



## ADAP ADVOCACY ASSOCIATION

aaa+

### 2012 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 to improve access to care for persons living with HIV/AIDS.

aaa+ works with advocates, community organizations, health care groups, government agencies, 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](http://www.adapadvocacyassociation.org).



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#### **SUMMARY:**

The ADAP Advocacy Association (aaa+) witnessed the end of the “Perfect Storm” that had ravished the AIDS Drug Assistance Programs (ADAPs) for nearly four years, forcing literally thousands of people living with HIV infection nationwide to be denied access to timely and appropriate care and treatment. A culmination of grassroots advocacy efforts – some of which were even spearheaded by the organization itself – led to additional federal appropriations to the cash-strapped program in FY2011 and FY2012 ADAP funding, along with FY2011 emergency funds, which resulted in a nearly 99 percent reduction in the size of the ADAP waiting lists.

According to the **National Alliance of State & Territorial AIDS Directors** (NASTAD), there were 4,717 people in 12 states on ADAP waiting lists, as of January 12, 2012. As a result of FY2011 ADAP emergency funding, Alabama, Florida, Georgia, Idaho, Louisiana, Montana, North Carolina, Ohio, South Carolina, Utah, and Virginia were able to reduce the overall number of people on their waiting lists.<sup>1</sup> As of April 19, 2012, that number had decreased 3,079 people on ADAP waiting lists in 10 states.<sup>2</sup> By mid-year, there are 2,170 people on ADAP waiting lists in 9 states. The total number of people on waiting lists had decreased 77 percent since a high of 9,298 individuals on September 1, 2011.<sup>3</sup> The most dramatic decrease occurred in the latter part of the year when NASTAD reported only 58 people on ADAP waiting lists in four (4) states, as of December 13, 2012.<sup>4</sup>

State ADAPs are primarily federally funded under Part B of the Ryan White Comprehensive AIDS Resources Emergency (“CARE”) Act. ADAPs provide medications to treat HIV disease and prevent and treat AIDS-related opportunistic infections to low income, uninsured and underinsured individuals living with HIV/AIDS in the fifty states, District of Columbia, Puerto Rico, Guam, U.S. Virgin Islands, American Samoa, Marshall, and Northern Marianas Islands. Additional funding is directed toward state ADAPs from other Ryan White CARE Act funds, including Part A Eligible Metropolitan Area (“EMA”) funds. Many states also directly contribute funding. ADAPs represent the “access to treatment” window for the community-based continuum of HIV/AIDS healthcare so carefully built and supported by all the Parts of the Ryan White CARE Act, which was reauthorized for four years by both Houses of Congress and signed into law by President Barack Obama on October 30, 2009. The law in general has enjoyed strong bipartisan support since it was first passed in the 1990s, and ADAPs specifically have been a Return on Investment (“ROI”) model since the federal government began pumping money into them.

Whereas ADAPs have routinely faced funding shortfalls and waiting lists, at no time in the program’s history was the crisis as severe as in 2011. The ADAP crisis was fueled, by in large, because federal spending has been inadequate – despite small budget increases under both President George W. Bush and President Barack Obama between FY2003 and FY2010. The federal share of ADAP funding had fallen steadily over the last several years. In FY2003 the federal earmark was 72 percent of the overall ADAP budget; in FY2010, the federal share had fallen to approximately 48 percent of the ADAP budget. ADAPs have long had a strong state-federal partnership; however despite the economic downturn many states have increased funding in FY2010 by an additional \$121 million dollars for a total of \$346.2 million. Pharmaceutical manufacturers have also helped to alleviate fiscal challenges for ADAP by agreeing to lower drug prices and enhanced rebates.<sup>5</sup>

<sup>1</sup> National Alliance of State & Territorial AIDS Directors (NASTAD), The ADAP Watch, January 13, 2012.

<sup>2</sup> National Alliance of State & Territorial AIDS Directors (NASTAD), The ADAP Watch, April 20, 2012.

<sup>3</sup> National Alliance of State & Territorial AIDS Directors (NASTAD), The ADAP Watch, June 8, 2012.

<sup>4</sup> National Alliance of State & Territorial AIDS Directors (NASTAD), The ADAP Watch, December 14, 2012.

<sup>5</sup> The ADAP Coalition, ADAP Need FY2012, January 2011.



## ADAP ADVOCACY ASSOCIATION

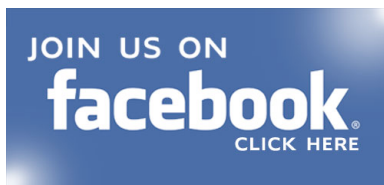
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### 2012 Annual Report



#### HIGHLIGHTS:

- Released Annual Report highlighting 2011 accomplishments;
- Seated one new community leaders to the organization's Board of Directors;
- Increased the size of the organization's list-serve by approximately 20 percent;
- Garnered support from thirty-one (31) corporate entities;
- Renewed strategic partnerships with the **National Network of ADA Centers, Community Access National Network, Flowers Heritage Foundation, Housing Works** and **AIDS Healthcare Foundation**;
- Hosted four wine tasting benefits, which were held as Quarterly Membership Meetings;
- Released Congressional Scorecard evaluating Members of Congress on their support for the AIDS Drug Assistance Programs (ADAPs).
- Hosted an **ADAP Solutions Summit** in Washington, DC;
- Published ADAP Solutions Summit Final Report, outlining key programmatic remedies to eliminate ADAP waiting lists.
- Supported local advocates in Puerto Rico calling on officials to provide proper health management & treatment
- Recognized by KwikMed as one of the "**16 Five Star Rated AIDS Information Sites & Blogs**" for excellence due to the contribution its top quality editorial offers the AIDS information world.
- Hosted its **5<sup>th</sup> Annual Conference, AIDS Drug Assistance Program Crisis: "STAMP" Out ADAP Waiting Lists** in Washington, DC;
- Hosted 2<sup>nd</sup> Annual ADAP Leadership Awards Dinner;
- Funded forty-four (44) scholarships;
- Supported ten (10) national sign-on letters addressing various HIV/AIDS and healthcare initiatives;
- Circulated one (1) legislative Action Alert on ADAP-related funding issues;
- Published twenty (20) blogs about ADAP-related issues;
- Conducted four (4) online stakeholder polls.



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#### TIMELINE OF EVENTS:

**January 11, 2012** – The ADAP Advocacy Association announced that it had appointed Eric Flowers, President and CEO of Ramsell Holding Corporation, to its board of directors. The aaa+® board voted unanimously to add Flowers as the third corporate representative on the board, joining executives from Walgreens and Walmart.

**February 8, 2012** – The ADAP Advocacy Association announced that it would host an "ADAP Solutions Summit" in Washington, DC on April 2-3, 2012. The summit, which was held in partnership with the **Community Access National Network (CANN)**, focused on identifying numerous short-term and long-term solutions, including – but not limited to – increased federal/state funding, access to patient assistance programs, drug pricing & drug rebates, program efficiencies (i.e., eligibility determination), access to generics, etc.



**February 14, 2012** – The ADAP Advocacy Association praised President Barack Obama for his proposed budget for Fiscal Year (FY) 2013, and its commitment to shoring-up the cash-strapped AIDS Drug Assistance Programs (ADAP) under the Ryan White CARE Act. Nationwide, as of February 9th, there were 4,111 individuals living with HIV/AIDS in the United States being denied access to appropriate, timely care and treatment on ADAP waiting lists. President Obama is proposing an increase of \$102 million.

**February 24, 2012** – The ADAP Advocacy Association joined local advocates in Puerto Rico calling for better health management and treatment of patients living with HIV/AIDS who are hospitalized and going without their anti-retroviral (ARV) medications. The dire circumstances facing these patients was first brought to light by two organizations, AIDS Patients pro Sane Policy and the Permanent Assembly of Persons Infected and Affected with HIV/AIDS (APPIA).

**March 1, 2012** – The ADAP Advocacy Association released its 2011 Congressional Scorecard evaluating Members of Congress on their support for the AIDS Drug Assistance Programs (ADAPs). The scorecard demonstrated a marked improvement over last year because the vast majority of both the U.S. House of Representatives and U.S. Senate received passing grades. Republicans and Democrats both supported additional federal funding, which contributed to the improved rankings last year.



**April 13, 2012** – The ADAP Advocacy Association released its 2011 Annual Report. Despite a very challenging year facing the nation's AIDS Drug Assistance Programs and the nearly 10,000 people living with HIV/AIDS who were being denied access to timely and appropriate care and treatment, aaa+® achieved significant milestones throughout the year. Among them serving as the facilitator to bring ADAP stakeholders together to identify solutions to the ongoing crisis. > [Download 2011 Annual Report](#)

**April 24, 2012** – The ADAP Advocacy Association announced that it has released the Final Report from its "ADAP Solutions Summit" – which was held in partnership with the **Community Access National Network (CANN)**. The purpose of this Final Report is to convey some of the programmatic changes, improvements and reforms that could enhance ADAPs to better serve the needs of the consumers/clients. There were 3,097 people living with HIV/AIDS on ADAP waiting lists in 10 states, as of April 12, 2012 – including 503 people in Florida, 957 people in Georgia, 11 people in Idaho, 368 people in Louisiana, 4 people in Montana, 220 people in Nebraska, 124 people in North Carolina, 0 people in South Carolina, 0 people in Utah and 910 people in Virginia.

> [Download 2012 ADAP Solutions Summit Final Report](#)



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**May 11, 2012** – The ADAP Advocacy Association announced that it would host its 5th Annual Conference on August 19-21, 2012. The conference – held in partnership with the Community Access National Network (CANN) and Housing Works – was themed the "**AIDS Drug Assistance Program Crisis: "STAMP" Out ADAP Waiting Lists!**" It was held at the Westin Washington DC City Center, located at 1400 M Street, NW, Washington, DC 20005.

**May 22, 2012** – The ADAP Advocacy Association opened nominations for its 2012 Annual ADAP Leadership Awards. The awards will recognize individual, community, government and corporate leaders who are working to improve access to care and treatment under the AIDS Drug Assistance Programs.

**July 9, 2012** – The ADAP Advocacy Association announced that its weekly blog about the AIDS Drug Assistance Programs (ADAPs) had been recognized as by KwikMed as one of the "**16 Five Star Rated AIDS Information Sites & Blogs**" for excellence due to the contribution its top quality editorial offers the AIDS information world. This year, KwikMed's specialist panel of judges reviewed hundreds of different sites from across the Internet before hand picking the very best for each category. The **aaa+®** blog is among the elite selection of awardees that their judges felt made a real contribution to the AIDS information category.

**July 12, 2012** – The ADAP Advocacy Association announced the recipients for its 2012 Annual ADAP Leadership Awards, which recognizes individual, community, government, media and corporate leaders who are working to improve access to care and treatment under the AIDS Drug Assistance Programs. The eight leadership awards were presented during the **2nd Annual ADAP Leadership Awards Dinner** on Monday, August 20th at 7:00 pm in Washington, DC. The 2011-2012 award recipients included: ADAP Champion of the Year: **Edward "Eddie" Hamilton**; ADAP Emerging Leader of the Year: **Kevin Maloney of the Community Access National Network**; ADAP Corporate Partner of the Year: **Walgreens**; ADAP Community Organization of the Year: **AIDS Alabama**; ADAP Lawmaker of the Year: **The Honorable Jim McDermott, M.C. (WA-7), The Honorable Barbara Lee, M.C. (CA-9), The Honorable Trent Franks, M.C. (AZ-2)**; ADAP Social Media Campaign of the Year: **Maria's Journal by Maria Mejia**; ADAP Grassroots Campaign of the Year: **Florida ADAP Campaign by FHAAN (via The AIDS Institute)**; and ADAP Media Story of the Year: **Iowa Insurance Pool is a Colossal Failure by Andie Dominick, Des Moines Register**.

**July 20, 2012** – The ADAP Advocacy Association welcomed the Obama Administration's announcement that it is awarding \$80 million in grants to increase access to HIV/AIDS care across the United States. The funding will eliminate waiting lists under the AIDS Drug Assistance Programs, as well as expand care and treatment to 14,000 new patients. As of July 12, 2012, there remained 2,030 people living with HIV/AIDS languishing on ADAP waiting lists in nine states, but that figure does not accurately reflect the thousands of patients remaining on "invisible" ADAP waiting lists.



**November 30, 2012** – The ADAP Advocacy encouraged people living with HIV/AIDS, their families and supporters to remain vigilant on World AIDS Day. Despite the tremendous progress achieved over the last year to eliminate waiting lists under AIDS Drug Assistance Programs, there remain nearly one hundred people living with HIV/AIDS being denied access to appropriate, timely care and treatment. Celebrating World AIDS Day should represent an important first step in the coming year to completely eliminate ADAP waiting lists nationwide.



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### **CORPORATE SUPPORT:**

#### **Corporate Members**

Morgali Films – Corporate Leader  
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Southwest Airlines – Corporate Associate  
Gilead Sciences – Corporate Affiliate  
Walgreens Co. – Gold Member  
MedData Services – Silver Member  
AIDS Alabama – Bronze Member  
Wells Fargo – Bronze Member

Merck & Co., Inc. – Corporate Partner  
Flowers Heritage Foundation – Corporate Leaders  
ViiV Healthcare – Corporate Associate  
Janssen Therapeutics – Corporate Associate  
Community Access National Network – Silver Member  
The Macsata-Kornegay Group, Inc. – Silver Member  
Bristol-Myers Squibb – Bronze Member

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Flowers Heritage Foundation  
Janssen Therapeutics  
Bristol-Myers Squibb  
The Macsata-Kornegay Group

Morgali Films  
Housing Works  
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OraSure Technologies  
Gilead Sciences  
MedData Services  
ViiV Healthcare  
Starbucks

#### **Annual ADAP Leadership Awards Gala Sponsors**

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GettingHired.com  
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#### **Strategic Partners**

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AIDS 2012 Reunion

Community Access National Network  
The Macsata-Kornegay Group  
DC'S Most Fabulous Magazine  
Base Connect

#### **Individual Event Sponsors**

Dr. Ali Harake

Dr. Philip Haddad



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2012 Corporate Members & Strategic Partners

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**ACKNOWLEDGEMENTS:**

In 2012, the ADAP Advocacy Association exceeded the \$200,000.00 threshold for the first time thanks to the financial support of its corporate members, corporate sponsors, programmatic supporters, individual donors, in-kind donations, and the meaningful events hosted by the organization. Whereas donations to the organization’s scholarship fund were down last year, most other funding streams actually maintained their support levels, or even experienced increases.

The following chart demonstrates the diversity of the organization’s funding in 2012:

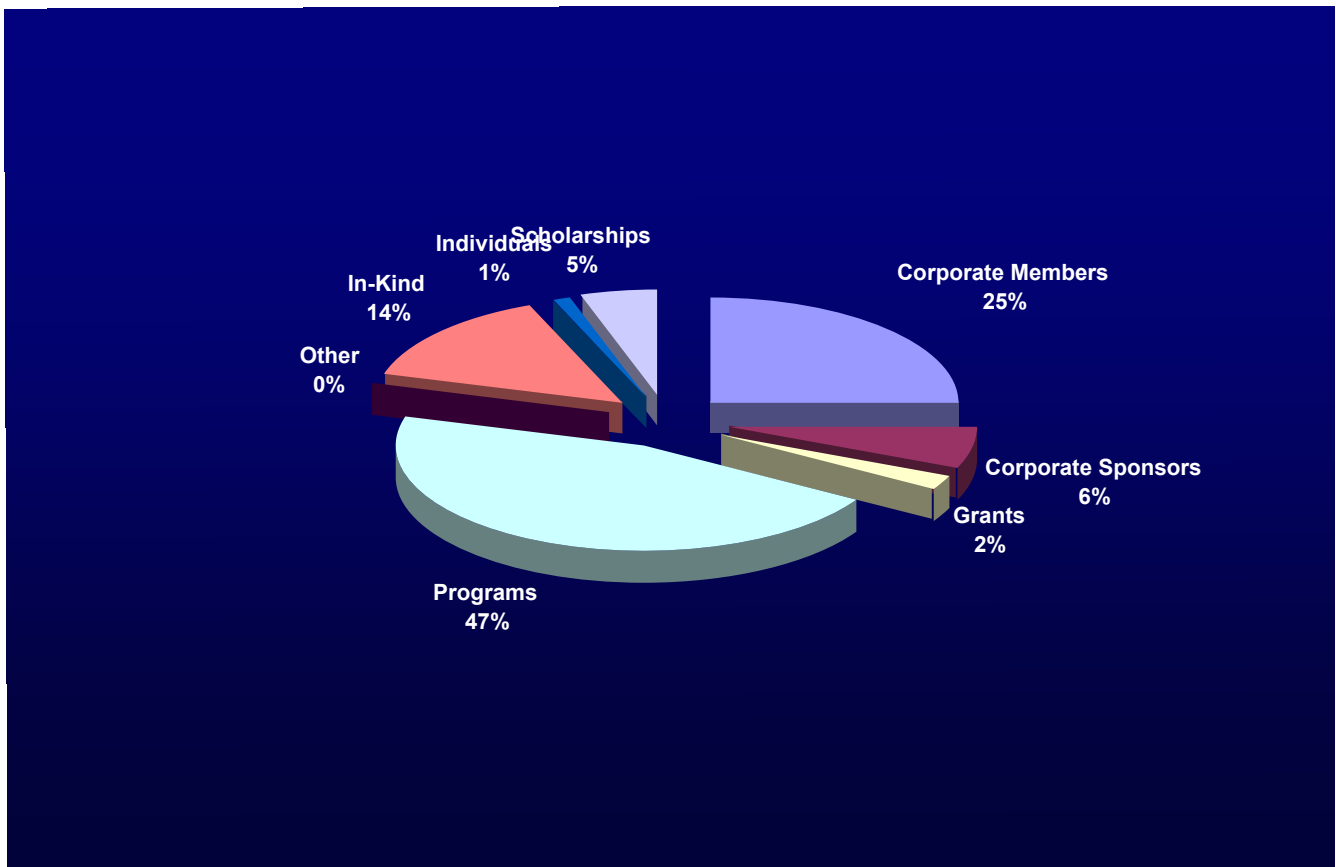


Figure 1 - 2012 Revenue by Source

**CONCLUSION:**

The challenges that led to waiting lists under the AIDS Drug Assistance Programs approaching nearly 10,000 patients finally subsided during the year, resulting in a dramatic reduction in ADAP waiting lists. The ADAP Advocacy Association continued to leverage its infrastructure and national network to cultivate relationships and ongoing partnerships among various ADAP stakeholders. The end result was educational patient-centered programming that continued to raise awareness that people living with HIV-infection were being denied access to timely and appropriate care.