Funders Concerned About AIDS

Mobilizing Philanthropic Leadership, Ideas, and Resources in the Fight Against AIDS

LOOKING BACK, FORGING AHEAD

25 YEARS OF FCAA

"In order to shape and to understand progress, it is necessary to know not only where one is, but also where one has been."

- *Philanthropy and AIDS: Assessing the Past, Shaping the Future. A report on a FCAA/Gallup.* 1998.

This year marks the 25th anniversary of Funders Concerned About AIDS' work to mobilize philanthropic leadership, ideas, and resources in the fight against AIDS.

We are using this occasion to remember, recommit and reinvigorate. We remember the lives lost to the disease, and the catalytic influence of the philanthropic sector in achieving successes to date. We recommit to our work of convening the sector, providing timely and relevant information to enlighten your grantmaking, and providing the important time and space for funder networking and exploration of collaborative approaches to current challenges. Finally, we will use this quarter century mark to reinvigorate the philanthropic sector—seeking to re-engage those funders who've moved on from AIDS, as well as reaching out to those working in adjacent areas of health, human rights, and social justice to highlight the important intersections in our work.

Divided into four distinct eras—1981–1986 (Pre-FCAA), 1987–1996 (Founding and Establishment of FCAA), 1997–2005 (Momentum Builds), and 2005–Present (At the Crossroads)—this timeline aims to document the history of FCAA and the AIDS philanthropic sector alongside key milestones from the global AIDS response in effort to highlight our sector's signature role in driving innovation, focusing on marginalized populations, and holding governments accountable. This information is not meant to be exhaustive, and as possible, we offer links to further resources (*such as the updated publication archive on* our website*, or the terrific* Global HIV/AIDS Timeline *from the Kaiser Family Foundation*).

But more importantly, this recounting of the past is intended to strengthen our collective resolve to ensure the investments of the last three decades were not made in vain. After years of scaling up both public and private investment in HIV research, prevention, care, treatment and human rights protections, we now find ourselves in an era of diminishing resources—at precisely the time when sustained investment offers the greatest promise of achieving an AIDS-free generation.

When FCAA was founded in 1987, we were just discovering what caused AIDS and how it was transmitted. Now, more than ever, we have the ability to prevent new infections, keep those already infected healthy, and protect the human rights of those living with and at highest risk for HIV. As FCAA continues to update this timeline, we hope that we will be able to document that, when we found ourselves at the crossroads of great promise and tremendous challenge, the philanthropic sector continued to drive the response to HIV/AIDS and achieving the dream of ending AIDS.

Thank you to our past and current staff and Board, and an inspirational community of funders whose prolific work made this possible.

Warmest Regards,

John L. Barnes
Executive Director

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25 YEARS: 1987 - 2012

PRE-FCAA (PRE–1987)

FUNDERS CONCERNED ABOUT AIDS

- Affinity groups (AGs), a new form of philanthropic infrastructure support, come into existence in the 1970s and early 80s. By 1987 there are 10–12 AGs.
- Earliest meetings of what was to become the founders group of FCAA take place (1983).
- Read more about this early era: *Meeting the Challenge: Foundation Responses to Acquired Immune Deficiency Syndrome* (Michael Seltzer, 1987).

PHILANTHROPIC RESPONSES

- Philanthropic response to HIV/AIDS slow to start; the first five private foundation grants are awarded in 1983, amounting to $216,000. By comparison, total U.S. philanthropic giving in the same year is estimated at $4.48 billion.
- The first AIDS grants awarded by the **New York Community Trust**, the **San Francisco Foundation**, the **United Hospital Fund**, the **Charles A. Dana Foundation**, and the **Joint Foundation Support**.
- By 1987 significant ramp-up: 85 private funders (in 20 states) in HIV/AIDS work; total grants since 1983 now at $18 million.

HIV/AIDS

- First reported cases of HIV break (1981).
- Government response grossly inadequate; only $8 million in federal spending on HIV/AIDS by 1982.
- First International AIDS Conference (IAC) held in Atlanta (1985).
- There are 40,000 deaths in the U.S. by 1987, and an estimated four million people living with HIV globally.
- By 1987 AIDS is leading cause of death in New York and San Francisco for men 25–44 and women 25–34.

*In 1982 the **Levi Strauss & Co. and the Levi Strauss Foundation (LSF)** become one of the first corporations to get involved in HIV/AIDS through volunteerism, fundraising, and matching employee contributions. In 1985 LSF makes its first direct AIDS grant. Visit a timeline of LSF's response to fighting AIDS.*

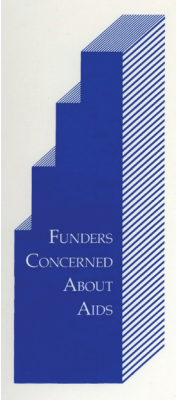
***The American Foundation for AIDS Research (amfAR)** is founded in 1985 to encourage and support AIDS research. In addition to pioneering AIDS fundraising, amfAR focuses on public education and public policy efforts.*

*In 1986 the **Robert Wood Johnson Foundation (RWJF)** becomes one of first private foundations to include AIDS programs in their annual budget. RWJF's "AIDS Health Services Program," serves as a precursor to the Ryan White CARE Act. Read how "AIDS changed the Robert Wood Johnson Foundation."*

FOUNDING & ESTABLISHMENT OF FCAA (1987–1996)

FUNDERS CONCERNED ABOUT AIDS

- FCAA officially established in 1987, led by Executive Director Michael Seltzer and Board Chair Joyce Bove.
- FCAA publishes first publication—*A Funders' Guide to AIDS Grantmaking: Action Strategies* (1988).
- FCAA takes advocacy approach, publishing *AIDS, Public Policy and Philanthropy* (1990); and hosting "HIV/AIDS Public Policy & Advocacy: A Training Institute for Grantmakers" (1992).
- FCAA publishes a guide to international AIDS grantmaking (1993).
- FCAA co-sponsors the first-ever White House Conference on AIDS (1995).
- Fred Silverman serves as Board Chair from 1995–1999.
- FCAA joins the private/public partnership Business Responds to AIDS/Labor Responds to AIDS (1996).



AIDS Memorial Quilt displayed at the Council on Foundations Annual Conference.

The New York Times (*"Ford Foundation Leads Delayed Philanthropic Response to AIDS"*) details the 1988 creation of first national funding pool, the National Community AIDS Partnership (later known as the National AIDS Fund, now ***AIDS United***).

New FCAA advocacy messaging and education aims to reach "non-HIV" funders: "If you fund housing, health care access, bio-medical research, civil rights, LGBT, community services, etc…you can fight AIDS."

IF YOU FUND CIVIL LIBERTIES, YOU CAN FIGHT AIDS.

People living with AIDS risk losing their jobs and homes. So when the J.M. Kaplan Fund in New York City funds an effort to end AIDS-related discrimination, it's not just fighting against AIDS, it's fighting for social justice.

To find out how you can get involved, contact Funders Concerned About AIDS, 130 West 42nd Street, Suite 801, New York, New York 10036.

AIDS. Something good must come of it.

FUNDERS CONCERNED ABOUT AIDS

HIV/AIDS

- U.S. FDA approves first antiretroviral drug—Zidovudine or AZT (1987).
- President Reagan makes first public speech about AIDS (1987).
- Foreigners with the HIV virus no longer allowed into the US (1989).
- Ryan White CARE Act passes (1990).
- Clinton Administration establishes White House Office of National AIDS Policy (1992), and the Presidential Advisory Council on AIDS (1995).
- **UNAIDS** founded (1996).
- David Ho named *Time* magazine's man of the year in 1996 for his discovery of highly active anti-retroviral therapy (HAART).
- By 1996, 18 million people worldwide are infected with HIV; AIDS is leading cause of death in U.S. for all 25–44 year olds.

PHILANTHROPIC RESPONSES

- The **Ford Foundation** begins funding HIV/AIDS initiatives, followed by major AIDS funding by the **Aaron Diamond Foundation,** the **MacArthur Foundation** and the **Rockefeller Foundation** (among others).
- The **Elton John AIDS Foundation (EJAF)** established (1992); EJAF-UK (1993).
- **Positive Action** launches (from Glaxo and Wellcome, now **ViiV Healthcare)** to support community-focused projects that reach those most affected by HIV (1992).
- Equity Fights AIDS and Broadway Cares merge to become **Broadway Cares/Equity Fights AIDS,** one of the nation's leading industry-based, nonprofit AIDS fundraising and grant-making organizations (1992).
- M.A.C Cosmetics establishes the **M•A•C AIDS Fund** (1994).
- By 1996, total U.S. philanthropic funding for HIV/AIDS reaches an estimated $58.8 million. This still represents less than 1% of total U.S. foundation funding for same year ($13.8 billion).

MOMENTUM BUILDS (1997–2005)

FUNDERS CONCERNED ABOUT AIDS

- Richard Turner, former Board Chair (1993–1995), becomes Executive Director to lead the organization through a transitional period following the departure of founding Executive Director and Board.
- Under the new leadership of Paul Di Donato (1997–2005), FCAA expands global programming, including strategic new collaborations with UNAIDS, the **Global Fund to Fight AIDS, Tuberculosis and Malaria**, and major U.S.-based international AIDS grantmakers; convenes or co-convenes major meetings on funding the response to the global pandemic (White Oak meeting, 1998; Gates Foundation meeting, 2000).
- Len McNally (2000–2004) and Beth Darmstadter (2004–2008) serve as Board Chair during this era.
- FCAA helps to found the **European HIV/AIDS Funders Group.**
- FCAA publishes first resource tracking report (2002).
- FCAA hosts "Domestic Philanthropy Summit on HIV/AIDS" in effort to also reenergize domestic grantmaking on HIV (2004).
- FCAA facilitates first AIDS-focused issue of the COF's *Foundation News & Commentary Magazine* (2004).

*The **Bill and Melinda Gates Foundation** is created in 2000, ushering in a new era of growth for global AIDS philanthropy. Learn more on how the emergence of the Gates Foundation helped to finance the global response.*

*The government bans the use of federal funds for syringe access programs, despite overwhelming evidence of their effectiveness, and the link between injection drug use and HIV. In 2004 a unique funding collaborative—the **Syringe Access Fund (SAF)**—is created to fill this critical gap by supporting syringe exchange and related public policy activities. Founding partners include: Levi Strauss Foundation, Elton John AIDS Foundation, the **Irene Diamond Fund**, the **Tides Foundation** and AIDS United (formerly National AIDS Fund). Since its inception SAF partners have also included **Public Welfare Foundation**; and current partners include: Levi Strauss Foundation, Elton John AIDS Foundation, the Irene Diamond Fund, **Open Society Foundations** and AIDS United. Since 2004, the SAF has invested over $10 million dollars in support of syringe access.*

HIV/AIDS

- By the late 1990s, most HIV/AIDS funding for the domestic U.S. epidemic comes from the federal health programs of Medicaid, Medicare, and the Ryan White CARE Act.
- Dramatic advances in treatment break onto scene in 1996–97. By 1997–98 there is 40% decline in AIDS deaths as compared to 1994–95 in U.S.
- UN Security Council holds special session on AIDS as global security crisis in 2000; in 2001, UN General Assembly convenes first ever special session on AIDS (UNGASS).
- Millenium Development Goals announced (2000).
- As of 2002, AIDS is leading cause of death worldwide for 15–59 year olds.
- Global Fund launches (2002).
- President Bush announces PEPFAR, the President's Emergency Plan for AIDS Relief, a 5-yr $15 billion initiative to fight AIDS, TB and malaria in highly impacted countries (2003); WHO launches the "3 by 5" initiative (3 million on treatment by 2005) in same year.
- The President's FY 2005 budget request includes an estimated $19.8 billion for domestic and global HIV/AIDS funding.

PHILANTHROPIC RESPONSES

- In response to rising rates of HIV infection among youth, PBS airs the special *Sex and other Matters of Life and Death* in 1997 to raise awareness on HIV and teen pregnancy. Many funders support the effort, including: The **New York Community Trust**, **Abbott Laboratories, John M. Lloyd Foundation,** and the **H. van Ameringen Foundation** (among others).
- In 2000, U.S. philanthropic funding for HIV/AIDS increases from $76.1 million in 1999 to at least $312.4 million in 2000, due in large part to one funder—the Gates Foundation.
- Two major corporate funding initiatives begin in this era: Secure the Future® (**Bristol-Myers Squibb**, 1999), and the African Comprehensive HIV/AIDS Partnership (a partnership between **Merck**, the Gates Foundation, and the government of Botswana, 2002).
- The **Kaiser Family Foundation** and UNAIDS launch the Global AIDS Media Initiative (2004).
- U.S.-based philanthropy takes more of a leadership role in addressing the global epidemic. In 2000 just over 16% of all HIV/AIDS grantmaking is directed outside of the U.S.; by 2005 that share increases to 66%.

AT THE CROSSROADS (2005–PRESENT)

In July 2010 ***AIDS United*** *receives a $3.6 million Social Innovation Fund (SIF) grant to expand its Access to Care (A2C) initiative. This grant represents the "single largest award for HIV/AIDS made in decades by the federal government from new and non-AIDS-specific funds."*

"Every new infection is on us." *In the era of "treatment as prevention," this quote from Anu Gupta, Director of Corporate Contributions at Johnson & Johnson, sparks new urgency among the funding audience at* ***FCAA's 2011 AIDS Philanthropy Summit.***

Funders Concerned About AIDS
AIDS PHILANTHROPY SUMMIT
FROM DATA TO IMPACT
12.5.11 | Washington, DC

FUNDERS CONCERNED ABOUT AIDS

- In 2005 FCAA, EFG and UNAIDS form partnership to harmonize collective approaches to global resource tracking.
- Sunita Viswanath is named as FCAA's first female, and first person of color, Executive Director (2005–2009).
- Desiree Flores (2008–2009), LaTida Smith (2009–2011), and Daniel Lee (2011–present) serve as Board Chair during this era.
- FCAA co-hosts "Dialogue About Collaborative Funding" at the XVI IAC in Toronto (2006), and "Funder Partnerships" at the XVII IAC in Mexico City (2008).
- FCAA launches a new program "Spotlight: Alabama," in 2008 to examine the epidemic and philanthropic response in Alabama. Future spotlights focus on Washington, D.C.; state budget cuts; and Puerto Rico.
- Long-time board member John Barnes transitions to serve as interim (and eventual) Executive Director (2009–present).
- Strategic planning in 2007and 2009 refocus FCAA on maximizing impact through evidence-based funding, and putting philanthropic efforts in a broader context of public funding.
- FCAA convenes its first-ever annual gathering in 2009, bringing together more than 200 U.S. HIV/AIDS funders.
- FCAA retools staff and structure by end of 2009, moving from staff of six to two, and taking up residence at the COF in DC, after years based in NYC.
- FCAA launches new website and social media presence in 2010.
- FCAA and EFG convene first-ever joint reception at the XVIII IAC in Vienna, featuring Bill Gates and Annie Lennox.
- FCAA strengthens ties and strategic programming with **Grantmakers in Health** in 2012 to reach broader health funders about the need to re-emphasize the importance of medical interventions in both the treatment and prevention of HIV.
- FCAA commemorates 25th anniversary in 2012, and enters into 2013–2015 strategic planning process.

PHILANTHROPIC RESPONSES

- The HIV/AIDS philanthropic sector experiences another dramatic expansion between 2005 and 2006—an estimated total commitment of $979 million—due mainly to increased funding by the world's now largest private funder of HIV/AIDS, the Gates Foundation.
- A new specialist HIV company—**ViiV Healthcare**—launches from **GlaxoSmithKline** and **Pfizer** (2009), and by 2010 ranks among the top 10 private HIV/AIDS funders in the U.S. and Europe.
- **HIV Young Leaders Fund** is established to enable new leadership in the HIV response among young people most affected by HIV (2009).
- The field of HIV/AIDS-related philanthropy continues to remain highly concentrated; the top 10 funders annually represent around 80% of total funding. The Gates Foundation alone accounts for 47% of all disbursements in 2010.
- At least 20 former major HIV/AIDS funders shift away from HIV/AIDS as a funding focus from 2007 to 2010.
- The National AIDS Fund and AIDS Action merge to form AIDS United (2010).
- The Ford Foundation closes its Global HIV/AIDS Initiative (2010).
- Total HIV/AIDS disbursements by U.S-based philanthropies total $459 million in 2010, a 7% decrease from 2009.

HIV/AIDS

- By 2012 there have been 30 million AIDS-related deaths, and 34 million people are living with HIV.
- There are currently 1.2 million PLWHA in the United States, where the largest number of new HIV infections continue to occur among gay and bisexual men and other men who have sex with men.
- Globally women comprise half of all adults living with HIV.
- In 2009, President Obama launches the **Global Health Initiative**; lifts 22-yr old HIV travel ban.
- The ban prohibiting federal support for needle-exchange programs is lifted in 2009, and reinstated in 2012.
- Obama Administration announces the first **U.S. National HIV/AIDS Strategy** (2010).
- International AIDS assistance from donor governments totals $6.9 billion in 2010, a 10% decrease from 2009, after years of steady and significant growth from 2002–2008.
- June 5, 2011 marks 30 years since the first reported AIDS case.
- Secretary of State Clinton calls for a "AIDS-Free Generation," (2011).
- In 2011, UNAIDS estimates gap of $7 billion annually between available resources and what is needed to achieve universal access by 2015.
- Global Fund cancels new grantmaking in its 10th year due to lack of funding (January 2012).
- The FDA grants approval to first drug developed to prevent HIV infection (May 2012).
- XIX IAC to take place in Washington, DC (July 2012), first time on U.S. soil in over 20 years.

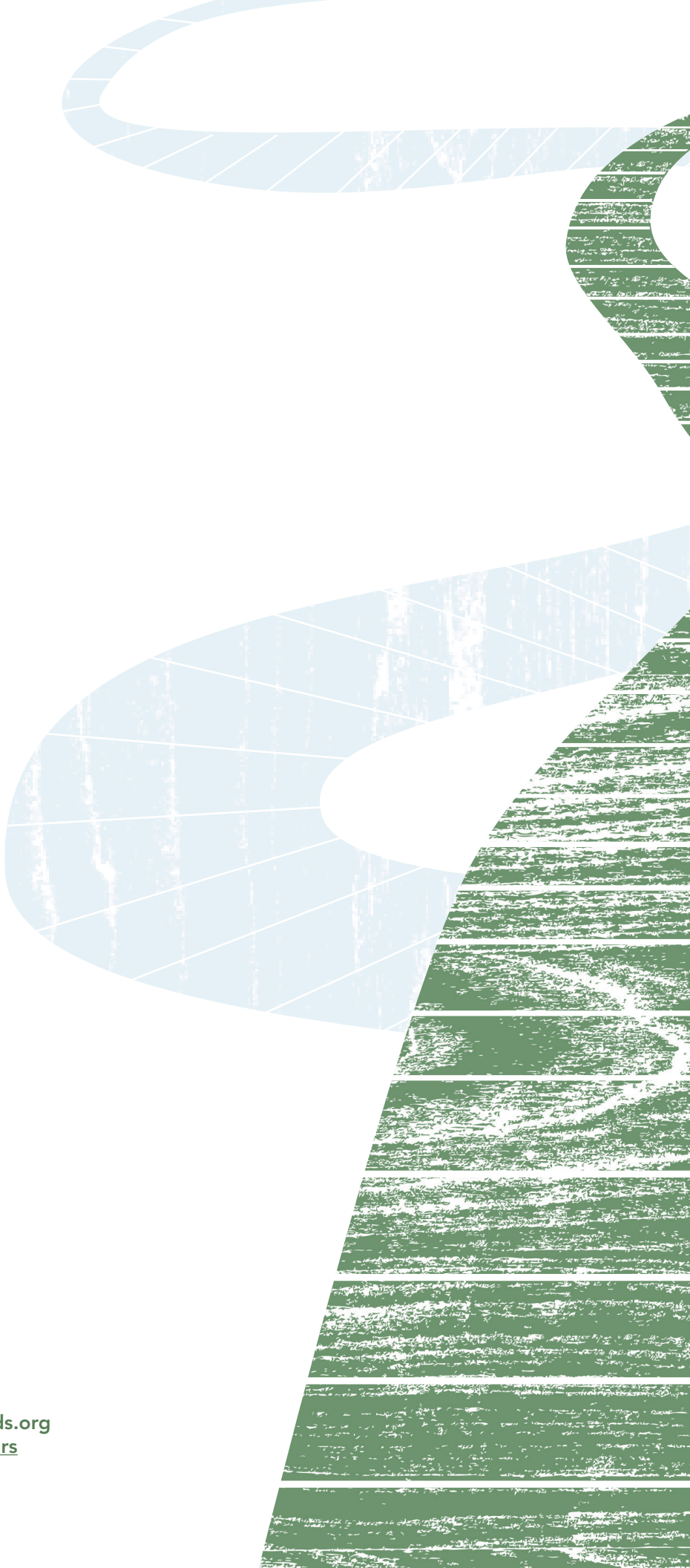
In 2007 the Open Society Foundation's Improving Outcomes: Blueprint for a National AIDS Plan for the United States became a focal point for AIDS advocates and grantmakers, leading to the formation of the Coalition for a National AIDS Strategy (CNAS). Funded in part by Broadway Cares/Equity Fights AIDS and the M•A•C AIDS Fund, the CNAS and other advocates kept the idea of a national strategy in the forefront of the 2008 presidential campaign, resulting in both major candidates promising a national strategy should they be elected.

FCAA toolkit
Funders' Guide to the National HIV/AIDS Strategy

The FCAA toolkit: A Funders' Guide to the National HIV/AIDS Strategy (NHAS) launches in December 2011.

"At this 'all-hands-on-deck' moment, we must work in new ways, across disciplines and organizations, to make lasting progress on the American HIV/AIDS epidemic-especially in terms of reducing HIV-related health disparities. The new online toolkit is an important step in advancing the contributions of the nation's vital philanthropic sector to achieving the vision of the NHAS."

Ronald Valdiserri, M.D., M.P.H., Deputy Assistant Secretary for Health, Infectious Diseases, and Director, Office of HIV/AIDS Policy, U.S. Department of Health and Human Services, AIDS.gov blog (Dec. 2011).



For more information, visit **www.fcaaids.org**
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