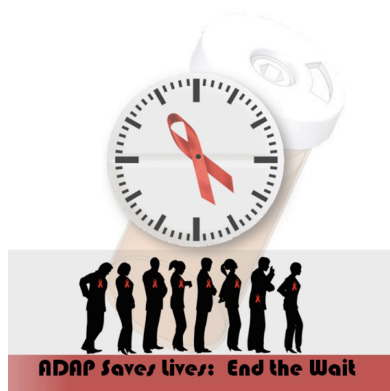




## ADAP ADVOCACY ASSOCIATION



### 2011 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).



## ADAP ADVOCACY ASSOCIATION

aaa+

### 2011 Annual Report



#### **SUMMARY:**

The ADAP Advocacy Association (aaa+) faced serious challenges last year with a record number of people living with HIV/AIDS being denied access to timely and appropriate care and treatment under the AIDS Drug Assistance Programs (“ADAPs”). Nationally, ADAP waiting lists ballooned to nearly 10,000 PLWHAs as the program continued to battle the “ADAP Perfect Storm” – but the wait-lists only represented the tip of the iceberg as more states adopted restrictive cost containment strategies as they attempted to balance their budgets.

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 when President Bill Clinton and Speaker Newt Gingrich were in office.

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 ongoing 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 since 2005. The federal share of ADAP funding has 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>1</sup> But more needs to be done!

The problem of growing ADAP waiting lists is exacerbated because the U.S. is facing a “Southern” HIV/AIDS epidemic of devastating proportion. According to some estimates, the number of people living with HIV/AIDS in the U.S. was approximately two million by the end of 2010. These numbers are not due to decrease in the near future. In 2006 alone, the Centers for Disease Control & Prevention (“CDC”) estimated that there have been more than 56,000 new HIV infections per year for the last decade. If this was not severe enough, the disease is far from color blind. Currently, the incidence rate of new HIV infection among African American men and women is seven times that of the Caucasian population. Furthermore, racial disparities are echoed regionally as the epidemic has seen its most recent unfettered growth in Southern states, which often times have smaller state budgets and fewer access points to comprehensive care. Nearly 96 percent of the ADAP wait-lists are in southern states.

The ADAP need is being driven by simple factors. As we all know AIDS treatments (Highly Active Anti-Retroviral Therapy) has dropped U.S. death rates from AIDS by about 75% starting in 1996. Whereas annual AIDS deaths used to run about 40,000 a year, now 15,000 to 17,000, even less in areas of very good medical care.

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<sup>1</sup> The ADAP Coalition, ADAP Need FY2012, January 2011



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While dramatic improvements in lifespan and quality of life are almost miraculous, HAART treatments must continue for ADAP patients. Therefore patients living longer will likely require ADAP services for medications longer. Based on conservative estimates, there are 200,000 to 300,000 Americans who are unaware that they are HIV-positive. Extensive multi-million dollar efforts for outreach and HIV testing are going on all over the country, and the CDC now urges routine testing for those at risk for HIV. Funded by churches, foundations, Minority Health Initiatives, pharmaceutical companies and AIDS service groups, these efforts are identifying “hard to reach” populations many of whom lack adequate health insurance. These individuals, when identified, must look to ADAP to cover the costs of their drugs. For most, access to Medicaid is limited. State Medicaid programs typically require disease progression to full-blown AIDS to meet the Social Security definition of disabled. U.S. government treatment guidelines consider progression to full-blown AIDS to be months and years too late for optimum treatments.

Since Congress failed to pass the Early Treatment for HIV Act (“ETHA”) – which would have allow states the option to provide HIV care and treatments through Medicaid early in the disease process when health benefits are greater and costs are less – PLWHAs are stuck trying to qualify for Medicaid and looking to ADAP for basic coverage. Increases in private sector health insurance costs forces steady streams of HIV-positive patients from private health insurance programs to state ADAPs. This is a result of rising costs in premiums and co-payments that become unaffordable, and in some instances by HMO-type providers with drug benefits leaving the market for more profitable locations. These factors together, ensure need for state ADAPs for the coming years. The increasing rate of need will be substantial until key provisions of the **Patient Protection and Affordable Care Act (“PPACA”)** can provide adequate benefits to our entire senior, elderly and disabled populations. As the profile of the American AIDS epidemic has expanded further into communities of color, marginalized populations, rural areas, and particularly to women of color in their child bearing years, ADAPs feel these additional strains from groups which traditionally may work low-paying jobs with inadequate health insurance or no healthcare benefits.

In 2011, twenty (20) state ADAPs instituted other cost-containment strategies, including **Arizona**: Reduced formulary, **Arkansas**: Reduced formulary, lowered financial eligibility to 200% of FPL, (disenrolled 99 clients in September 2009), **Colorado**: Reduced formulary, **Florida**: Reduced formulary, lower financial eligibility to 300% FPL, transition clients to Welvista from 2/14-3/31/11, **Georgia**: Reduced formulary, implemented medical criteria, continued participation in the Alternative Method Demonstration Project (AMDP), **Idaho**: Capped enrollment **Illinois**: Reduced formulary, instituted monthly expenditure cap, **Kentucky**: Reduced formulary, **Louisiana**: Discontinued reimbursement of laboratory assays, **North Carolina**: Reduced formulary, **North Dakota**: Capped enrollment, instituted annual expenditure cap, lowered financial eligibility to 300% FPL, **Ohio**: Reduced formulary, lowered financial eligibility to 300% of FPL (disenrolled 257 clients), **Puerto Rico**: reduced formulary, **South Carolina**: Lowered financial eligibility to 300% FPL **Utah**: Reduced formulary, lowered financial eligibility to 250% of FPL (disenrolled 89 clients), **Virginia**: Reduced formulary, only distribute 30-day prescription refills, **Washington**: Instituted client cost sharing, reduced formulary (for uninsured clients only), only pay insurance premium for clients currently on antiretrovirals, and **Wyoming**: Reduced formulary, instituted client cost sharing.

In response to the escalating ADAP waiting list / cost containment crisis, aaa+ embarked on an aggressive campaign to engage **ALL** stakeholders to identify, evaluate and implement public policy solutions, programmatic educational activities, grassroots advocacy efforts and public relations tactics.



## ADAP ADVOCACY ASSOCIATION

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### 2011 Annual Report



#### HIGHLIGHTS:

- Released Annual Report highlighting 2010 accomplishments;
- Seated two new community leaders to the organization's Board of Directors;
- Garnered support from thirty-two (32) corporate entities (up from 25 in 2010);
- Renewed strategic partnerships with the **National Network of ADA Centers, Community Access National Network, Housing Works** and **AIDS Healthcare Foundation**;
- Hosted four wine tasting benefits, which were held as Quarterly Membership Meetings;
- Launched 'Obama-ADAP Twitter Day' social media campaign focusing on eliminating ADAP waiting lists;
- Released two ADAP-specific public service announcements (*which were filmed in September 2010*);
- Hosted an **Emergency ADAP Summit** in Fort Lauderdale, FL;
- Hosted its **4<sup>th</sup> Annual Conference, AIDS DRUG ASSISTANCE PROGRAM Crisis: When will Washington come to the rescue** in Washington, DC;
- Hosted two (2) educational virtual trainings on pharmaceutical company patient assistance programs;
- Sponsored Congressional Briefing on Capitol Hill calling attention to growing ADAP waiting lists;
- Initiated and sent two (2) national sign-on letters on ADAP-related issues;
- Supported 21 national sign-on letters addressing various HIV/AIDS and healthcare initiatives;
- Circulated one (1) legislative Action Alert on ADAP-related funding issues;
- Published weekly blogs about ADAP-related issues;
- Submitted Congressional Testimony about the proven ROI around early ARV therapy and the role of the AIDS Drug Assistance Program;
- Submitted letter to Disability Rights Florida seeking their legal intervention on behalf of Floridians living with HIV/AIDS under their "PAIR" program (Protection & Advocacy for Individual Rights) to alleviate the ADAP waiting list crisis in Florida;
- Submitted public comment to the Florida Department of Health in response to its proposed rule to change that state's ADAP eligibility guidelines;
- Launched groundbreaking partnership with MyGov365;
- Collaborated with former U.S. Surgeon General David Satcher to raise awareness about ADAPs among Members of Congress; and
- Initiated ADAP Leadership Awards, which were presented during the ADAP Leadership Awards Gala.



## ADAP ADVOCACY ASSOCIATION

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### 2011 Annual Report

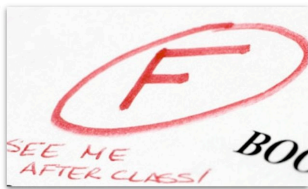


#### TIMELINE OF EVENTS:

**January 30, 2011** – The ADAP Advocacy Association hosted its 2011 Emergency ADAP Summit in Fort Lauderdale, Florida, as the AIDS Drug Assistance Programs continued to face crisis.

**February 4, 2011** – The ADAP Advocacy Association sent a letter to President Barack Obama and his Office of National AIDS Policy director, Jeff Crowley, seeking an immediate fix to the ongoing crisis facing the cash-strapped ADAPs. The letter, which was drafted and circulated for signatures during the 2011 Emergency ADAP Summit in Fort Lauderdale, Florida, demonstrated that ADAP stakeholders nationwide remained optimistic that their advocacy efforts would not be in vein. Download letter:

[http://www.adapadvocacyassociation.org/pdf/2011\\_aaa\\_Letter\\_ADAP-Crisis\\_Obama\\_Crowley\\_01-31-11.pdf](http://www.adapadvocacyassociation.org/pdf/2011_aaa_Letter_ADAP-Crisis_Obama_Crowley_01-31-11.pdf)



**February 7, 2011** – The ADAP Advocacy Association released its 2010 Congressional Scorecard evaluating Members of Congress on their support for ADAPs. Despite ADAPs enjoying strong bipartisan support, partisan gridlock led to total inaction in the U.S. Congress, resulting in thousands of people living with HIV/AIDS being denied care. aaa+ took the bold step of failing the entire Congress, although several 'Honorable Mentions' were issued.

**February 7, 2011** – The ADAP Advocacy Association announced that it has released two Public Service Announcements (PSAs) on the struggling ADAPs. The landmark PSAs – which include both a 60-second spot for television and another 5-minute spot for the Internet – represent the first time public service announcements have focused on ADAPs. Award-winning producer Neil Romano of The Romano Group, LLC, produced the PSAs.



> [WATCH PSAs](#)

**February 18, 2011** – The ADAP Advocacy Association applauded the leadership demonstrated by U.S. Representative Alcee Hastings (D-Fla.) on the crisis facing ADAPs and the thousands of people living with HIV/AIDS languishing on waiting lists nationwide in ten states. On February 17th, Rep. Hastings offered an [amendment](#) to the "Full-Year Continuing Appropriations Act, 2011" (H.R.1), which would have re-allocated \$48 million to the cash-strapped ADAPs. The amendment was approved by unanimous consent.

**March 8, 2011** – The ADAP Advocacy Association released its 2010 Annual Report. aaa+ completed its third full year of operations since being incorporated in July 2007, and in 2010 reached significant milestones that encompassed all aspects of the organization's mission and related operations. > [Download 2010 Annual Report](#)



**April 5, 2011** – The ADAP Advocacy Association announced its 2011 Annual Conference, which was held together with its Lead Sponsor the AIDS Healthcare Foundation (AHF) – in partnership with the Community Access National Network (CANN) and Housing Works – on Tuesday, July 5th - Thursday, July 7th in Washington, DC. The summit was themed "**AIDS DRUG ASSISTANCE PROGRAM Crisis: When will Washington come to the rescue.**" The event represented the organization's 4th Annual Conference and built on the success from the Emergency ADAP Summit held earlier in the year.





## ADAP ADVOCACY ASSOCIATION

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**April 15, 2011** – The ADAP Advocacy Association praised the bipartisan Congressional support for the additional \$48 million included in the final Fiscal-Year (“FY”) 2011 budget for the AIDS Drug Assistance Program. The budget provides \$885 million for ADAP, which was \$25 million, more than was obligated in FY10, after the President’s mid-year emergency \$25 million transfer to address waiting lists. The bill provided \$8 million more than the original budget introduced in the House of Representatives (H.R.1).

**May 11, 2011** – The ADAP Advocacy Association issued a Call for Nominations for its 2011 Annual ADAP Leadership Awards. The 1st Annual Awards Dinner was held during 4th Annual Conference, recognizing individual, community, government and corporate leaders who worked to improve access to care and treatment under the AIDS Drug Assistance Programs.

**June 29, 2011** – The ADAP Advocacy Association announces the recipients for 2011 Annual ADAP Leadership Awards, whereby the leaders received their awards at 1st Annual Awards Dinner on July 6<sup>th</sup>. The 2010-2011 award recipients included: ADAP Champion of the Year: **Richard “Dab” Garner of Dab the AIDS Bear Project**; ADAP Emerging Leader of the Year: **Jason King of AIDS Healthcare Foundation**; ADAP Corporate Partner of the Year: **The Honorable Neil Romano of The Romano Group, LLC**; ADAP Community Organization of the Year: **Stephen Gunsallus of Counseling Ministries Dot Org**; ADAP Lawmaker of the Year: **The Honorable Alcee Hastings, M.C. (FL-23)**; ADAP Social Media Campaign of the Year: **AIDS Activism 101 by Mark King of MyFabulousDisease**; ADAP Grassroots Campaign of the Year: **Butch McKay of Positive Living Conference / ActivateU**; and ADAP Media Story of the Year: **HIV S.O.S. by Charles Blow of the New York Times**.

**July 20, 2011** – The ADAP Advocacy Association announced an innovative partnership with MyGov365 designed to foster communication and collaboration between people living with HIV/AIDS with the general public, peers and elected officials. The partnership was the first in a series of steps aaa+ took to better engage ADAP constituencies and stakeholders to educate lawmakers at national, state and local levels on the importance of the AIDS Drug Assistance Program.

**September 8, 2011** – The ADAP Advocacy Association announced that it seated two new members to its Board of Directors, as well as returned five current members. The aaa+ Board of Directors voted unanimously to seat newcomers **Janine Brignola** of Omaha, Nebraska, and **Darryl Fore** of Cleveland, Ohio. The additions to the board expand the organization’s representation by people living with HIV/AIDS into the Midwest and Great Plains States.

**September 9, 2011** – The ADAP Advocacy announced that it spearheaded a national “Obama-ADAP Twitter Day,” which was held on Thursday, September 15, 2011. The purpose of the campaign was to raise awareness about the growing waiting lists under the AIDS Drug Assistance Programs by leveraging one of the leading social media outlets. Twitter users were asked to direct their hashtag #ObamaADAP Tweets at President Obama using handle @whitehouse.



**September 22, 2011** – The ADAP Advocacy Association announced that it collaborated with **Dr. David Satcher**, former U.S. Surgeon General, sending Members of Congress a letter outlining the importance of the AIDS Drug Assistance Programs. Dr. Satcher, who served as the 16th Surgeon General of the United States has been a vocal critic of the ADAP waiting lists.

> [Download Dr. Satcher's Congressional Letter.](#)



## ADAP ADVOCACY ASSOCIATION

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**September 28, 2011** – The ADAP Advocacy Association announced that it sent an appeal to the entire House of Representatives asking them to join the new HIV/AIDS Caucus. The letter was sent using MyGov365, a nonpartisan civic engagement platform, and it stressed the need for bipartisanship to successfully combat HIV/AIDS in general, and the crisis facing ADAPs in the United States, specifically.

> [Download MyGov365 Congressional Letter.](#)

**October 19, 2011** – The ADAP Advocacy Association announced that it was hosting its 2011 Virtual Conference Trainings “**Accessing & Understanding HIV/AIDS Patient Assistance Programs**” in partnership with the Community Access National Network (CANN), HealthHIV, AIDS Alabama, Broward House and the Great Lakes ADA Center. The virtual trainings were held to raise awareness about pharmaceutical patient assistance programs (PAPs), in an effort to alleviate the ongoing crisis facing ADAPs. There was an introductory training for ADAP stakeholders who have little or no knowledge about PAPs, and an advanced training for ADAP stakeholders who were well versed with PAPs, but seek additional information.



**December 1, 2011** – The ADAP Advocacy Association commemorated World AIDS Day by asked every American to reflect on the millions of lives lost in the struggle against HIV/AIDS, as well as the ongoing stigma and criminalization facing people living with the disease. It also asked the President and Congress to use World AIDS Day to immediately unveil solutions to end the waiting lists under the AIDS Drug Assistance Programs that are denying people living with HIV/AIDS access to appropriate, timely access to care and treatment.



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- 2%** donation on gas and grocery purchases
- 1%** donation on all other purchases
- Up to 10%** of purchases made at select merchants!





## ADAP ADVOCACY ASSOCIATION

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#### **CORPORATE SUPPORT:**

##### **Corporate Members**

Ramsell Holding Corporation – Corporate Leader  
Merck & Co., Inc. – Corporate Leader  
Morgali Films – Corporate Leader  
ViiV Healthcare – Corporate Associate  
Walgreens Co. – Gold Member  
Diplomat Specialty Pharmacy – Silver Member  
MedData Services – Silver Member  
Health Management Services – Bronze Member  
Wells Fargo – Bronze Member

Flowers Heritage Foundation – Corporate Leader  
AIDS Healthcare Foundation – Corporate Leader  
Gilead Sciences – Corporate Partner  
Abbott Laboratories – Corporate Associate  
EMD Serono – Gold Member  
Community Access National Network – Silver Member  
The Macsata-Kornegay Group, Inc. – Silver Member  
AIDS Alabama – Bronze Member

##### **Annual Conference Sponsors**

AIDS Healthcare Foundation  
Community Access National Network  
Merck & Co.  
Flowers Heritage Foundation  
American Association for Homecare  
EMD Serono  
The Macsata-Kornegay Group

Public Sector Solutions  
Housing Works  
Ramsell Holding Corporation  
Gilead Sciences  
MedData Services  
ViiV Healthcare  
Starbucks

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

Abbott Laboratories  
Southern AIDS Coalition  
Broward House  
Gilead Sciences  
Merck & Co., Inc.  
ViiV Healthcare

AIDS Alabama  
AIDS Healthcare Foundation  
GettingHired.com  
HealthHIV  
Ramsell Holding Corporation  
The Macsata-Kornegay Group, Inc.

##### **Virtual Conference Sponsors**

National Network of ADA Centers (DBTACs)  
HealthHIV  
Community Access National Network

Broward House  
AIDS Alabama

##### **Wine Tasting Sponsors**

Bender Consulting  
Hire Disability Solutions  
DC Business Leadership Network  
Justin's Café  
Kellari  
Broward House

Community Access National Network  
The Macsata-Kornegay Group  
DC'S Most Fabulous Magazine  
O.B. Sweet  
Health Management Systems  
Alibi Wilton Manors

##### **Individual Event Sponsors**

Dr. Ali Harake

Dr. Philip Haddad





## ADAP ADVOCACY ASSOCIATION

aaa+  
2011 Annual Report



### 2011 Corporate Members & Strategic Partners





# ADAP ADVOCACY ASSOCIATION

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## 2011 Annual Report



### ACKNOWLEDGEMENTS:

In 2011, the ADAP Advocacy Association could not have completed its third complete fiscal year without the financial support of its corporate members, corporate sponsors, programmatic supporters, individual donors, in-kind donations, and the meaningful events hosted by the organization. The organization's scholarship fund grew considerably, which was established to provide a restricted funding stream to fund travel and lodging for people living with HIV/AIDS to become better self-advocates.

The following chart demonstrates the diversity of the organization's funding in 2011:

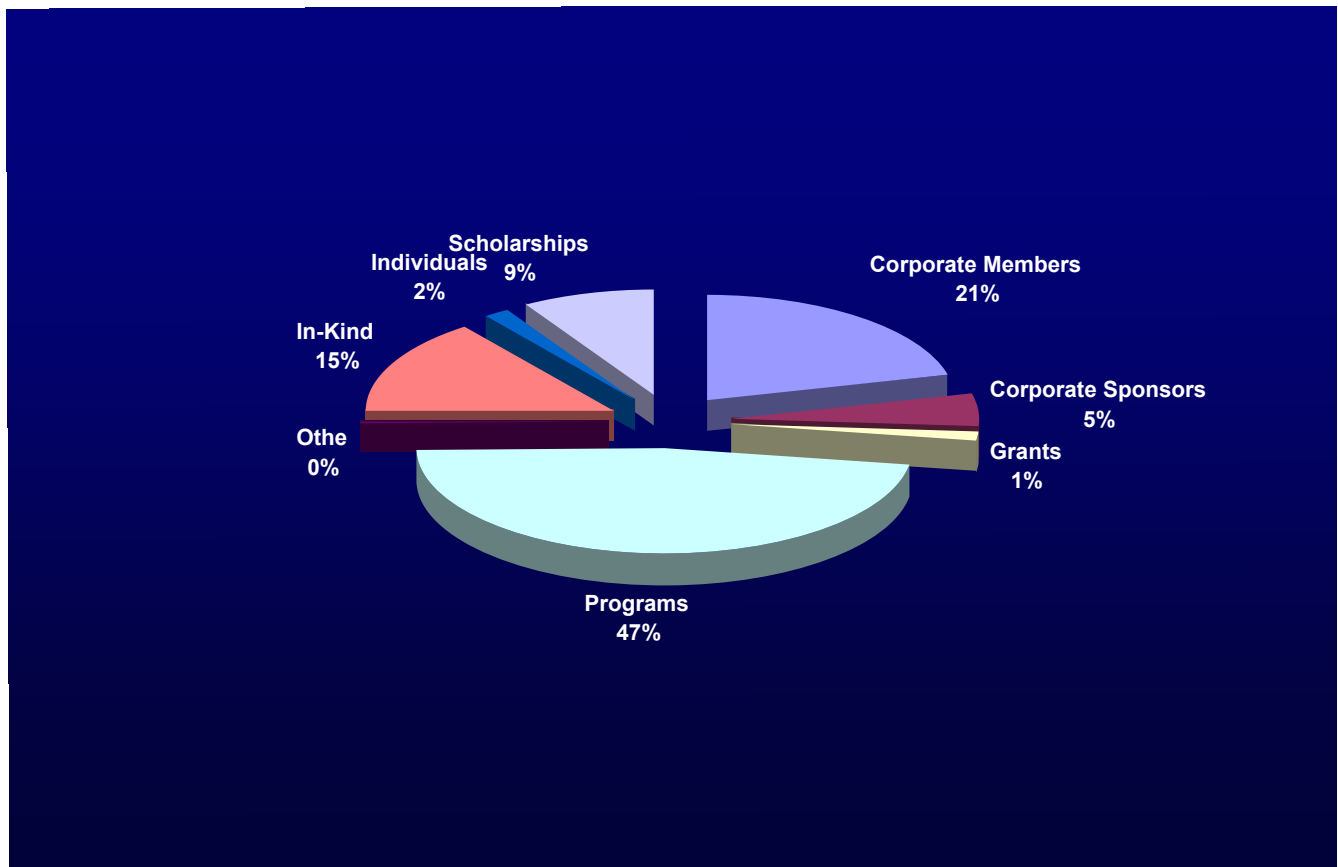


Figure 1 - 2011 Revenue by Source

### CONCLUSION:

Despite a very challenging year facing the nation's AIDS Drug Assistance Programs and the nearly 10,000 PLWHAs who were being denied access to timely and appropriate care and treatment, the ADAP Advocacy Association achieved significant milestones throughout the year. Among them serving as the facilitator to bring ADAP stakeholders together to identify solutions to the ongoing crisis. Through a robust series of educational programming – including its 4<sup>th</sup> Annual Conference – aaa+ continued to put the voice of the consumer at the center of the debate.