



ADAP ADVOCACY ASSOCIATION

aaa+

2009 Annual Report



The ADAP Advocacy Association (aaa+) is a national 501(c)(3) nonprofit organization incorporated in the District of Columbia to promote and enhance the AIDS Drug Assistance Programs (ADAPs) and improve access to care for persons living with HIV/AIDS.

aaa+ works with advocates, community, health care, government, patients, pharmaceutical companies and other stakeholders to assure that access to services recognize and afford persons living with HIV/AIDS to enjoy a healthy life.

The following value statements are the foundational ideals under which aaa+ operates. aaa+ consistently strives to achieve them, while encouraging its supporters to do the same.

- That the voice of persons living with HIV/AIDS shall always be at the table and the center of the discussion.
- That HIV/AIDS advocates should welcome the opportunity to join the skills, experience and voices with others on issues of disability and access to adequate healthcare for all Americans.
- That advocacy efforts targeted to our federal government shall always carry the needed messages applicable at the state and local level.
- That messages and information shall be in accessible formats understandable to – and also deliverable by – grassroots advocates in any setting.

Learn more about aaa+ online at:
www.adapadvocacyassociation.org



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SUMMARY:

The ADAP Advocacy Association had another successful year by all accounts in 2009, accomplishing many of its stated advocacy objectives to improve access to care for people living with HIV/AIDS. **aaa+** provided numerous meaningful educational opportunities for ADAP stakeholders, expanded its national grassroots advocacy network and raised record-level funding for a small nonprofit in only its third year. Despite the organization's success, **aaa+** – along with other national HIV/AIDS advocacy groups – witnessed an exacerbating growth in the number of people living with HIV/AIDS placed on waiting lists to access life-saving medications under the AIDS Drug Assistance Programs (ADAPs). In fact, ADAP waiting lists increased by over 1,000% last year so that by year's end the waiting lists stood at 540 individuals in nine states.

In response to this growing crisis, **aaa+** launched its '**End the Wait**' campaign to raise awareness about ADAP waiting lists and the perpetual under-funding of the AIDS Drug Assistance Programs. The sustained national effort was designed to better educate the public about the important role ADAPs play in maintaining the health of people living with HIV/AIDS – a message that was symbolized during the national debate over health care reform.

HIGHLIGHTS:

- Released Annual Report highlighting 2008 accomplishments;
- Seated four (4) community leaders to the organization's Board of Directors;
- Garnered support from seventeen (17) corporate entities;
- Garnered support from three (3) government entities;
- Hosted three (3) wine tasting benefits (Ft. Lauderdale, FL; Wilmington, NC; and Washington, DC);
- Launched 'End The Wait' public awareness campaign focusing on eliminating ADAP waiting lists;
- Initiated interactive media clips about ADAP-specific issues on adapadvocacyassociation.org;
- Hosted successful **2nd Annual Conference: Early Treatment for HIV Summit** in Washington, DC;
- Hosted informative virtual **HIV EMPLOYMENT EDUCATIONAL SERIES: Promoting 'Positive' Work**;
- Sponsored two (2) Congressional Briefings on Capitol Hill calling attention to growing ADAP waiting lists;
- Published issue papers providing in-depth analysis of the following:
 - ***The International vs. National Debate: Is the President's Emergency Plan for AIDS Relief (PEPFAR) international commitment to combating HIV/AIDS succeeding at the expense of those people living with the disease in the United States? – March 2009***
 - ***HIV/AIDS and African Americans: A Terrible Truth – February 2009***
 - ***ADAPs in Crisis: Waiting Lists Then and Now – January 2009***;
- Issued two (2) legislative action alerts raising visibility on important policy initiatives;
- Submitted public comment to CDC on removing HIV-related travel restrictions in the United States;
- Sent four (4) support letters on various HIV/AIDS-related issues;
- Supported sixteen (16) national sign-on letters addressing various HIV/AIDS initiatives; and
- Launched newly-redesigned website and obtained 9,231 website hits.



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TIMELINE OF EVENTS:

January 22, 2009 – The ADAP Advocacy Association released its 2008 Annual Report. Only being the second year in existence as a new organization, aaa+ once again demonstrated success on multiple levels.

February 4, 2009 – The ADAP Advocacy Association called on President Obama and leaders of both political parties in Congress to end nearly a decade of neglect and fully fund the AIDS Drug Assistance Programs (ADAPs). As of February 4th, insufficient federal and state funding had led to 53 people living with HIV/AIDS in three states to be placed on waiting lists for their medications.

March 19, 2009 – The ADAP Advocacy Association announced that it has seated two community leaders living with HIV/AIDS to its Board of Directors. The aaa+ Board of Directors voted unanimously to seat both **Michelle Anderson** and **Duane Malone**, both known for their AIDS activism in their respective communities.



May 28, 2009 – The ADAP Advocacy Association sponsored a Congressional Briefing on the AIDS Drug Assistance Programs (ADAPs). The briefing was hosted by the Community Access National Network (CANN) – formerly the Title II Community AIDS National Network.

June 9, 2009 – The ADAP Advocacy Association raised serious concern over the growing number of people living with HIV/AIDS in America who are waiting to gain access to their medications through the AIDS Drug Assistance Programs (ADAPs). According to the National Alliance of State & Territorial AIDS Directors (NASTAD), 99 people living with HIV/AIDS in four states were on ADAP waiting lists.

June 24, 2009 – The ADAP Advocacy Association added interactive media clips to its website to raise awareness about ADAP-specific legislation pending before the U.S. Congress.

July 21, 2009 – The ADAP Advocacy Association – in partnership with the Community Access National Network (CANN) – successfully convened its 2nd Annual Conference in Washington, DC on July 20-21, 2009. The “**Early Treatment for HIV Summit**” called attention to early HIV/AIDS diagnosis, care and treatment. The Summit was sponsored by Ramsell Holding Corp., Flowers Heritage Foundation, Merck & Co., Gilead Sciences, Tibotec Therapeutics, Job Accommodation Network (JAN), MOMS Pharmacy, Diplomat Specialty Pharmacy and the Social Security Administration’s Ticket-to-Work Program.



July 24, 2009 – The ADAP Advocacy Association commended Gilead Sciences and Tibotec Pharmaceuticals for its agreement to develop and commercialize a new fixed-dose combination of Gilead's Truvada® (emtricitabine and tenofovir disoproxil fumarate) and Tibotec's investigational non-nucleoside reverse transcriptase inhibitor (NNRTI) TMC278. This agreement, if approved by the U.S. Food & Drug Administration (FDA), would represent only the second complete antiretroviral treatment regimen for HIV available in a single tablet taken once daily.

August 4, 2009 – The ADAP Advocacy Association announced that it had seated two new members to its Board of Directors, as well as returned three previous members. The aaa+ Board of Directors voted unanimously to seat newcomers **Glen Pietrandoni** of Deerfield, Illinois and **Joey Wynn** of Fort Lauderdale, Florida, both known for their activism in their respective communities.



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August 31, 2009 – The ADAP Advocacy Association applauded the addition of its former board member, **James Albino**, to the White House in the Office of National AIDS Policy (ONAP) as the Senior Program Manager. Albino served on the **aaa+** board of directors from July 2008 to August 2009.



September 23, 2009 – The ADAP Advocacy Association announced that it launched a national public awareness campaign called **"End The Wait"** designed to call attention to growing waiting lists for the AIDS Drug Assistance Programs (ADAPs). Nationwide, ADAP waiting lists increased to 157 people living with HIV/AIDS.

November 1, 2009 – The ADAP Advocacy Association announced that HIV Plus Magazine named its CEO, **Brandon Macsata**, as one of the top 25 GLBT leaders fighting HIV/AIDS in its ["Honoring 25 of today's leaders ensuring the HIV fight rages on"](#).

November 20, 2009 – The ADAP Advocacy Association – with underwriting support from the National Network of ADA Centers (DBTACs), US Business Leadership Network (USBLN®), Community Access National Network (CANN), Bender Consulting, GettingHired.com, SunTrust Banks and the Social Security Administration's Ticket to Work program – successfully convened its virtual **"HIV EMPLOYMENT Educational Series: Promoting 'Positive' Work"** in the Virtual World on November 18-20, 2009. The virtual conference put people living with HIV/AIDS in touch with leading experts on a wide array of employment-related information and resources available to people living with HIV/AIDS – as well as providing useful tips about workplace accommodations and legal protections!



December 1, 2009 – The ADAP Advocacy Association in observance of World AIDS Day called on President Barack Obama and the U.S. Congress to go beyond issuing fancy proclamations about HIV/AIDS, and provide meaningful leadership to address the plight of people living with HIV infection in the United States. It is unacceptable that on the very day the nation is asked to learn more about HIV/AIDS there are hundreds of people living in America – which is the wealthiest nation in the world – waiting to access life-saving medications from the AIDS Drug Assistance Programs (ADAPs) because of insufficient federal funding.

December 3, 2009 – The ADAP Advocacy Association sponsored another Congressional Briefing on the AIDS Drug Assistance Programs (ADAPs) to call further attention to the growing waiting lists. The briefing was hosted by the Community Access National Network (CANN) – formerly the Title II Community AIDS National Network.

December 3, 2009 – The ADAP Advocacy Association announced that **William "Bill" Arnold** was the recipient of its **"2009 ADAP Champion"** award. The annual award recognizes a leader in the HIV/AIDS community who has demonstrated his/her commitment to improving access to care for people living with HIV/AIDS by promoting and enhancing the AIDS Drug Assistance Program (ADAP).

December 22, 2009 – The ADAP Advocacy Association initiated a "Cause" on Facebook to further call attention to the importance of the AIDS Drug Assistance Programs (ADAPs). The "Cause" aims to engage ADAP stakeholders using proven social media strategies.



CORPORATE SUPPORT:

Corporate Members

Ramsell Holding Corporation
Flowers Heritage Foundation
Tibotec Therapeutics
Health Management Services
Bristol-Myers Squibb
Diplomat Specialty Pharmacy
Community Access National Network
Walgreens Co.
MedData Services
AIDS Alabama
AIDS-Drugs-Online

Annual Conference Sponsors

Merck & Co.
Ramsell Holding Corporation
Flowers Heritage Foundation
Gilead Sciences

Annual Conference Exhibitors

Diplomat Specialty Pharmacy
MOMS Pharmacy
Tibotec Therapeutics
Job Accommodation Network
SSA Ticket-to-Work

Virtual Conference Sponsors

National Network of ADA Centers
US Business Leadership Network
GettingHired.com
SunTrust Bank
SSA Ticket-to-Work

Wine Tasting Sponsors

Bender Consulting
Community Access National Network
SunTrust Banks
Tibotec Therapeutics
DC'S Most Fabulous Magazine

Individual Event Sponsors

Dr. Ali Harake
Dr. Philip Haddad
Mr. Henry Faircloth
Ms. Amanda Kornegay





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ACKNOWLEDGEMENTS:

In 2009, the ADAP Advocacy Association could not have completed its first complete fiscal year without the financial support of its corporate sponsors and exhibitors, individual donors and the meaningful events hosted by the organization.

The following chart demonstrates the diversity of the organization’s funding in 2009:

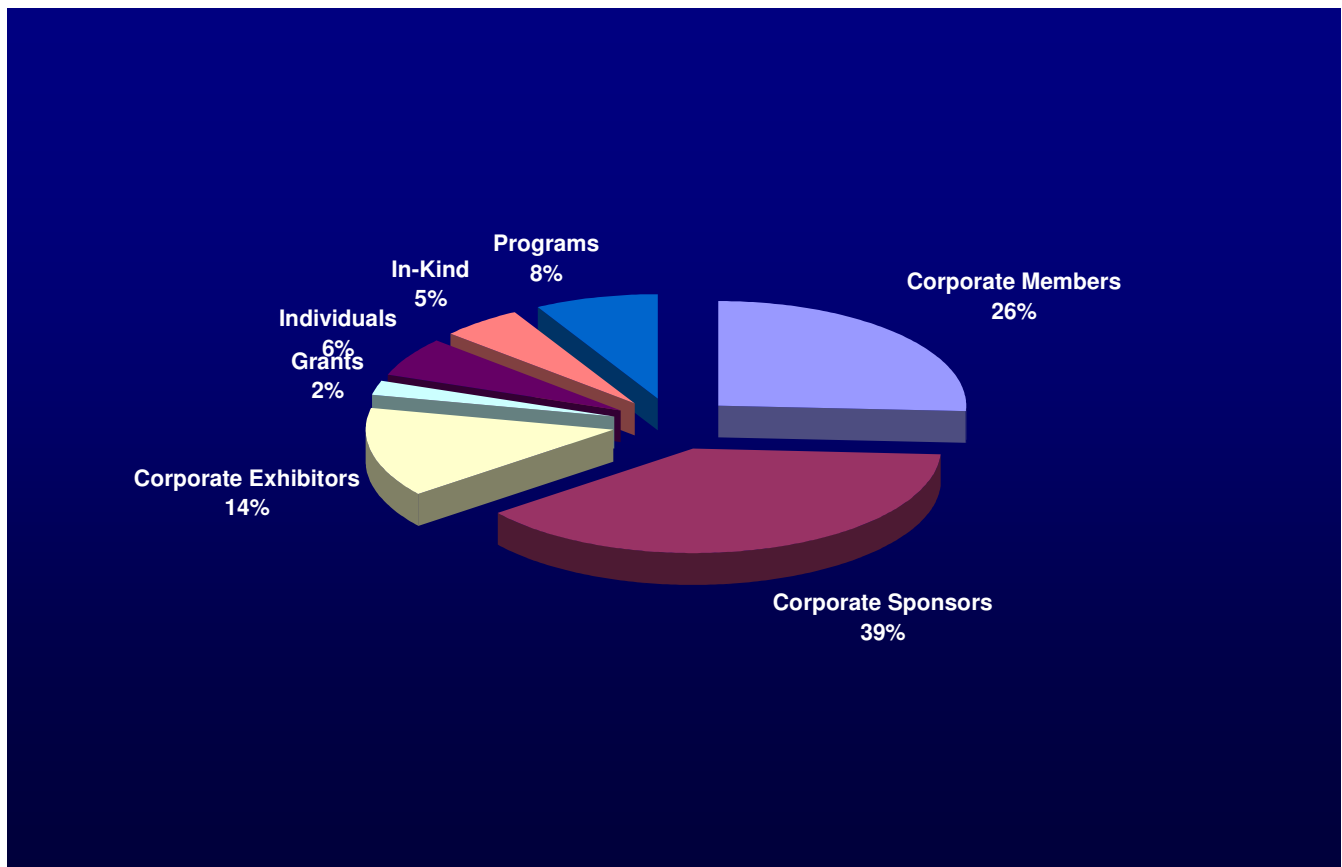


Figure 1 - 2009 Revenue by Source

CONCLUSION:

The ADAP Advocacy Association had a record fundraising year in 2009, despite the “Great Recession” – but it also achieved some important organizational outcomes that will help its advocacy efforts at the national level. Among them, launching a national public awareness campaign designed to highlight the growing ADAP waiting lists resulting from inadequate federal funding (Between 2000 and 2008, states increased their share of the ADAP budget by 155% while the federal government increased its share by only 46% overall). In 2010, many challenges will face **aaa+** and other HIV/AIDS initiatives – including how best to galvanize public support behind an FY10 Emergency ADAP Supplemental, as well as sufficient federal funding for Part B in FY11.