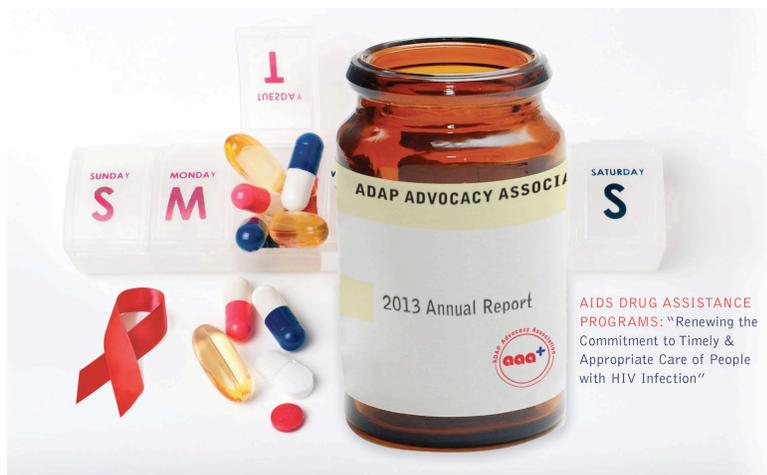




ADAP ADVOCACY ASSOCIATION



2013 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.



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SUMMARY:

On November 25, 2014, ADAP stakeholders celebrated the news that all AIDS Drug Assistance Program waiting lists had been eliminated under Part B of the Ryan White Comprehensive AIDS Resources Emergency (“CARE”). The ADAP Advocacy Association (aaa+®) applauded the diligent work done by every single ADAP stakeholder to eliminate these dreaded waiting lists, but most of all, recognized the thousands of patients living with HIV/AIDS who rely on ADAPs who stood up and demanded that their collective voices be heard.

According to the **National Alliance of State & Territorial AIDS Directors** (NASTAD), “The elimination of ADAP waiting lists was possible in part due to ADAPs’ receiving FY2013 Emergency Relief Funds (ERF). FY2013 ERF consisted of a total of \$75 million distributed to states that demonstrated financial need as a result of waiting lists or other cost-containment measures. Despite sequestration cuts to ADAP formula funding awards in FY2013, ERF funds allowed ADAPs to maintain their provision of ARV medications to individuals in need. In addition, continued supplemental rebates and discounts and price freezes on medications negotiated between the ADAP Crisis Task Force and pharmaceutical companies allowed ADAPs to maintain stability in their expenditures.”¹

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 2011-2012. At the peak of the crisis, nearly 10,000 patients living with HIV/AIDS were forced onto ADAP waiting lists. This crisis was fueled, by in large, by inadequate federal funding – despite small annual budget increases under both President George W. Bush and President Barack Obama between FY2003 and FY2011. The federal share of ADAP funding had fallen steadily, and state level budgetary cutbacks only exacerbated the problem. 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. The ADAP crisis was alleviated, in large part, by the pharmaceutical manufacturers by agreeing to lower or freeze drug prices and enhanced rebates,² as well as making available free medications through their Patient Assistance Programs.

In an ongoing effort to keep the patient voice a central theme during this process, aaa+® worked 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. To that end, aaa+® hosted numerous patient advocacy and educational events were hosted throughout the year.

¹ National Alliance of State & Territorial AIDS Directors, “The ADAP Watch,” November 25, 2013.

² The ADAP Coalition, ADAP Need FY2012, January 2011.



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HIGHLIGHTS:

- Released Annual Report highlighting 2012 accomplishments;
- Increased the size of the organization's list-serve by approximately 5 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 **HealthHIV**;
- Hosted one wine tasting benefit, which was held as Quarterly Membership Meetings;
- Urged Anthem Blue Cross of California to change its Mail-Order only pharmacy policy;
- Released Congressional Scorecard evaluating Members of Congress on their support for the AIDS Drug Assistance Programs (ADAPs);
- Hosted an **HIV/HCV Co-Infection ADAP Summit** in Las Vegas, Nevada;
- Published an HIV/HCV Co-Infection ADAP Summit Final Report, outlining key strategies to address co-infection;
- Host Town Hall meeting in Washington, DC to highlight HIV Criminalization;
- Hosted its **6th Annual Conference, "AIDS Drug Assistance Programs: Renewing the Commitment"** in Washington, DC;
- Hosted its **3rd Annual ADAP Leadership Awards Dinner**;
- Presented the Honorable Tommy G. Thompson with its Lifetime Achievement Award;
- Hosted Virtual Webinar, "**Impact of the Affordable Care Act, Medicaid Expansion & Insurance Exchanges on HIV/AIDS and Viral Hepatitis Services**";
- Funded fifty-one (51) scholarships;
- Supported nine (9) national sign-on letters addressing various HIV/AIDS and healthcare initiatives;
- Circulated one (1) legislative Action Alert on ADAP-related funding issues;
- Published fourteen (14) blogs about ADAP-related issues;
- Conducted twelve (12) online stakeholder polls.





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TIMELINE OF EVENTS:

February 13, 2013 – The ADAP Advocacy Association urged Anthem Blue Cross of California to reverse course on its recent decision requiring that certain members only obtain their medications by mail order. The policy adversely impacted members living with HIV/AIDS because direct patient-pharmacist consultation is widely recognized as improving treatment adherence.

March 19, 2013 – The ADAP Advocacy Association announced its “HIV/HCV Co-Infection ADAP Summit” being held in Las Vegas, NV on April 25-26, 2013. The summit, which was held in partnership with the Community Access National Network (CANN) and facilitated by HealthHIV, focused on the latest information on Hepatitis C drug development, patient assistance programs, and other updates about HIV/HCV co-infection, among other things.

April 24, 2013 – 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.



May 13, 2013 – The ADAP Advocacy Association announced its 6th Annual Conference on July 7-9, 2013. The conference – held in partnership with the Community Access National Network (CANN) – was themed the "AIDS Drug Assistance Program: Renewing the Commitment to Timely and Appropriate Care of People with HIV Infection!"

May 16, 2013 – The ADAP Advocacy Association opened nominations for its 2013 Annual ADAP Leadership Awards. The awards recognize individual, community, government and corporate leaders who are working to improve access to care and treatment under the AIDS Drug Assistance Programs.

May 22, 2013 – The ADAP Advocacy Association commended the Obama Administration’s announcement that it re-programmed \$35 million to increase access to HIV/AIDS care and treatment under the AIDS Drug Assistance Programs (ADAPs). The emergency funding restored the \$35 million that was lost in the Consolidated and Further Continuing Appropriates Act of 2013, which was signed into law on March 26, 2013. The move ensured that nearly 8,000 people living with HIV/AIDS would not lose access to their life-saving medications and placed on ADAP waiting lists.



June 13, 2013 – The ADAP Advocacy Association announced that the **Honorable Tommy G. Thompson**, former Governor of Wisconsin and former Secretary of the U.S. Department of Health & Human Services (HHS), would be the featured keynote speaker at its 2013 Annual ADAP Leadership Awards. The awards recognize individual, community, government and corporate leaders who are working to improve access to care and treatment under the AIDS Drug Assistance Programs.

June 24, 2013 – The ADAP Advocacy Association announced the recipients for its 2013 Annual ADAP Leadership Awards. The eight leadership awards would be presented during the **3rd Annual ADAP Leadership Awards Dinner** held on Monday, July 8th at 7:00 pm in Washington, DC. The award honorees reflected the 6th Annual Conference’s "Commitment to Ryan White" theme.



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The 2012-2013 award recipients included: ADAP Champion of the Year: **President Barack Obama**; ADAP Emerging Leader of the Year: **Julio Fonseca of HealthHIV**; ADAP Corporate Partner of the Year: **HarborPath**; ADAP Community Organization of the Year: **AIDS Foundation of Chicago**; ADAP Lawmaker of the Year: **The Honorable Tom Coburn, M.C., US Senate (Oklahoma), The Honorable Donna Christensen, M.C. (Delegate, Virgin Islands)**; ADAP Social Media Campaign of the Year: **My HIV Journey by Aaron Laxton**; ADAP Grassroots Campaign of the Year: **Syringe Decriminalization Campaign by the North Carolina Harm Reduction Coalition**; and ADAP Media Story of the Year: **Why Some with HIV Still Can't Access Treatment by Sarah Childress, PBS Frontline**.



July 11, 2013 – The ADAP Advocacy Association released its 2012 Annual Report. After the AIDS Drug Assistance Program had been ravaged by the "Perfect Storm" for several years, ADAP waiting lists finally decreased during the year.

> [Download 2012 Annual Report](#)

July 12, 2013 – The ADAP Advocacy Association saluted former Wisconsin Governor and U.S. Health and Human Services Secretary Tommy G. Thompson in Washington with the **Lifetime Achievement Award** for helping people living with HIV/AIDS. The award was presented to Thompson at the 3rd Annual ADAP Leadership Awards Dinner.

September 5, 2013 – The ADAP Advocacy Association released the Final Report from its "HIV/HCV Co-Infection ADAP Summit" – which was held in partnership with the Community Access National Network (CANN) in Las Vegas, NV. The Final Report conveyed some of the programmatic changes, improvements and reforms that could improve access to care for patients living with both HIV-infection and HCV-infection, including leveraging the AIDS Drug Assistance Program (ADAP) to better serve the needs of the consumers/clients

> [Download 2013 HIV/HCV Co-Infection ADAP Summit Final Report](#)

September 19, 2013 – The ADAP Advocacy Association announced an educational webinar on the Affordable Care Act and other health expansion initiatives. The webinar – held in partnership with the **Community Access National Network (CANN)**, **Great Lakes ADA Center** and **HealthHIV** – was themed the "Impact of the Affordable Care Act, Medicaid Expansion & Insurance Exchanges on HIV/AIDS and Viral Hepatitis Services."

November 20, 2013 – The ADAP Advocacy Association urged the United States Senate to Ratify the United Nations Convention on the Rights of People with Disabilities (CRPD). The purpose of the CRPD is 'to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.'

November 25, 2013 – The ADAP Advocacy Association welcomed the news reported by the National Alliance of State & Territorial AIDS Directors (NASTAD) that for the first time since January 2008, there were no waiting lists under the AIDS Drug Assistance Programs (ADAPs).

December 1, 2013 – The ADAP Advocacy Association celebrated World AIDS Day.



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 Janssen Therapeutics – Gold Member
 AbbVie – Silver Member
 HealthHIV – Silver Member
 Community, A Walgreens Pharmacy – Bronze Member
 MedData Services – Bronze Member
 Walgreens – Bronze Member
 Community Access National Network (CANN) – Associate Member

Gilead Sciences – Gold Member
 Merck & Co. – Gold Member
 Bristol-Myers Squibb – Silver Member
 Ramsell Corporation – Silver Member
 Duane Reade Pharmacy – Bronze Member
 The Macsata-Kornegay Group, Inc. – Bronze Member
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2013 Corporate Members & Strategic Partners



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ACKNOWLEDGEMENTS:

In 2013, the ADAP Advocacy Association maintained a strong base of diversified financial support. The organization’s corporate members, corporate sponsors, programmatic supporters, individual donors, in-kind donations funded numerous advocacy and educational events hosted throughout the year, all aimed at making people living with HIV-infection better self-advocates. Areas that experienced funding increases last year included: corporate members, grants, and scholarship fund donations.

The following chart demonstrates the diversity of the organization’s funding in 2013:

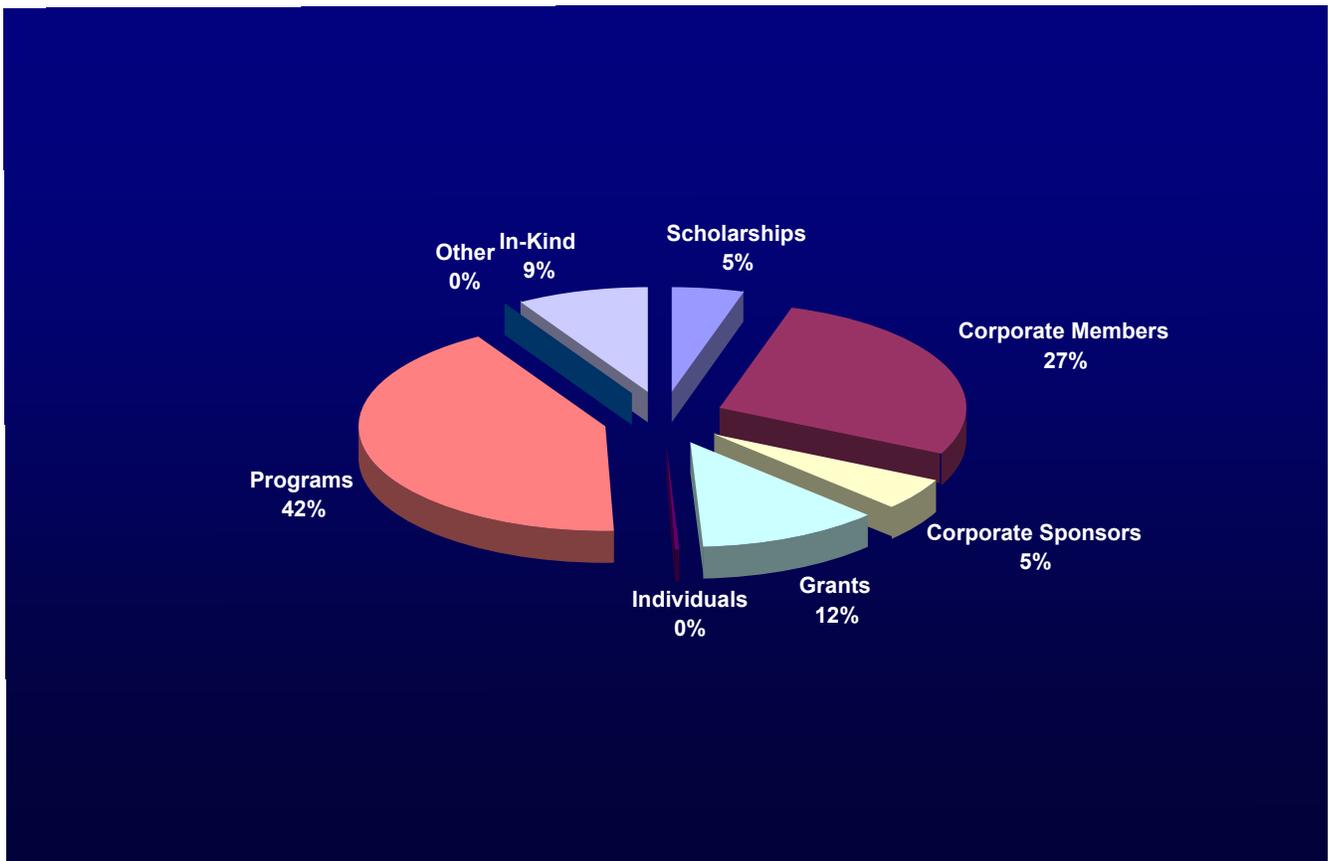


Figure 1 - 2013 Revenue by Source

CONCLUSION:

Whereas the AIDS Drug Assistance Program waiting lists were finally eliminated last year, significant fiscal pressures continue to restrict access to appropriate, timely care and treatment in many states. The implementation of the Affordable Care Act is expected to provide some relief, but uncertainty also remains over the possible unintended consequences of the law. The ADAP Advocacy Association’s effort to provide advocacy and educational opportunities for people living with HIV-infection was widely recognized by many ADAP stakeholders; that platform shall be continued moving forward into 2014.