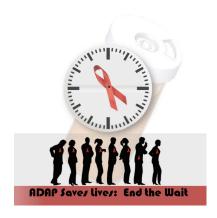


aaa+

2010 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.

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





# aaa+ 2010 Annual Report

### **SUMMARY:**

The ADAP Advocacy Association (aaa+) concluded another productive year in 2010, despite the backdrop of the escalating waiting lists under the AIDS Drug Assistance Programs ("ADAPs") nationally reaching historic levels. The ADAP crisis – which became commonly known as the "Perfect Storm" – was fueled by the bad economy, more people being tested and thus trying to access Ryan White services, state budgetary cut backs, and another year of inadequate federal funding (federal spending on ADAP as a percentage fell to 49% in 2010 from 72% in 2005). Last year from January to December, ADAP waiting lists increased by over 1,500% from 361 individuals in nine states to just shy of 5,000 individuals in ten states. In response to the ongoing ADAP crisis, aaa+ provided ten virtual trainings throughout the year, convened its 3<sup>rd</sup> Annual Conference, continued to expand its national grassroots advocacy network, produced two public service announcements and identified new partnerships with AIDS Healthcare Foundation, Housing Works and the Campaign to End AIDS (C2EA).

Once again partnering with the Community Access National Network, aaa+ used 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.

# **HIGHLIGHTS**:

- Released Annual Report highlighting 2009 accomplishments;
- Seated four new community leaders to the organization's Board of Directors;
- Garnered support from twenty-five (25) corporate entities (up from 17 in 2009);
- Formed two strategic partnerships with the National Network of ADA Centers and WE Movement;
- Hosted two wine tasting benefits in Washington, DC);
- Launched 'End The Wait' social media campaign focusing on eliminating ADAP waiting lists;
- Filmed two ADAP-specific public service announcements (which were later released in January 2011);
- Hosted successful 3<sup>rd</sup> Annual Conference: ADAPs in Crisis in Washington, DC;
- Hosted nine (9) educational virtual trainings on pharmaceutical company patient assistance programs;
- · Hosted virtual training on Welvista Solution;
- Sponsored two Congressional Briefings on Capitol Hill calling attention to growing ADAP waiting lists;
- Launched "ADAP Pill Box" a monthly e-publication of all things ADAP;
- Participated in two press conferences at the National Press Club on ADAP waiting lists;
- Initiated and sent three national sign-on letters on various HIV/AIDS-related issues;
- Supported nine (9) national sign-on letters addressing various HIV/AIDS initiatives;
- Circulated four legislative Action Alerts on ADAP-related issues; and
- Sent "Open Letter" in form of YouTube video to President Obama.







### TIMELINE OF EVENTS:

**January 21, 2010** – The ADAP Advocacy Association announced that it is participating in Capitol One®'s Card Lab Connect Program.

January 21, 2010 – The ADAP Advocacy Association blasted remarks made by radio personality Jim Quinn for the bigoted, irresponsible remarks he made during his January 14th radio program about HIV/AIDS. He falsely claimed that the "doors open up" to people living with HIV infection in the United States - completely overlooking the reality that most people living with HIV infection are gainfully employed, and those who are not most often find themselves trapped well below the federal poverty level. Audio clip: http://mediamatters.org/mmtv/201001190032



**February 1, 2010** – The ADAP Advocacy Association released its inaugural Congressional Scorecard evaluating Members of Congress on their support for the AIDS Drug Assistance Programs (ADAPs). Despite passing grades being received by majorities in both chambers, what was revealed by the rankings is more needs to be done to educate lawmakers about the importance of ADAPs in the states and territories.

**February 2, 2010** – The ADAP Advocacy Association thanked President Barack Obama for his leadership on HIV/AIDS issues, including his FY2011 Budget calling for an additional \$20 million for the AIDS Drug Assistance Programs (ADAPs). The small proposed increase will help the cash-strapped ADAPs, which have been perpetually under-funded by the federal government - but more needs to be done now to alleviate growing ADAP waiting lists nationwide.

**February 23, 2010** – The ADAP Advocacy Association released its 2009 Annual Report. 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 community stakeholders, expanded its national grassroots advocacy network and raised record-level funding for a small nonprofit in only its third year.

March 1, 2010 – The ADAP Advocacy Association announced that it has seated two new members to its Board of Directors. The aca+ Board of Directors voted unanimously to seat newcomers Robert Breining of Philadelphia, Pennsylvania and Anthony Jackson of New York, New York, both living with HIV infection and enrolled in the AIDS Drug Assistance Program.

**April 8, 2010** – The ADAP Advocacy Association urged President Barack Obama to support an emergency Fiscal Year 2010 supplemental appropriation of \$126 million for the AIDS Drug Assistance Program (ADAP). The critical appeal came in the form of an "Open Letter" video released on <u>YouTube</u> - offering an historical perspective to the plight facing hundreds of Americans currently on ADAP waiting lists in thirteen states.

April 14, 2010 – In response to the growing ADAP waiting list crisis nationwide, ADAP stakeholders were invited by the ADAP Advocacy Association, in coordination with the Community Access National Network (CANN), Flowers Heritage Foundation (FHF), National Alliance of State & Territorial AIDS Directors (NASTAD) and National Network of ADA Centers (DBTACs), to participate in an online training to learn about pharmaceutical company patient assistance programs (PAPs). This training was offered weekly over nine weeks.



### aaa+ 2010 Annual Report



May 12, 2010 – The ADAP Advocacy Association – in partnership with CANN and Housing Works – announced its 2010 Annual Conference as an "AIDS Drug Assistance Program Summit" to raise awareness about the ongoing ADAP waiting list crisis. The conference's theme was "ADAPs in Crisis: Moving Beyond Wait Lists & Improving Access to Care," assembled ADAP stakeholders from all of the various constituency groups – including patients, advocates, service providers, health care providers, pharmaceutical companies, allied health professionals, specialty pharmacies and others. The conference was the 3<sup>rd</sup> Annual Conference for the organization.



May 26, 2010 – The ADAP Advocacy Association urged Congress to immediately pass the "Addressing Cost Containment Measures to Ensure the Sustainability and Success of the ADAP Act" (S.3401). The ACCESS ADAP Act, which was introduced by Sen. Richard Burr (R-NC) and Sen. Tom Coburn (R-OK), would transfer \$126 million from discretionary amounts appropriated under the American Recovery and Reinvestment Act (Public Law 111-5) that remain unobligated, to be used by the Secretary of Health & Human Services in fiscal year 2010 to provide assistance in reducing waiting lists under the AIDS Drug Assistance Programs. aaa+ was among the leading national organizations supporting the legislation, which was the only ADAP-specific legislation introduced in the 111<sup>th</sup> Congress!

**June 11, 2009** – The ADAP Advocacy Association sponsored a Congressional Briefing on the AIDS Drug Assistance Programs. The briefing, which was hosted by CANN, was held in the House of Representatives Cannon Building and attended by Rep. Joseph Cao (R-LA).

June 25, 2010 – The ADAP Advocacy Association announced that its 2010 Annual Conference was going "Green" for the first time. "ADAPs in Crisis: Moving Beyond Wait Lists & Improving Access to Care" was the first environmentally-friendly conference hosted by aaa+, thanks in part to <a href="The Macsata-Kornegay Group">The Macsata-Kornegay Group</a>, Inc. donating the necessary flash drives.

**July 7, 2010** – The ADAP Advocacy Association – in partnership with CANN – hosted a Congressional Briefing on the AIDS Drug Assistance Programs as part of its 2010 Annual Conference. The briefing, which successfully concluded the 3-day conference in Washington, DC, was held in the House of Representatives Cannon Building.

**July 8, 2010** – The ADAP Advocacy Association rejected President Barack Obama's proposed \$25 million solution to alleviate the national crisis plaguing the AIDS Drug Assistance Programs. The reallocated funding was labeled as insufficient since the conservative "need" number was \$125 million.



July13, 2010 – The ADAP Advocacy Association questioned the effectiveness of the newly released National AIDS Strategy because it lacked the necessary funding to implement it. At the same time the Obama Administration released its NAS, thousands of people living with HIV/AIDS languished on waiting lists in thirteen states trying to access life-saving medications. aaa+ joined AIDS Healthcare Foundation at the National Press Club for a press conference themed, "Who's Better on AIDS?" – which compared the record of President Obama to President George W. Bush. Both organizations called the NAS a "day late and dollar short" because ADAP waiting lists continue to grow despite plan seeking to "establish a seamless system to immediately link people to continuous and coordinated care when they learn they are infected with HIV."



# aaa+ 2010 Annual Report



**August 23, 2010** – The ADAP Advocacy Association praised President Barack Obama and the Office for National AIDS Policy ("ONAP") for submitting to Congress a Fiscal Year 2011 ("FY2011") Budget Amendment calling for an additional \$30 million for ADAPs. The proposed \$30 million increase follows the \$20 million increase already included in the Obama Administration's proposed budget blueprint for next year to help the cash-strapped ADAPs. Unfortunately, it did nothing to help the 2,937 Americans currently on ADAP waiting lists!

September 16, 2010 – The ADAP Advocacy Association issued a 'Call to Action' to President Barack Obama, Senate Majority Leader Harry Reid, House Speaker Nancy Pelosi and Members of the Congressional Black Caucus, pleading with them to eliminate the expanding waiting lists under the AIDS Drug Assistance Programs. The appeal urged them to put partisan politics aside for the greater good of improving access to care for people living with HIV/AIDS! Download the ADAP Crisis Sign-On Letter.

**September 23, 2010** – The ADAP Advocacy Association sponsored a Congressional Briefing on the AIDS Drug Assistance Programs. The briefing, which was hosted by CANN, was held in the U.S. Senate Dirksen Building and attended by Sen. Richard Burr (R-NC) and Rep. Donna Christensen (D-V.I.).

October 1, 2010 – The ADAP Advocacy Association called on all drug manufacturers of highly active antiretroviral treatments ("HAART") to design a streamlined enrollment process for their respective patient assistance programs ("PAPs"). HIV/AIDS patients currently on waiting lists to access their medications under the AIDS Drug Assistance Programs would be better-served if existing barriers to care were eliminated by the drug companies collaborating together to simplify their PAP application and eligibility.

October 5, 2010 – The ADAP Advocacy Association praised Senator Olympia Snowe (R-ME) for supporting the "Addressing Cost Containment Measures to Ensure the Sustainability and Success of the ADAP Act" (S.3401). The ACCESS ADAP Act would transfer \$126 million from discretionary amounts appropriated under the American Recovery and Reinvestment Act (Public Law 111-5) that remain unobligated, to be used by the Secretary of Health & Human Services in fiscal year 2010 to provide assistance in reducing waiting lists under the AIDS Drug Assistance Programs.



**November 16, 2010** – The ADAP Advocacy Association cautioned that the growing waiting lists under the AIDS Drug Assistance Programs are only the "tip-of-the-iceberg" as thousands more are being adversely impacted by other cost containment strategies.

**December 1, 2010** – The ADAP Advocacy Association commemorated World AIDS Day by remembering the nearly 600,000 Americans who lost their lives to HIV/AIDS, supporting the million-plus people who are currently living with HIV/AIDS in the United States and reaffirming its commitment to ensure that every American has access to the appropriate medical care and treatment they deserve. With over 4,000 Americans living with HIV/AIDS on waiting lists for the AIDS Drug Assistance Programs, any proclamation or statement is marred by the mere fact that thousands woke-up on World AIDS Day without access to their life-saving medication in the richest nation on the planet.

**December 6, 2010** – In response to the growing ADAP crisis, ADAP stakeholders were invited by the ADAP Advocacy Association, in coordination with CANN and the DBTACs, to participate in an online training to learn about the Heinz-Welvista solution and how it can help patients on ADAP waiting lists.

**December 31, 2010** – The ADAP Advocacy Association announced that **Jeffrey Lewis**, President & CEO of the Heinz Family Philanthropies, was the recipient of its **"2010 ADAP Champion"** award.







#### **CORPORATE SUPPORT:**

**Corporate Members** 

Ramsell Holding Corporation – Corporate Leader

 ${\sf Merck\ \&\ Co.,\ Inc.-Corporate\ Leader}$ 

Gilead Sciences – Corporate Partner

Abbott Laboratories – Corporate Associate MedData Services – Platinum Member

EMD Serono – Gold Member

Diplomat Specialty Pharmacy – Silver Member

AIDS Alabama - Bronze Member

**Annual Conference Sponsors** 

Community Access National Network

Merck & Co.

Flowers Heritage Foundation

HealthHIV

MedData Services

The Macsata-Kornegay Group

**Housing Works** 

Ramsell Holding Corporation

Flowers Heritage Foundation – Corporate Leader

Health Management Services - Platinum Member

Community Access National Network - Bronze Member

Tibotec Therapuetics – Corporate Partner

ViiV Healthcare - Corporate Associate

Bristol-Myer Squib - Silver Member

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**EMD Serono** 

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**Diplomat Specialty Pharmacy** 

MOMS Pharmacy ViiV Healthcare

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Gilead Sciences Merck & Co.

ViiV Healthcare

EMD Serono

MedData Services

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Dr. Ali Harake

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Dr. Philip Haddad

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National Network of ADA Centers (DBTACs)

WE Movement





# aaa+ 2010 Annual Report









































### **ACKNOWLEDGEMENTS:**

In 2010, the ADAP Advocacy Association could not have completed its second 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 2010:

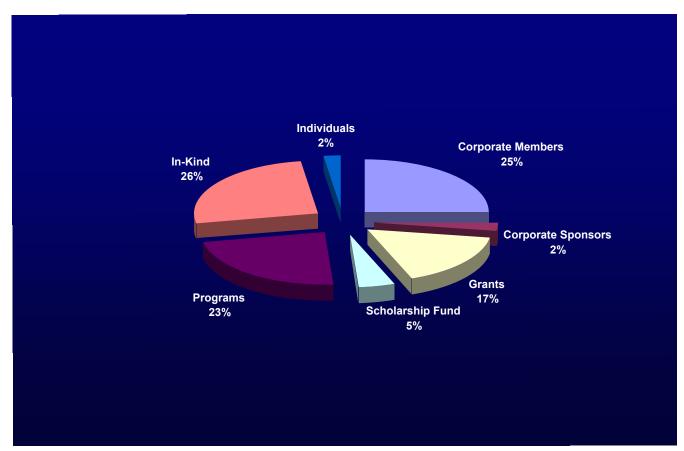


Figure 1 - 2009 Revenue by Source

### **CONCLUSION:**

The ADAP Advocacy Association for the third consecutive year reached a fundraising milestone in 2010, expanding all aspects of its donor base. That success allowed <code>aaa+</code> to host or sponsor a litany of educational programming – including ten virtual trainings – designed to better inform people living with HIV/AIDS about numerous patient access and health care resources. Additionally, <code>aaa+</code> focused additional resources on trying to influence public opinion last year with the use of social media, public service announcements, blogs and other techniques not previously used by the organization. But there remains much work to be done.





### aaa+ 2010 Annual Report

The 2010 midterm elections, characterized by most respected political pundits as a GOP tidal wave, swept into power a record number 63 Republicans to the House of Representatives and bringing their total to 242 seats - which is the most the GOP has held in more than 60 years. The Republican Party also gained a respectable 6 seats in the Senate, despite losing some marquee races headlined by Tea Party candidates where GOP-gains seemed eminent - including Colorado, Delaware and Nevada. The shift in power provides HIV/AIDS activists with some new opportunities, as well as some serious challenges. Among the emerging opportunities is the GOP's top two House leaders hailing from Ohio (Rep. John Boehner as Speaker) and Virginia (Rep. Eric Cantor as Majority Leader) where the political embarrassment of current ADAP waiting lists could force both lawmakers to seek additional funding, as well as the historical perspective that some of the largest ADAP funding increases occurred after the GOP was swept into power after the 1994 midterm congressional elections. But there remain significant challenges, such as Republican rhetoric to scale back recent health care reform legislation, and efforts by budget deficit hawks to scale back federal discretionary appropriations to 2008 levels.

The mere fact that the Democratic controlled-Congress did little to address the ongoing ADAP crisis, despite super majorities in both chambers of Congress coupled with a Democrat in the White House, left the HIV/AIDS advocacy community splintered and divided. While in some instances congressional Republicans failure to support emergency supplemental funding, their minority status in both the House and Senate shouldn't have been a deterrent to Democrats seeking and approving a legislative remedy to the crisis. The lack of uniformity in the community's message made successful advocacy efforts moving forward even more problematic. In 2011, successful HIV/AIDS advocacy during the 112th Congress will be left more so in the hands of local grassroots efforts, where most real change occurs.