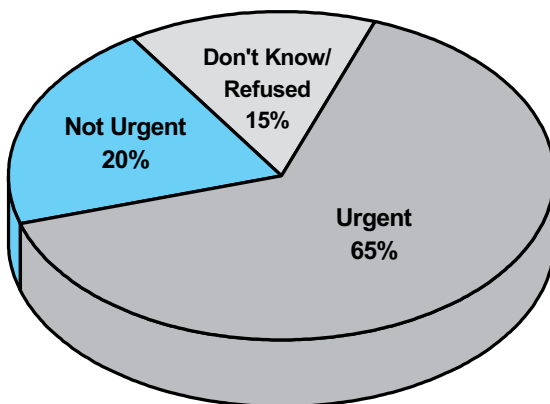
FCAA Gallup survey respondents have maintained a sense of urgency regarding HIV/AIDS, yet feelings of urgency often do not translate into grantmaker action

There continues to be a significant sense of urgency about the HIV/AIDS crisis, according to the FCAA Gallup survey. Nearly two-thirds (65%) of organizations responding report that HIV/AIDS is still an urgent issue for them.

One element of this sense of urgency is also indicated by the fact that many of the same funders also express dissatisfaction with certain aspects of this nation’s response to HIV/AIDS,

even in light of recent progress and advancements. Most notably, fewer than half of respondents say they are at least somewhat satisfied with advancements in HIV prevention (45%) and public policies concerning HIV/AIDS (41%). Substantially more, 61%, are at least somewhat satisfied with HIV/AIDS treatment, and 59% are somewhat satisfied with biomedical research related to HIV/AIDS. This response is to be expected given the recent advances in drug treatment.

Urgency of HIV/AIDS for FCAA Gallup Survey Respondents' Organizations



Source: FCAA 1998 Gallup Survey

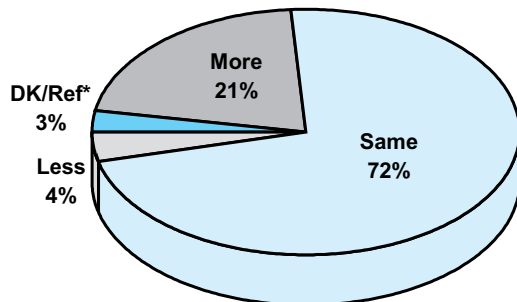
(n=276)

One would expect that a high sense of urgency and some level of dissatisfaction with progress on the issue would equate to action, and in the case of philanthropy this would mean grantmaking. The FCAA Gallup survey data, however, do not support this. The majority

(72%) of FCAA Gallup Survey respondents who report that HIV/AIDS is an urgent issue for their organization believe that their current year’s level of funding is about the same as last year’s, and four percent report that it is even less. Sixty-nine percent of grantmaking institutions that reported an actual decrease in HIV/AIDS funding on the survey said that HIV/AIDS is still an urgent issue for their organization. In addition, 13% of the organizations that state that HIV/AIDS is an urgent issue are not currently funding HIV/AIDS at all.

It is clear from the survey findings that having a sense of urgency about the HIV/AIDS epidemic is not a key determinant for philanthropic funding. More than half (54%) of respondents who say that HIV/AIDS is an urgent issue for their organization at the same time say that it is a low funding priority (1,2 or 3 on a five-point scale where 1 means low priority and 5

Changes in HIV/AIDS Funding Levels from the Last to the Current Year for FCAA Gallup Survey Respondents for Whom HIV/AIDS is an Urgent Issue



*Don't Know/Refused

Source: FCAA 1998 Gallup Survey

(n=179)

It is easy for philanthropy to say there are other more pressing problems. You are forced to advocate for yourself in light of other problems that are important.

—HIV/AIDS Service Organization

other issues, there is a fear that newer foundation staff will not pursue the legacy of these early philanthropic leaders.

The FCAA Gallup survey and related interviews find several, sometimes contradictory explanations for current HIV/AIDS funding trends

The FCAA Gallup survey was not able to identify one single or primary factor causing current trends in HIV/AIDS funding, but instead suggests many related and sometimes contradictory explanations. Changes in the HIV/AIDS epidemic, declining public and private sector leadership, problems with the AIDS service sector, and funder fatigue all appear to be playing a role. As one service provider noted, “Other issues do not bring as much baggage with them.” As the HIV/AIDS crisis ages and changes, the questions for philanthropy are, has the baggage become too heavy, and if so, why?

In the key informant interviews, several grantmaking institutions noted that they have decreased support for HIV/AIDS due to an overall change in funding strategy. A large foundation explained that it decreased funding for HIV/AIDS and other disease-specific health issues in favor of funding focused on improving the overall system of healthcare. With HIV/AIDS becoming more of an endemic health problem, the rationale is that it will still be supported, just through different, less-specific means. Another grantmaker, speaking on behalf of a small foundation that has supported HIV/AIDS for many years, indicated that they had withdrawn all health-related funding, including HIV/AIDS, because of the massive infusion of private dollars from the new healthcare and hospital conversion foundations. The underlying assumption is that these new foundations will support HIV/AIDS. However, this may not turn out to be true. While these new foundations are mandated to support health and healthcare, as of yet few have emerged as key funders in HIV/AIDS.

Changes in grantmaking, regardless of the issue, are due, in part, to the fact that the amount of resources available to funders varies over time. The recent growth of the stock market is a major reason many grantmaking institutions have more funds to grant at present. Of the FCAA Gallup survey respondents who report an increase in their HIV/AIDS funding, almost half (49%) said this is

means extremely high priority). One explanation for this may be the growing number of health and social concerns competing for the relatively limited amount of philanthropic dollars.

Grantmakers have also noted that the same individual grantmakers have been involved with HIV/AIDS philanthropy over time. The same faces appear at meetings and conferences and are the same individuals advocating for and granting resources, regardless of the institution they happen to be working in at the time. The concern is that there is a need for broader participation and new leadership within the sector. “It is hard to sustain this work over time,” comments one long-time HIV/AIDS grantmaker. As the individuals most committed to HIV/AIDS issues retire or refocus their attention on

The overall private funding pot is growing, but the pot for HIV is not.

—Midwest HIV/AIDS Service Organization

due to having greater resources. Only 15% cite an increase in need as the explanation for their increased support. This is also cause for concern. If the strength of the economy is the primary reason for increases in HIV/AIDS funding, this suggests that a weaker economy could lead to a further stagnation or a dramatic drop off in funding regardless of increasing need or other developments surrounding HIV/AIDS.

FCAA Gallup survey respondents reporting a reduction in HIV/AIDS funding explain this decline in several ways. Some report receiving fewer or no funding proposals, while others indicate having fewer resources available for HIV and AIDS. Still others clearly cite a shift in their organization's funding priorities. One respondent also spoke to philanthropy's limited attention span, saying, "We have many requests for our funds, and we will not fund the same program every year."

People with HIV don't look as much like grantmakers as they used to. Higher numbers of people with AIDS are impoverished, substance-abusing, mentally ill, homeless – populations that foundations have difficulty impacting. AIDS is now combined with many complex social issues - this is too difficult for foundations to address.

—HIV/AIDS Funding Collaborative

There are major changes in the HIV/AIDS epidemic that are not yielding concomitant changes in philanthropy's response. The HIV/AIDS epidemic is spreading fastest in minority communities and yet the funding trend generally for ethnic and racial groups appears to be on the decline. According to the 1998 Foundation Grants Index, funding for racial and ethnic groups (not just related to HIV/AIDS) fell from 9.3% of philanthropic dollars in 1996 to 7.9% in 1997. This is the lowest level of minority-specific funding in the 1990s.

Both funders and HIV/AIDS service providers point to the community-based organizations themselves as being to some extent responsible for some of the funding declines. From the perspective of some funders interviewed, service providers have become entrenched and bureaucratized. While the development of formal organizations, programs and services was necessary to deal with the enormity and complexity of the problem, some see the large AIDS organizations as less capable of responding to changes in the epidemic or sponsoring innovative programs. "The trouble is that it is an industry, not a movement," said one grantmaker. "It is harder to change an industry than a movement." The seeds planted by philanthropy in grassroots organizations a decade ago have now grown into larger, more professional nonprofits. The dilemma presented here is that some funders indicate that the most established and well-funded organizations are the least capable of innovation and risk-taking. Yet, these very organizations report that it is private funding that encourage and enable them to take risks.

They (philanthropy) are saying, "We want innovation, we want new things." As the epidemic changes, most of it is just taking old programs and switching populations. Old programs for new populations may not be innovation for funders, but it is what is needed.

—Midwest HIV/AIDS Service Organization

In the key informant interviews, HIV/AIDS organizations themselves admit that, "we in the community did a really bad job in engaging philanthropy." They cite ongoing leadership changes and relative instability as significant barriers to engaging philanthropy consistently over time. In addition, when government resources became more plentiful starting in 1991, the need for organizations to fundraise from the private sector became less of a priority. Now that the pot of government resources is slowing in growth and the number of clients and need for other AIDS initiatives continue to rise, organizations are needing to rethink their relationship to philanthropy. Unfortunately, many are finding that they have no pre-existing relationships with the sector or are trying to engage funders just as the funders are disengaging from the issue.

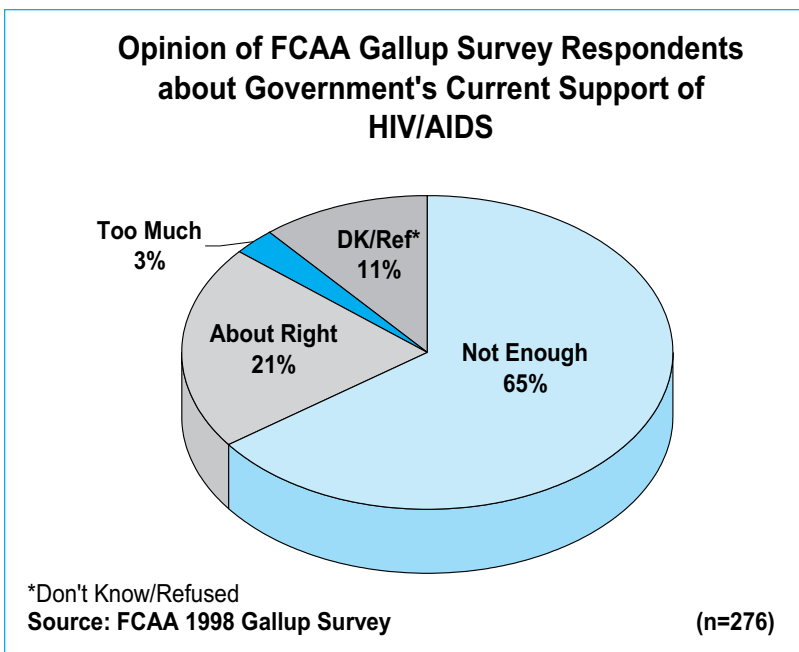
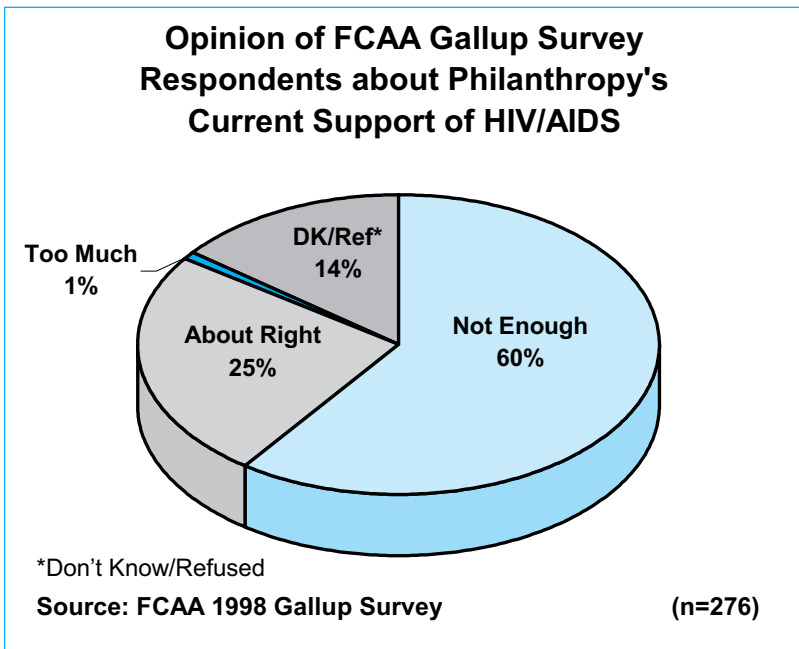
There are lots of leadership changes in AIDS organizations. Individuals and communities are burned-out and this makes us less effective advocates. And there are lots of ASOs that should fold. We have given philanthropy lots of excuses not to fund us.

—HIV/AIDS Service Organization

Some of that (private foundation) money was for our controversial projects... So when it disappears, it forces us to find other support or use other unrestricted funds for these projects. The more we do that, the less we have for the really controversial programs like needle exchange... It hinders our ability to respond quickly and it forces us to make Sophie's choices.

—HIV/AIDS Service Organization

While funders recognize that the amount of government resources for HIV/AIDS has significantly increased in recent years, to a total of \$4.9 billion in federal government support in 1998, it does not appear to be a major reason why they are pulling back. Sixty-five percent of funders indicate on the FCAA Gallup survey that the government is not doing enough in HIV/AIDS, even greater than the 60% who feel that philanthropy is not doing enough. Clearly philanthropy sees a role not only for itself, but also for government, in supporting HIV/AIDS, and feels that the epidemic demands more, not less support, from both sectors.



IV. Philanthropy's Response To The International HIV/AIDS Pandemic

Internationally, philanthropy can fund programs that governments have been unable to fund. In HIV/AIDS, the United Nations is limited. Philanthropy has looked at innovative, daring and risky programs and funds them in a microcosm. This shows and demonstrates new and effective interventions that have been adopted by larger funders and sometimes governments. In this way, philanthropy has been trailblazing.

—International Corporate HIV/AIDS Funder

While U.S.-based, private philanthropic giving around the globe is on the rise, it is unclear whether there will be a concurrent rise in HIV-specific, private international grantmaking. According to a 1997 Foundation Center study, international giving in all areas increased by 18% from 1990 to 1994. The number of international grants increased by 30%, and new foundations and other funders making international grants for the first time accounted for roughly half of the added grant dollars. The question is whether this growth in international funding will extend to HIV/AIDS.

Trends in the International HIV/AIDS Pandemic

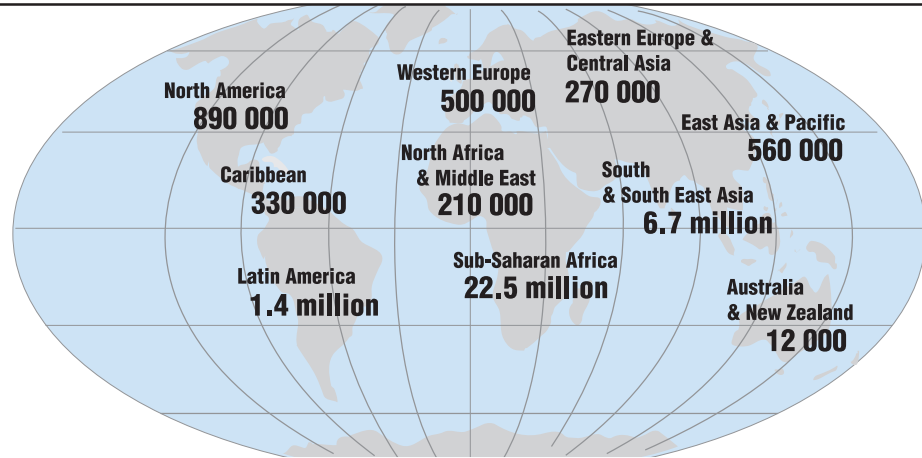
HIV/AIDS weighs a heavy and escalating burden on the international landscape. As 1998 came to a close, an estimated 33.4 million children and adults were living with HIV/AIDS across the globe, 10% more than just one year earlier. During 1998, 11 men, women and children were infected with HIV each minute. In total, AIDS had claimed 13.9 million lives; 2.5 million lives were lost in 1998 alone.

End-1998 global estimates Adults and children

- **People living with HIV/AIDS 33.4 million**
- **New HIV infections in 1998 5.8 million**
- **Deaths due to HIV/AIDS in 1998 2.5 million**
- **Cumulative number of deaths due to HIV/AIDS 13.9 million**

Source: UNAIDS

Adults and children estimated to be living with HIV/AIDS as of end 1998



Total: 33.4 million

Source: UNAIDS

More than 95% of HIV-infected people live in the developing world, which has also experienced a similar percentage of the world's AIDS deaths. Heterosexual sex is the primary mode of HIV transmission in most developing countries, followed by needle sharing related to injection drug use. Sub-Saharan Africa, with approximately 22.5 million people currently living with HIV/AIDS, has clearly been most severely impacted. In particular, between 20% and 26% of people between the ages of 15 and 49 in Botswana, Namibia, Swaziland and Zimbabwe are currently living with HIV or AIDS.

The impact of HIV/AIDS is global, with virtually every country in the world experiencing new HIV infections in 1998. In particular, there is increasing concern about the rapid spread of HIV on the Asian continent, especially in South Asia and East Asia.

The prevention and care efforts in most countries are making little or no difference. Infection rates are still high, and in the undeveloped worlds, death rates are staggering. To some, this demonstrates that the public health approaches have not been effective. This is dangerous. It encourages AIDS fatigue, because it demonstrates that approaches we have taken in the past haven't worked. The risk here is that we think there is nothing we can do. The continued rates of infection highlight the problem, but [they] can also lead to despondency. For funders that have been involved for ten years or so, they say, "We have done it and not much has changed."

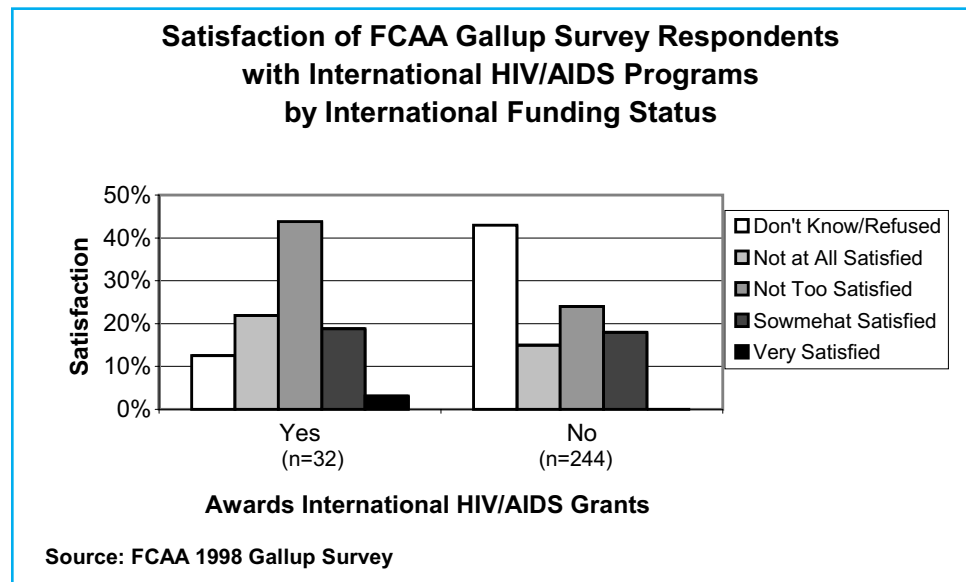
—International Corporate HIV/AIDS Funder

Internationally, HIV is spreading most rapidly among young adults; people between the ages of 15 to 24 accounted for approximately half of the world's new HIV infections in 1998. By affecting individuals who are entering their peak productive and reproductive years, HIV and AIDS pose a very real barrier to development in some countries. In addition, one-tenth of new infections in 1998 were among children under 15 years of age. Most are believed to have been infected through their mothers, before or at birth or through breastfeeding. A total of 1.2 million children living in the world are now infected with HIV.

Although HIV infection spreads at different rates through different populations, several factors have been found to drive the HIV/AIDS epidemic, regardless of country. All relate to people in vulnerable situations. People moving away

from their families, either to escape abusive situations or conflicts or in search of new economic opportunities, are more likely to be exposed to HIV, as are people dealing with high levels of stress and danger in their lives. Those in conflict and refugee situations, for example, not only have little control over their lives and their exposure to HIV, but also may worry less about the long-term implications of HIV/AIDS in the face of their daily struggle for survival. The stigma associated with HIV/AIDS also plays a powerful role in deterring appropriate preventive behaviors – seeking HIV testing or using condoms.

There is no arguing that the HIV/AIDS crisis globally is one of the most serious public health problems of this or any century. While the statistics demonstrate that there is compelling need, philanthropy can look at the crisis as being insurmountable – so great that any private investment could have little or no impact.



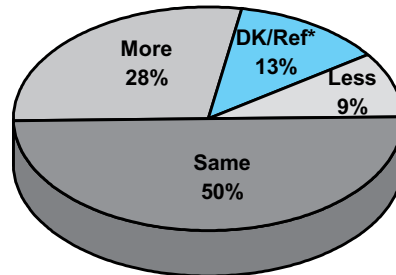
The FCAA Gallup survey finds that there is a great sense of urgency regarding the international HIV/AIDS pandemic, yet few grantmakers are funding in this area

Philanthropy is both aware of and greatly concerned about the international HIV/AIDS crisis, according to FCAA Gallup survey findings. Funders surveyed also believe that more needs to be done to combat the pandemic across the globe. Two-thirds (66%) of respondents who fund HIV/AIDS internationally are dissatisfied with the progress that has been made with the international pandemic. Even funders that do not fund internationally are twice as likely to be dissatisfied (39%) as satisfied (18%) with international developments.

Grantmakers who are involved with international HIV/AIDS funding were also asked about their organization's current sense of urgency about the international pandemic. While half (50%) of respondents feel that their organizations' current sense of urgency is about the same as five years ago, three times as many respondents feel it has increased (28%) rather than decreased (9%).

There are two ways by which funders can support international HIV/AIDS initiatives. They can fund U.S.-based programs that work abroad or they can fund organizations in other countries. However, the vast majority of U.S. grantmakers do not fund outside of the U.S. According to the FCAA Gallup survey, only 12% of respondents fund HIV/AIDS internationally, which appears to be consistent with the proportion of all U.S. philanthropic funding dedicated to international issues.

Level of Current Organizational Urgency about International HIV/AIDS Epidemic as Compared to 5 Years Ago among FCAA Gallup Survey Respondents

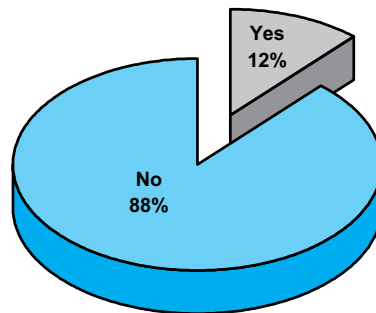


*Don't Know/Refused

Source: FCAA 1998 Gallup Survey

(n=32)

Percent of FCAA Gallup Survey Respondents Awarding International HIV/AIDS Grants



Source: FCAA 1998 Gallup Survey

(n=276)

domestically in treatment and prevention is transported overseas without the need for philanthropic investment.

The Foundation Grants Index reports that roughly 11% of all foundation grant dollars were awarded for international activities in 1997.

The limit on international philanthropic support of HIV/AIDS may be largely due to the domestic funding limitations in many foundation charters. Yet, when faced with dire international needs, even grantmakers with the flexibility to fund overseas face a difficult dilemma: fund at home or fund overseas. According to some informants, key constituents such as donors to advised funds and board members will often pressure grantmaking institutions to fund at home, not internationally.

There are several different impressions expressed among grantmakers as to why international funding of HIV/AIDS is where it is right now. One informant noted that there is a mistaken impression that the recent progress made domestically to combat HIV/AIDS has also occurred globally. This thinking assumes that the progress made

People equate what is happening domestically to what must be happening internationally. AIDS is well funded by government in the U.S. now and it is not as much of a killer here, so people feel it does not deserve as much attention. The urgency isn't seen.

—International HIV/AIDS Organization

One funder believes that philanthropy has not shown the same magnitude of risk taking in its grantmaking overseas as it has within the United States. Yet another is more optimistic, noting that, "It is getting easier to get involved in AIDS internationally," adding, "grantmakers are becoming more daring and more comfortable in tackling issues of gender, sexuality and working with marginalized populations."

There does seem to be a consensus that the crisis nature of the HIV/AIDS pandemic globally demands a response from the international community generally and the philanthropic community specifically. Perhaps there are lessons to be drawn from the domestic experience that can in fact be transported by philanthropy to the developing world. Perhaps there are strategies,

programs, services and organizations that can help to stem the tide of the raging pandemic overseas. These are issues worth exploring as we enter the third decade of HIV/AIDS. Where and how can philanthropy use its experience, its resources, its flexibility and its commitment to yield the greatest possible return on investment?

V. A Call To Action: The Future Role Of Philanthropy In HIV/AIDS

As the survey and other research data in these pages detail, there are significant changes in the philanthropic response to HIV/AIDS. The reasons for these are varied, have many nuances and are at times contradictory. The bottom line, however, is that we are at a very troublesome juncture in the philanthropic response to HIV/AIDS. It appears that a mix of some domestic successes in addressing the epidemic, general “AIDS fatigue,” the growing endemic nature of the problem, and the sheer explosion of the crisis globally has led to a verifiable and significant diminution in the grantmaking response.

If this is the beginning of a larger, broad-based trend, grantmakers may be on the verge of a systematic retreat from HIV/AIDS funding. The specter of such a retreat from a wholly unsolved human tragedy raises many disturbing questions, especially at a time when available philanthropic resources overall are growing at record levels. The challenges of this drift in the philanthropic response to HIV/AIDS are even more daunting when placed in the larger resource context. As private institutional support is beginning to waver, AIDS organizations are reporting drops in many other revenue sources for their programs, such as individual donors, special events and even certain types of city and state government funding. Even modestly increasing federal government funding in some HIV/AIDS programs cannot replace such losses, let alone meet the escalating demands for most HIV/AIDS programs.

The results of the FCAA Gallup survey and the related research presented here are a wake-up call to private philanthropy that their ongoing – or newly initiated – engagement in fighting HIV/AIDS is critical in the coming years. Hopefully, the information and analysis contained in this publication will help funders assess their current and future grantmaking plans and can lead to many innovative and strategic ways to reinvigorate the philanthropic response.

We appreciate that in prioritizing funding issues, shaping grant portfolios and making decisions on ways that funders exercise leadership on any issue, there are numerous factors and variables to be considered. We offer the following list of suggestions – some rather specific, others more like general principles – by way of illustration to spark contemplation, discussion and most importantly – action!

VI. FCAA's Blueprint For The Next Generation Of HIV/AIDS Philanthropy

- Philanthropy should stay the course on HIV/AIDS funding, especially in ways that build upon its inherent strengths and realize the unique role the sector can play in the fight against HIV/AIDS. One example is providing funding to programs unlikely to be supported completely, or in some cases at all, by individuals or government, such as needle exchange programs or advocacy efforts. Another example is seeding innovative or severely underfunded approaches in a geographic area, population group or sector of HIV/AIDS work, such as funding traditional health care approaches to HIV/AIDS in some countries or microbicide development for women globally. In addition, funders should focus resources on specific projects, problems or communities. Even relatively small, targeted grants can leverage impacts far greater than the actual grantsize might predict.
- Grantmakers should respond to the facts, not the fiction, of HIV/AIDS. Funding involving care, services, prevention, advocacy and research should be guided by data rather than newspaper headlines or a general sensibility about what is or is not needed or what is or is not working. Whether from the field of epidemiology, evaluation research, public policy, medicine or other key sources, philanthropy is well situated to create and use data to support and replicate effective programs.
- Funders should be open to providing general operating grants to existing, high quality HIV/AIDS organizations. Such general support grants are very desirable because they are both flexible from the funder and grantee perspective and also meet the need to support otherwise underfunded core organizational functions. Such grants can also strategically fill critical gaps that are often created out of the many restrictions and requirements accompanying government funding to HIV/AIDS organizations.
- Grantmakers should be open to targeted grants for organizational capacity building. This can include grants for technical assistance for staff as well as other programs that promote the long-term viability and efficiency of an agency. Strong, well-developed organizations have a better potential for delivering strong programs and services and changing effectively to meet the needs of a dynamic disease and ever-changing social service and health care environments. This strategy can also support another important goal – sustainability. Capacity building is particularly relevant as HIV/AIDS' disproportionate impact on minority communities grows. Organizations based in these communities are often newer and less well funded and can benefit enormously from capacity building grants.
- Philanthropy should build on existing, high quality programs and should also support only those that remain necessary and responsive to HIV/AIDS at this point in time. Proven programs serving continuing needs still require and deserve funding. Funders should in the course of this process consider whether programs (even entire organizations) should be narrowed, re-focused, otherwise redefined, merged with other projects or agencies, or abandoned entirely. Fund new agencies or new programs only if they are necessary for the population served,

complement and support the grantee's mission and fall within the grantee's capacity to deliver the proposed program. The goal should not, however, be funding innovation for its own sake.

- Funders should seek opportunities for cross category funding of HIV/AIDS initiatives involving health care access, racial disparity, public health, substance abuse, STD prevention and treatment and family planning to name but a few areas. Proposed solutions to these larger problems should also contain solutions to the HIV/AIDS crisis. In this way, funders do not have to begin an AIDS-exclusive funding stream to become or remain an effective HIV/AIDS funder. In other words, funders can and should explore all of the necessary and creative ways that their funding initiatives in other areas do and can relate to HIV/AIDS. As long as the programmatic connections between HIV/AIDS and the other issues are real and explicit, such funding can be both innovative as well as responsive to the interconnected nature of HIV/AIDS in people's lives.
- Grantmakers who have the ability to do so should assess the explosion of HIV/AIDS internationally. The dimensions of the impact of HIV/AIDS within the developing world are astounding, especially in Sub-Saharan Africa and many parts of Asia. Collaboration is also essential in the international arena. Increased private funding needs to be coupled with new partnerships at the international level between private international funders, multi-national corporations, donor countries and United Nations agencies.
- Grantmakers in HIV/AIDS can enhance their funding by engaging in more collaboration with other HIV/AIDS grantmakers. It appears that many HIV/AIDS funders in a particular area or that fund a specific issue do so without knowledge of other funders with similar interests and initiatives. Who else is doing HIV/AIDS funding in your current (or proposed) geographic area or on your specific target issue? Does or will your funding initiative differ from theirs? Should it differ or can it be structured to effectively supplement it? Can similar efforts be combined or leveraged in some way to realize even greater private funding or some or more government funding?
- Grantmakers should play a role in the diversification of the field of HIV/AIDS philanthropy. Until the recent downward trend in HIV/AIDS grantmaking, the overall response to the pandemic from organized philanthropy was significant both in size and the growing diversity of funders and programs. Funders themselves can play a critical role in this diversification through active support of funding collaboratives and similar vehicles that bring new and more diverse funders into the HIV/AIDS arena, perhaps even as a means to smoothly and strategically replace long-term funders who no longer will fund HIV/AIDS.
- Funders should partner more with HIV/AIDS organizations and other organizations with existing HIV/AIDS programs to meet the many new challenges of HIV/AIDS. A partnership model of grantmaking is increasingly essential if programs are to be effective, sustainable and accountable. The same is especially true if funders have doubts about the need, effectiveness or stability of particular HIV/AIDS initiatives or organizations or are wary of the need for a new program in the area. Such partnerships are also an important means to insure the involvement of people living with HIV/AIDS in the funding process. The existence of long-term, respectful, two-way relationships between funders and grantees can not only avoid unpleasant surprises for each, but can also lead to maximizing the energy, focus, creativity and impact of the grants and the programs they fund.

VII. Conclusion

For readers of this publication who have in some way been confronted by or involved with HIV/AIDS issues and work for some time – as funders, volunteers or persons living with HIV/AIDS – reactions to the data and analysis presented here are no doubt complex. There is perhaps relief at all the “good news” about HIV/AIDS, including satisfaction about the critical role that philanthropy has played to date in fighting this disease. There is also possibly fatigue from being so involved for so long in such a complex and emotionally draining issue, frustration with the needs that still exists and desperation about how to prevent these realities from sapping philanthropy’s commitment to help win the fight. For those readers who FCAA believes should be joining the HIV/AIDS fight – new corporate funders, healthcare conversion foundations, new foundations and recently established donor-advised funds – the information here may simply represent the “usual” ebb and flow of philanthropy’s interest in or commitment to any one of many pressing issues.

But, for every reader and for all of organized philanthropy, FCAA’s message is straightforward and direct. All of our hopes and dreams aside, there simply is no fairy-tale ending to the story of HIV/AIDS, yet. No one person, community, institution or government can pat itself on the back for ending AIDS, yet. Simply put, our collective work is not done.

We stand at a historic moment in the HIV/AIDS pandemic and, more specifically for the work of FCAA and the purposes of this publication, this sector’s response to it. We can be a part of seizing that moment, realizing philanthropy’s important investment to date and starting down a road of actually ending this disease and its many consequences, domestically and internationally. Or, we can lose our focus, reduce our sense of urgency for this issue, and thus reduce this sector’s commitment to HIV/AIDS initiatives (or watch as that commitment lessens). If we choose by action or inaction the latter approach, it does not take a crystal ball nor would we be engaging in fancy to say that HIV/AIDS will simply continue to take a devastating toll. It will continue to ravage those most vulnerable in our communities – people of color, women, gay men, young people and injection drug users – and quite literally devastate entire populations of countries in the developing world.

Philanthropy can rise to this challenge as it did more than a decade ago when HIV/AIDS burst into the public’s consciousness. It will demand greater resources, better knowledge, sharpened focus, more collaboration and partnership, a stronger sense of urgency, and a willingness to convert urgency to action.

FCAA hopes that this study and all of our ongoing work will inspire and equip funders for the task. We welcome your comments, ideas and energy. We encourage funders to call us for more information or other types of assistance. We look forward to working with you to help eradicate HIV/AIDS and its consequences.

Appendix A: Technical Appendix

When interpreting these results, it should be kept in mind that all surveys are subject to limitations that affect the quality and generalizability of the results. The respondents in the FCAA Gallup survey represent a convenience sample, enrolled in the study because they were known by FCAA to have been involved in HIV/AIDS-related grantmaking or to be interested in HIV/AIDS-related issues. As such, the findings cannot be generalized to the full universe of philanthropy or a subset of philanthropy that would include every philanthropic organization known to be active in HIV/AIDS grantmaking (past or present) or interested in the topic. Rather, the findings are a reliable and robust portrait of those in philanthropy active in funding or interested in HIV/AIDS. The interpretation and discussion of the study findings account for this limitation.

FCAA contracted with the Gallup Organization to develop and implement the survey of philanthropy contained in this report. BTW Consultants — informing change was retained after the survey was designed and the data collected to perform the analysis of the survey results. BTW Consultants did not develop the survey instrument used for this study. As part of the reanalysis process, BTW Consultants collected additional primary qualitative information and secondary data to provide a more complete analysis.

The survey results are based on telephone interviews conducted by the Gallup Organization from July 8 – August 3, 1998. FCAA supplied Gallup with a master list of 653 persons, each from a different grantmaking institution, responsible for making grants to HIV/AIDS-related organizations and programs. Each person on the list was contacted at least once and was asked a screening question in order to ensure that they are the individual responsible for HIV/AIDS funding in their organization. Contact was made with 418 individuals, and of those 276 completed surveys. This represents a robust response rate of 66% and provides a sample size adequate for reliable statistical analysis.

In addition to the survey, FCAA contracted with BTW Consultants, a consulting firm specializing in evaluation, planning and organizational development in the philanthropic and non-profit sectors, to conduct additional research and provide additional information and analysis. As part of this process, BTW conducted structured interviews with 14 individuals for this project in early 1999. Individuals were drawn from the philanthropic and the HIV/AIDS sector and were chosen to provide anecdotal experiences to help illustrate key survey findings. The interviews utilized a standard set of open-ended questions. Respondents were promised confidentiality in order to garner more candid responses. The findings from the structured interviews represent the opinions and experiences of those interviewed and are not generalizable to the survey sample or the field of philanthropy as a whole.

Appendix B: Resources Section

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;
- suggest the many organizations and entities that can provide fertile ground for collaborations in the fight against the pandemic.

This resource section is by no means exhaustive. Therefore, we encourage 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.

Domestic HIV/AIDS and Related Issues

HIV/AIDS — General Information

The Rights of People Who are HIV Positive. William B. Rubenstein, Ruth Eisenberg, and Lawrence O. Gostin. Carbondale, IL: Southern Illinois University Press, 1996. This authoritative American Civil Liberties Union (ACLU) guide provides a comprehensive account of the rights and legal issues of people living with HIV disease and AIDS.

The Body

Website: <<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.

The Henry J. Kaiser Family Foundation

Website: <<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.

HIV/AIDS Internet Search Engine

Website: <<http://www.infoweb.org/search>>

This site provides a comprehensive HIV/AIDS search engine of the Internet.

HIV/AIDS — Divisions & 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: <<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 organizations, international and domestic, awarding grants to a variety of groups to support prevention activities based on science.

The CDC website features national and international statistics about HIV infection and AIDS cases, both current and projected.

NCHSTP News and Notes is the quarterly publication of the NCHSTP. It carries information on local, national and international prevention initiatives, disease treatment and conferences, among other things. To receive copies, call (404) 639-8939.

Office of National AIDS Policy (ONAP)

736 Jackson Place, NW

Washington, DC 20503

Phone: (202) 456-2437

The ONAP, created to provide a national focus and direction to the U.S. Government's response to HIV and AIDS, provides broad guidance for federal AIDS policy and fosters interdepartmental communication and coordination. ONAP also works closely with non-profit and for-profit organizations at multiple levels to ensure the broadest input into policy development and implementation. The ONAP also published *The National AIDS Strategy 1997*, a document outlining the framework for the U.S. response to HIV/AIDS.

Presidential Advisory Council on HIV/AIDS

736 Jackson Place, NW

Washington, DC 20503

Phone: (202) 456-2437

The Council, composed of a broad range of individuals from the public and private sectors, was organized to provide expert guidance to the President in determining national HIV/AIDS priorities and direction.

United States Agency for International Development (USAID)

Phone: (202) 712-0683

Website: <<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.

HIV/AIDS—National Advocacy Organizations

AIDS Action

1875 Connecticut Avenue, NW, Suite 700
Washington, DC 20009
Phone: (202) 986-1300
Website: <<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. AIDS Action is an excellent resource on federal HIV/AIDS public policy issues.

National Association of People With AIDS (NAPWA)

1413 K Street, NW
Washington, DC 20005-3442
Phone: (202) 898-0414
Website: <<http://www.napwa.org>>

NAPWA is a national organization that advocates for better health care access 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.

HIV/AIDS Among Specific Populations

The following resources provide further information on HIV/AIDS and specific populations.

PEOPLE OF COLOR

National Minority AIDS Council (NMAC)

1931 13th Street, NW
Washington, DC 20009
Phone: (202) 483-6622
Website: <<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.

National Black Leadership Commission on AIDS (BLCA)

105 East 22 Street, Suite 711
New York, NY 10010
Phone: (212) 614-0023
Website: <<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 effect participation of leadership in policy and resource allocation divisions at the national, state and local levels of communities of African descent nationwide.

National Council of La Raza (NCLR)

1111 19th Street, NW, Suite 1000
Washington, DC 20036
Phone: (202) 785-1670
Website: <<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 Survey of Latinos on HIV/AIDS. Menlo Park, CA: Kaiser Family Foundation, Spring 1998. This survey documents perceptions and knowledge about HIV/AIDS among thte Latino community nationwide. In addition, it provides statistical information on the impact of HIV/AIDS on the Latino population.

Asian and Pacific Islander American Health Forum (APIAHF)

942 Market St., Suite 200
San Francisco, CA 94102
Phone: (415) 954-9969
Website: <<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. APIAHF also publishes the quarterly newsletter *API HIV Forum*. The *Forum* contains current news on HIV/AIDS as it affects the Asian and Pacific Islander communities. It also includes information on related events and conferences. APIHF can additionally provide information on HIV/AIDS as it impacts immigrant communities.

The National Native American AIDS Prevention Center (NNAAPC)

134 Linden Street
Oakland, CA 94607
Phone: (510) 444-2051
Email: nnaapc@aol.com
Website: <<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. It also produces a newspaper, *In the Wind*, and a journal, *Seasons*. NNAAPC also maintains a public policy office in Washington, DC. The website contains previous issues of their publications, policy updates, and various statistics on HIV/AIDS as it affects native communities. It also provides links to other sites dealing with HIV/AIDS as it impacts Native communities.

WOMEN

Center for Women Policy Studies

1211 Connecticut Avenue NW, Suite 312
Washington, DC 20036
Phone: (202) 872-1770

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.

Women, Poverty and AIDS: Sex, Drugs and Structural Violence. Paul Farmer, Margaret Connors and Janie Simmons, editors. Monroe, ME: Institute for Health & Social Justice & Common Courage Press, 1996. To order, call Common Courage Press at (800) 497-3207.

YOUTH & ADOLESCENTS

AIDS Policy Center for Children, Youth, and Families

918 16th Street, NW, Suite 201
Washington, DC 20006
Phone: (202) 785-3564
Email: apccyf@aol.com
Website: <<http://www.aidspolicycenter.org>>

AIDS Policy Center 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

The Osborne Association
135 East Fifteenth Street
New York, NY 10003
Phone: (212) 673-6633
Website: <<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. Although working primarily within the New York prison system, the Project can provide information useful to those outside New York as well.

HIV/AIDS and the Workplace

A thorough understanding of workplace issues as they concern HIV/AIDS has never been more important. HIV-positive employees remain subject to discrimination. Corporate settings continue to play a significant role in HIV prevention. Employers and employees alike contribute much needed time and money to help sustain HIV/AIDS programs within their communities. The following resources are available to aid companies and labor groups in dealing with HIV/AIDS as they affect the working environment.

CDC Business Responds to AIDS (BRTA)/Labor Responds to AIDS (LRTA) Manager's and Labor Leader's Kits.

BRTA and LRTA are cooperative efforts between the CDC and the business and labor sectors. These AIDS in the workplace kits, produced as a result of those efforts, offer useful and comprehensive materials to develop programs on manager/labor leader training, employee education, education for employees' families, and community involvement and volunteerism.

To order, contact CDC National AIDS Clearinghouse BRTA Resource Service. The toll-free number is 1-800-458-5231.

Private Sector AIDS Policy: Businesses Managing HIV AIDS Kit. AIDS Control and Prevention Project (AIDSCAP), Family Health International, 1996. Arlington, VA: Family Health International. This 6 module kit helps businesses gain an understanding of how HIV/AIDS affects the workplace. Created to aid the domestic or foreign corporation, it provides steps on how to implement successful HIV/AIDS policies for the workplace. To order, call Mary O'Grady at AIDSCAP at (703) 516-9779, ext. 196, or fax (703) 516-9781.

HIV/AIDS Treatment

The following resources provide further HIV/AIDS treatment information.

Treatment Action Group (TAG)

200 East 10 Street

Box No. 601

New York, NY 10003

Phone: (212) 260-0300

Website: <<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. To further this end, TAG supports the work of treatment activists, lobbies public and private entities and produces *TAGLine*, a monthly paper of research and policy. The website also contains TAG's previously published articles and reports.

1998 Medical Management of HIV Infection. John G. Bartlett, M.D. Baltimore, MD: Johns Hopkins University, 1998. This clinical resource written by Dr. Bartlett of the Department of Infectious Diseases, Johns Hopkins University offers extensive information for HIV/AIDS patients, caregivers, and health professionals, including a summary of pertinent HIV treatments. To order, call 1-800-787-1254. An additional related resource is the *Hopkins HIV Report*, a newsletter published by the Johns Hopkins AIDS Service six times a year, which provides updates to the book. To order, contact the *Hopkins HIV Report*, P.O. Box 5252, Baltimore, MD 21224, Att: Distribution, or order from the Internet: <<http://hopkins-aids.edu>>.

HIV/AIDS Treatment Information Service (ATIS)

Phone: 1-800-HIV-0440; 1-888-480-3839 (TTY)

Website: <<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.

HIV/AIDS — Housing Issues

Housing Works, Inc.

594 Broadway, Suite 700

New York, NY 10012

Phone: (212) 966-0466

Email: hworks@dti.net

Website: <<http://www.housingworks.org>>

Housing Works is a community-based, non-profit agency providing housing, health care, advocacy, job training, and vital supportive services to homeless New Yorkers living with HIV and AIDS who have histories of chronic mental illness and/or chemical dependence. Although a New York-based organization, Housing Works is also a general resource on HIV/AIDS issues as they relate to housing.

Financing AIDS Housing. Seattle, Washington: AIDS Housing of Washington, 1998. This handbook comprehensively offers potential sources of funding, technical assistance and other practical information to assist development of supportive housing for people living with HIV/AIDS. For ordering information, call AIDS Housing of Washington at (206) 448-5242.

National Hotlines

AIDS Clinical Trials Information Service	1-800-TRIALS-A
CDC Hearing Impaired AIDS Hotline (TTY)	1-800-243-7889
CDC Labor Responds to AIDS Resource Service	1-800-458-5231
CDC National AIDS Hotline	1-800-342-AIDS
CDC National AIDS Hotline (classroom calls)	1-800-342-AIDS
CDC AIDS Hotline (Spanish Language)	1-800-344-7432
CDC National Prevention Information Network	1-800-458-5231
CDC National STD Hotline	1-800-227-8922
CDC — Recorded Information	
AIDS Statistical Information Line	1-888-232-3299
Fax Information Service Line	1-888-232-3299
Center for Substance Abuse Prevention (CSAP)	
National Clearinghouse Alcohol and Drug Information	1-800-729-6686
Children of the Night	
(help hotline for people of all ages)	1-800-551-1300
Hepatitis and Liver Disease Hotline	1-800-223-0179
HIV/AIDS Treatment Information Service	1-800-HIV-0440
National Child Abuse Hotline	1-800-422-4453

National Drug and Alcohol Treatment Routing Service	1-800-662-HELP
National Herpes Hotline	1-919-361-8488
Recorded Information on Herpes	1-800-653-4325
Project Inform (HIV Treatment Hotline)	1-800-822-7422
Rape Abuse & Incest National Network (RAINN)	1-800-656-HOPE

Hotlines Specific to Young People

Boystown National Hotline	1-800-448-3000
Covenant House Nineline/ Crisis Intervention Center	1-800-999-9999
HIPS Hotline (for adolescent prostitutes)	1-800-676-4477
National Gay and Lesbian Youth Hotline	1-800-347-TEEN
National Pediatric HIV Resource Center	1-800-362-0071
National Runaway Switchboard (adolescent crisis line)	1-800-621-4000
Teens Teaching AIDS Prevention (TEENS TAP)	1-800-234-TEEN
The Teen AIDS Hotline	1-800-440-TEEN

Global HIV/AIDS and Related Issues

AIDS in the World II: Global Dimensions, Social Roots, and Response. Jonathan M. Mann and Daniel Tarantola, editors. Cary, NC: Oxford University Press, 1996. To order, call Oxford University Press at (800) 451-7556, fax (919) 677-1303, or email oup@oup-usa.org.

Confronting AIDS: Public Priorities in a Global Epidemic. The World Bank. Cary, NC: Oxford University Press, 1998. To order, call Oxford University Press at (800) 852-7323, fax (919) 677-1303, or email oup@oup-usa.org.

Crossing Borders: Migration, Ethnicity and AIDS. Mary Haour-Knipe and Richard Rector, editors. Levittown, PA: Taylor and Francis Publishing, 1996. To order, call Taylor and Francis at (800) 821-8312.

Health and Human Rights: An International Quarterly Journal, Volume 2, Number 4. Special Focus Issue: HIV/AIDS and Human Rights. 1998. Sofia Grushkin, Jonathan Mann, and Daniel Tarantola, editors. To order, call the François-Xavier Bagnoud Foundation at the Harvard School of Public Health at (617) 432-4611 or fax (617) 432-4310.

Report on the Global HIV/AIDS Epidemic, June 1998. UNAIDS. Geneva, Switzerland: World Health Organization, 1998. To order, call UNAIDS at (41-22) 791-4506, or fax (41-22) 791-4898 or email unaids@unaids.org.

Children, Youth and HIV/AIDS: Establishing an International NGO Network, Report of a Satellite Symposium, XI International Conference on AIDS, Vancouver, Canada. Information about the Children and AIDS International NGO Network (CAINN), formed as a result of this symposium, is also available from Interagency Coalition on AIDS and Development (ICAD). Contact: ICAD, 100 Argyle Avenue, Ottawa, Ontario, K2P 1B4, Canada. Telephone: (613) 788-5107.

1998 International Conference on HIV/AIDS

<<http://www.aids98.ch>>

The home page of the 1998 International Conference on HIV/AIDS held in Geneva, Switzerland, this website offers session summaries, news bulletins, photos, and other information.

AIDS Education Global Information Systems (AEGIS)

<<http://www.aegis.com>>

The AEGIS website offers a useful archive of publications.

OneWorld

<<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.

Global HIV/AIDS - UN Agencies and Key Non-governmental Organizations (NGOs)

Joint United Nations Programme on HIV/AIDS (UNAIDS)

Website: <<http://www.unaids.org>>

This is the home page of UNAIDS with detailed information on the state of the global HIV/AIDS pandemic and the international response.

UNAIDS is composed of the following UN agencies. A particular agency may be contacted concerning agency specific HIV/AIDS-related projects and activity. The agency and its contact information follows:

United Nations Children's Fund (UNICEF)

UNICEF House

3 United Nations Plaza

New York, NY 10017

USA

Phone: (212) 326-7000

Website: <<http://www.unicef.org>>

United Nations Development Programme (UNDP)

1 United Nations Plaza

New York, NY 10017

USA

Phone: (212) 906-5000

Website: <<http://www.undp.org>>

United Nations Population Fund (UNFPA)

220 East 42nd Street

New York, NY 10017

USA

Phone: (212) 297-5000

Website: <<http://www.unfpa.org>>

United Nations Educational, Scientific and Cultural Organisation (UNESCO)

2 United Nations Plaza

New York, NY 10017

USA

Phone (212) 963-5995

Website: <<http://www.unesco.org>>

World Health Organisation (WHO)

Avenue Appia 20

1211 Geneva 27

Switzerland

Phone: (+00 41 22) 791 21 11

Website: <<http://www.who.org>>

World Bank

1818 H Street, NW

Washington, DC 20433

USA

Phone: (202) 477-1234

Website: <<http://www.worldbank.org>>

Global Health Council - Global AIDS Program

Website: <<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 Network of People Living with AIDS (GNP+)

Website: <<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. The website provides useful information on GNP+ and its work, as well as important information on the pandemic itself.

Human Rights Watch

Website: <<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. The archives at Human Rights Watch's website are a good source of information on HIV/AIDS and human rights.

International AIDS Vaccine Initiative (IAVI)

810 Seventh Avenue
New York, NY 10019
USA
Phone: (212) 655-0201
Website: <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. IAVI's website contains numerous articles and reports on vaccine development and progress.

International Center for Research on Women (ICRW)

1717 Massachusetts Avenue, NW, Suite 302
Washington, DC 20036
USA
Phone: (202) 797-0007
Email: icrw@igc.apc.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. ICRW's website provides a complete description of its work as well as a list of relevant publications.

The International Community of Women Living with HIV/AIDS (ICW)

Website: <<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.

Bridging the Gap: Addressing Gender and Sexuality in HIV Prevention. Washington, DC: International Center for Research on Women, 1998. To order, contact the Publications Department of the Center at (202) 797-0007.

International HIV/AIDS Alliance

2 Pentonville Road
London N1 9HF
England
Phone: (44) 171 841 3500
Email: mail@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.

HIV/AIDS Philanthropy

As illustrated by this publication, the need for organized philanthropy to pay additional attention to HIV/AIDS issues has never been greater. More information on the role of AIDS funding, as well as information on some of those currently funding HIV, can be found in the resources below.

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 <http://www.hsph.harvard.edu/hai/publications/index_fall98.html>.

"AIDS Funding: When the Red Ribbons Disappear." *Corporate Philanthropy Report*. April 1998, p. 1.

The Business Response to HIV/AIDS: Innovation and Partnerships. Geneva, Switzerland: Joint United Nations Programme on HIV/AIDS (UNAIDS) and the Prince of Wales Business Leaders Forum, 1997. To order, call UNAIDS at (41-22) 791-4506, or fax (41-22) 791-4898.

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.

1998 Guide to Funders of International HIV/AIDS Programs and Activities. Global Health Council, 1998. For more information on obtaining a copy, call (202) 833-5900.

Philanthropy - General Information

Grantmaking for the Global Village. Washington, DC: Council on Foundations (CoF), 1997. To order, call CoF at (888) 239-5221.

International Grantmaking: A Report on U.S. Foundation Trends. The Foundation Center, December 1997. A comprehensive review of international grantmaking as practiced by U.S. independent and corporate foundations. To order, call (212) 620-4230.

About Funders Concerned About AIDS

Organized in 1987 to advance the private philanthropic response to HIV/AIDS, FCAA's mission has remained one that focuses on the critical role grantmakers must play in addressing HIV/AIDS domestically and internationally:

Funders Concerned About AIDS mobilizes philanthropic leadership and resources, domestically and internationally, to eradicate the HIV/AIDS pandemic and to address its social and economic consequences.

As the pandemic and philanthropy's responses to it have evolved, especially in the last few years, FCAA's focus and work have also changed and will continue to do so to meet the challenges in this field. For the 1998 - 2000 period, FCAA's guiding vision is clear, forceful, and focused:

In this time of rapid change yet increasing need in the pandemic, FCAA seeks to not only sustain, but also increase the philanthropic resources available to fight HIV/AIDS and assist both current and new funders in enhancing the strategic nature of their HIV/AIDS-related grantmaking.

FCAA defines an increase in resources, domestically and internationally, as:

- an overall increase in philanthropic dollars invested in HIV/AIDS;
- an increase in the number and diversity of grantmakers supporting HIV/AIDS; and
- an increase in the integration of HIV/AIDS funding into all appropriate funding areas of grantmakers.

FCAA will assist philanthropy in being more aggressive and strategic in HIV/AIDS and related grantmaking areas by helping funders to:

- broaden the support and understanding of HIV/AIDS at the international, national, and local levels;
- view HIV/AIDS within the larger health, political and social context and integrate HIV/AIDS funding into the broader grantmaking agendas of funders;
- support high quality, effective, collaborative, and non-duplicative programs and services;
- target populations that are currently underserved by HIV/AIDS services and related health, welfare, and education services; and
- demonstrate explicit support for effective, new, and in some cases controversial approaches in the fight against HIV/AIDS.

FCAA develops programming and offers a variety of services and products to enable grantmakers and others in the philanthropic sector to respond to the pandemic as effectively as possible. FCAA strives to achieve its mission, goals, and objectives through:

- our regular newsletter, *bulletin*, other publications, and other materials;

- briefings, speeches, and other presentations across the country;
- primary and secondary research into HIV/AIDS funding issues and trends;
- technical assistance to the philanthropic sector;
- ongoing work with elected and appointed officials and grantmakers on issues ranging from public/private collaboration and partnerships to the relationship between public policy issues and private philanthropic efforts to address the pandemic; and
- ongoing participation in and support from the Centers for Disease Control and Prevention's Business Responds to AIDS/Labor Responds to AIDS (BRTA/LRTA) program, including specific corporate and business-related publications, material production, technical assistance, presentations, meetings, and other work.

FCAA today has a core constituency of approximately 2,100, including individuals from private foundations, corporate grantmaking departments and foundations, community foundations, United Ways, other charitable organizations, and government officials. Hundreds more individuals access FCAA's programming annually through attendance at conferences and events and contact with FCAA for technical assistance. FCAA reaches organizations in 48 states and 25 foreign countries.

FCAA is supported by approximately 200 foundations, corporations, and individuals. Nationally, 30 foundation and corporate grantmakers and others from philanthropy contribute their time, expertise, and leadership as members of our board of directors and board committees.

Funders Concerned About AIDS is a non-profit 501(c)(3) organization. FCAA is an official affinity group affiliated with the Council on Foundations (COF). FCAA works closely with many of the 35 other affinity groups of the COF, especially to ensure that issues of race, gender, sexual orientation, poverty, disability, and youth are appropriately and effectively reflected in our work as well as the work of these other affinity groups.

FCAA has also worked hard to carefully design, convene, and participate in strengthening existing linkages, and to create new partnerships between philanthropic organizations, public policy makers, and other important partners at the local, regional, national, and international levels. Some of these partners and collaborators include the Office of National AIDS Policy (ONAP); The President's Advisory Council on HIV/AIDS; The Centers for Disease Control and Prevention (CDC); local HIV Prevention Community Planning Groups; national, regional, and local HIV/AIDS organizations; USAID HIV Division; UNAIDS; World Bank; and the Global Business Council on HIV/AIDS.

For more information, please contact us by phone, fax, mail, or e-mail (paul@fcaaid.org, ging@fcaaid.org).

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50 East 42nd Street
19th Floor
New York, NY 10017
Tel 212 573.5533
Fax 212 949.1672