ADAP ADVOCACY ASSOCIATION

aaa+ ®

2014 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.
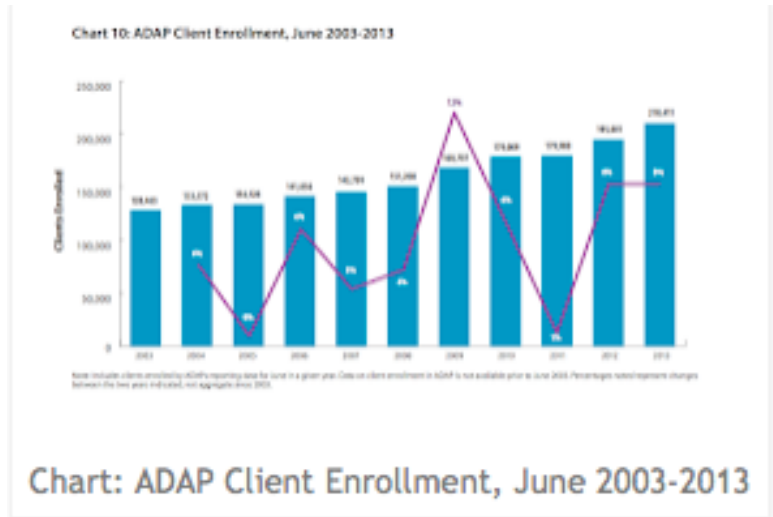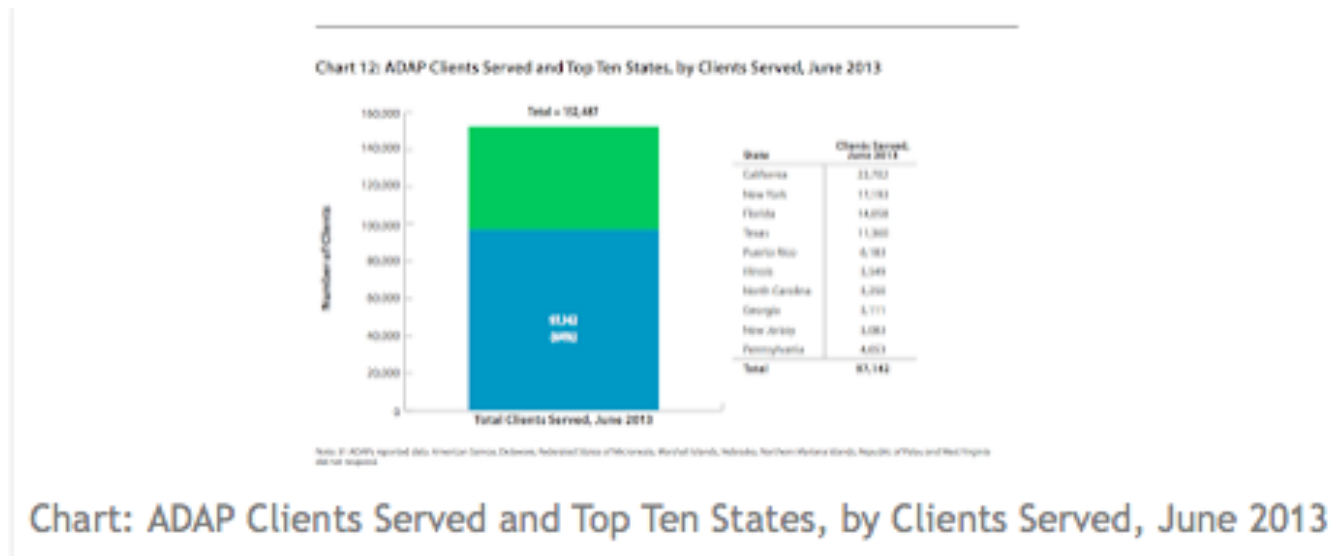
SUMMARY:

Over the last year, one of the most frequently asked questions by people living with HIV/AIDS, public policy advocates, representatives from the health care and pharmaceutical industries and others, "What is the future of the AIDS Drug Assistance Program now that the Affordable Care Act is law?"

The answer is simple: It is too early to know for certain!

At first glance, data trends suggest that the passage of the ACA and its subsequent implementation has not slowed down client enrollment in ADAPs nationwide. According to the "**National ADAP Monitoring Project - Annual Report**," published by the National Alliance of State & Territorial AIDS Directors (NASTAD), client enrollment increased by over 15,000 between 2012 and 2013, or about an 8% increase. Last year, over 210,000 people living with HIV/AIDS were enrolled in ADAP.[1]

Chart: ADAP Client Enrollment, June 2003-2013

Not surprisingly, California has the largest statewide enrollment, with 22,702 clients, followed by New York with 17,193 clients, and Florida with 14,058 clients. Over sixty percent (97,142 clients) of the total clients served by ADAP were served by the top ten states -- including Texas, Puerto Rico, Illinois, North Carolina, Georgia, New Jersey and Pennsylvania).[2]

Chart: ADAP Clients Served and Top Ten States, by Clients Served, June 2013

---

[1] NASTAD, National ADAP Monitoring Project Annual Report, February 2014, Chart 10, Page 13.

[2] NASTAD National ADAP Monitoring Project Annual Report - February 2014, Chart 12, Page 14.
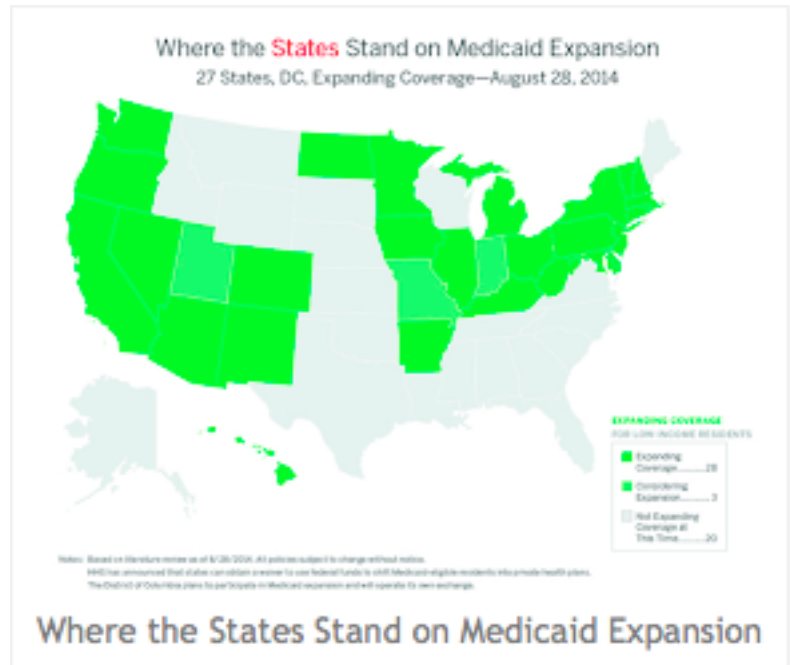
One of the consistent themes heard at our 2014 Summit ("Intersection between ACA & ADAP") and 2014 Annual Conference ("Future of the AIDS Drug Assistance Program") was without concrete data, it is premature to make any assumptions about the Ryan White CARE Act, in general, and the AIDS Drug Assistance Programs, specifically. Another message that was fairly consistent, there is a significant disconnect between the advocacy work being done on Capitol Hill and the boots on the ground in local communities. It is also ill advised to open-up the Ryan White law until we can better evaluate the intersection with the ACA, as well as the future of ADAP!

Clearly, ADAPs will remain a vital safety net for thousands of people living with HIV/AIDS next year and into the foreseeable future.

Probably one of the biggest unknown variables is the ongoing Medicaid expansion. "Spotty" is probably the best word to describe whether states are exercising the option to expand their Medicaid programs. Not surprisingly, some of the most resistance has come from southern states controlled by Republican Governors, or Republican State Legislatures.

To check out the most up-to-date information about state-by-state efforts to expand Medicaid, visit http://www.advisory.com/daily-briefing/resources/primers/medicaidmap.

Where the States Stand on Medicaid Expansion

Another added variable is the Republican electoral wave during the 2014 midterm election. Whereas some pragmatic Republican legislators have moved beyond the "Repeal & Replace" chatter about Obamacare, there remain plenty of hard-liners who wish to do away with the law, or at least strip it of some major provisions. It is clearly too early to tell, but President Obama's veto pen is probably the law's best defense.

The ACA is also fueling new challenges for people living with HIV/AIDS; among them, emerging discriminatory practices. Monitoring these trends is an essential responsibility for all ADAP stakeholders. These facts were illuminated during our free webinar, "Update on ACA Discriminatory Marketplace Exchange Practices," which was presented in collaboration with Lambda Legal. To download the webinar (and other presentations), go to http://www.adapadvocacyassociation.org/events_archives.html.

One thing is abundantly clear in this conversation, and that is nothing is clear whatsoever. There are so many moving parts that could potentially impact the access to care for people living with HIV/AIDS.

HIGHLIGHTS:

- Released Annual Report highlighting 2013 accomplishments;

- Increased the size of the organization's list-serve by approximately 3.5 percent;

- Garnered support from twenty-five (25) corporate entities;

- Renewed strategic partnerships with the **National Network of ADA Centers**, **Community Access National Network**, **Flowers Heritage Foundation**, **Housing Works** and **HealthHIV**;

- Expanded strategic partnerships to include **NeedyMeds** and **The Partnership for Safe Medicines**;

- Launched its comprehensive patient-centric ADAP Directory, http://adap.directory;

- Released White Paper on the impact of HIV/AIDS in the South, entitled "**THE SOUTHERN EPIDEMIC: Are the South's cultural, political and societal barriers making it difficult for public health programs, such as the AIDS Drug Assistance Programs, to function effectively in this region?**;

- Hosted an **Intersection Between ACA & ADAP Summit** in Washington, DC;

- Published an Intersection Between ACA & ADAP Summit Final Report, outlining key concerns;

- Hosted its **7th Annual Conference, "The Future of the AIDS Drug Assistance Program"** in Washington, DC;

- Hosted its **4th Annual ADAP Leadership Awards Dinner**;

- Hosted Virtual Webinar, "**Shifting Landscape of HIV Housing & its Impact on Healthcare**";

- Hosted Virtual Webinar, "**Update on ACA Discriminatory Marketplace Exchange Practices**";

- Hosted Virtual Webinar, "**Patient Access Network Foundation: A Free Financial Resource for Underinsured Patients**";

- Expressed concern over the return of ADAP waiting lists.

- Urged the Centers for Medicare and Medicaid Services (CMS) to issue a mandate to insurance companies to dictate that they accept third party payments from Ryan White CARE Act grantees for Marketplace Exchange insurance plans;

- Seated two new members to its Board of Directors: Aaron Baldwin and Chrys Thorsen;

- Funded fifty-eight (58) scholarships (*a new record!*);

- Supported twenty (20) national sign-on letters addressing various HIV/AIDS and healthcare initiatives;

- Submitted three (3) Public Comment on public health-related issues;

- Distributed twelve (12) press releases;

- Published eighteen (18) blogs about ADAP-related issues;

- Increased Twitter to 2,796 Followers;

- Increased Facebook to 1,794 Likes; and

- Increased LinkedIn to 302 Connections.

TIMELINE OF EVENTS:

January 23, 2014 – The ADAP Advocacy Association, together with the Community Access National Network (CANN) "Hepatitis: Education, Advocacy & Leadership" (HEAL) coalition, announced that it would host its annual summit on Sunday, April 13th – Tuesday, April 15th, 2014. The summit was themed "The Intersection Between ACA & ADAP Summit."

February 19, 2014 – The ADAP Advocacy Association urged the Centers for Medicare and Medicaid Services (CMS) to issue a mandate to insurance companies dictating that they accept third party payments from Ryan White CARE Act grantees for Marketplace Exchange insurance plans.

February 27, 2014 – The ADAP Advocacy Association expressed concern over the news that waiting lists were once again being reported under the AIDS Drug Assistance Programs (ADAPs). According to the National Alliance of State & Territorial AIDS Directors, Utah had placed three people living with HIV/AIDS on its ADAP waiting list.

March 25, 2014 – The ADAP Advocacy Association applauded the Centers for Medicare and Medicaid Services (CMS) for their interim final rule requiring health insurance companies participating in the Marketplace Exchange under the Affordable Care Act (ACA) to accept third-party payments from Ryan White CARE Act funds for cost sharing and premiums. The mandate alleviated one of the unintended barriers that could have prevented access to care for patients living with HIV/AIDS.

April 2, 2014 – The ADAP Advocacy Association announced the appointment of two new members to its Board of Directors. Aaron Baldwin of San Francisco, who works as an agent with New York Life Insurance and designed the first of its kind Positive Planning annuity for the HIV-positive community, and Chrys Thorsen of Los Angeles, who is a leading technology consultant and former IT project lead on a PEPFAR-funded electronic health record program.

April 8, 2014 – The ADAP Advocacy Association released it 2013 Annual Report. Whereas the AIDS Drug Assistance Program waiting lists were finally eliminated last year, significant fiscal pressures continued to restrict access to appropriate, timely care and treatment in many states. The implementation of the Affordable Care Act was expected to provide some relief, but uncertainty also remained over the possible unintended consequences of the law.

> Download 2013 Annual Report: http://www.adapadvocacyassociation.org/publications.html

May 16, 2014 – The ADAP Advocacy Association released an important White Paper on the impact of HIV/AIDS in the South, entitled "**THE SOUTHERN EPIDEMIC: Are the South's cultural, political and societal barriers making it difficult for public health programs, such as the AIDS Drug Assistance Programs, to function effectively in this region?**" The White Paper examined the numerous factors contributing to people living with HIV/AIDS in this region of the country experiencing more barriers to access healthcare. It also addressed the disproportionate impact of waiting lists under ADAPs that have historically plagued the South.

> Download White Paper: http://www.adapadvocacyassociation.org/publications.html

May 27, 2014 – The ADAP Advocacy Association opened nominations for its 2014 Annual ADAP Leadership Awards. The awards would recognize individual, community, government and corporate leaders who are working to improve access to care and treatment under the AIDS Drug Assistance Programs.

June 10, 2014 – The ADAP Advocacy Association released the Final Report from "The Intersection Between ACA & ADAP Summit" – which was held in partnership with the Community Access National Network (CANN) in Washington, DC earlier in the year. The purpose of the Final Report was to convey some of the programmatic changes, improvements and reforms that could be leveraged under the ACA to better serve people living with HIV-infection and/or Viral Hepatitis.

> Download Final Report: http://www.adapadvocacyassociation.org/publications.html

July 7, 2014 – The ADAP Advocacy Association announced the recipients for its 2014 Annual ADAP Leadership Awards. The eight leadership awards were presented during the 4th Annual ADAP Leadership Awards Dinner held on Monday, August 4th, 2015, in Washington, DC.

The award recipients included: ADAP Champion of the Year: **Kathie Hiers;** ADAP Emerging Leader of the Year: **Wande Brendle-Moss** of North Carolina**;** ADAP Corporate Partner of the Year: **Ramsell Corporation;** ADAP Community Organization of the Year: **Community Education Group;** ADAP Lawmaker of the Year: **The Honorable Henry Waxman, M.C. (California);** ADAP Social Media Campaign of the Year: *The Poz Life* **by Patrick Ingram;** ADAP Grassroots Campaign of the Year: *Moral Mondays*; and ADAP Media Story of the Year: *Continuing HIV Care for Formerly Incarcerated U.S. Citizens by Candace Y.A. Montague, TheBodyDotCom*.

August 4, 2014 – The ADAP Advocacy Association launched its comprehensive ADAP Directory at the opening ceremony of its 7th Annual Conference in Washington, DC. The ADAP Directory is its groundbreaking flagship program, made possible by the initial support from AbbVie, Merck, and Walgreens, providing a one-stop online resource center for the latest ADAP information.

> Go to the ADAP Directory: http://adap.directory

December 1, 2014 – The ADAP Advocacy Association reflected on the approximately 648,459 people in the United States who lost their lives to the struggle against HIV/AIDS. World AIDS Day is an opportunity for people worldwide to unite in the fight against HIV, show their support for people living with HIV and to commemorate people who have died.

CORPORATE SUPPORT:

Corporate Members

ViiV Healthcare – Corporate Leader

Gilead Sciences – Gold Member

Janssen Therapeutics – Gold Member

Merck – Gold Member

AbbVie – Silver Member

Bristol-Myers Squibb – Silver Member

HealthHIV – Silver Member

Ramsell Corporation – Silver Member

Community, A Walgreens Pharmacy – Bronze Member

Duane Reade Pharmacy – Bronze Member

MedData Services – Bronze Member

The Macsata-Kornegay Group, Inc. – Bronze Member

Walgreens – Bronze Member

AIDS Alabama – Associate Member

Community Access National Network (CANN) – Associate Member

Wells Fargo – Associate Member

Strategic Partners

Great Lakes ADA Center

Flowers Heritage Foundation

Housing Works

NeedyMeds

The Partnership for Safe Medicines

ADAP Directory Founding Corporate Sponsors

AbbVie

Janssen Therapeutics

Merck

Walgreens

Annual Event Sponsors

AbbVie

AIDS Alabama

AV & CS

Bender Consulting Services

Bristol-Myers Squibb

Community Access National Network

EMD Serono

Flowers Heritage Foundation

Gilead Sciences

HealthHIV

Housing Works

Janssen Therapeutics

MedData Services

Merck

Patient Access Network (PAN) Foundation

Ramsell Holding Corporation

The Macsata-Kornegay Group

ViiV Healthcare

Westin Washington DC City Center

Annual ADAP Leadership Awards Gala Sponsors

AbbVie

AIDS Healthcare Foundation

Community Access National Network (CANN)

Gilead Sciences

HealthHIV

Merck

The Macsata-Kornegay Group, Inc.

Walgreens

Individual Event Sponsors

Dr. Ali Harake

Dr. Philip Haddad

Trelvis Randolph

2014 Corporate Partners

ACKNOWLEDGEMENTS:

In 2014, the ADAP Advocacy Association maintained a strong base of diversified financial support. The organization's corporate partners, 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. These programs included the flagship ADAP Directory, in-person educational events, as well as virtual educational events.

The following chart demonstrates the diversity of the organization's funding in 2014:
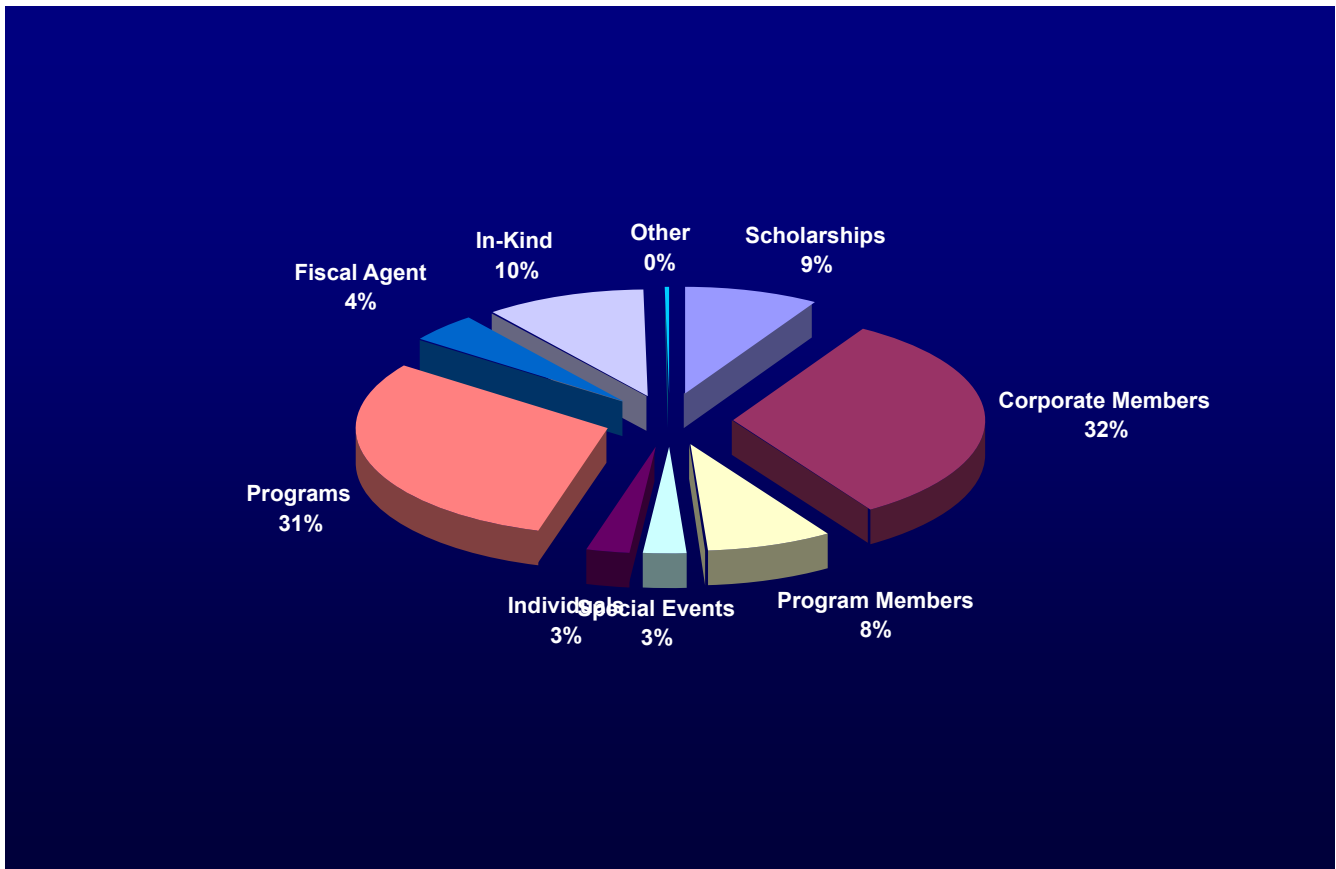

Figure 1 - 2014 Revenue by Source

CONCLUSION:

Waiting lists returned under the AIDS Drug Assistance Program in 2014, but significant progress was achieved putting more patients living with HIV/AIDS into care and treatment thanks to the implementation of the Affordable Care Act. Though the ACA has increased access to care and treatment, there are numerous unintended consequences causing anxiety for many patients. To that end, it remains important to arm patients with new resources and tools, such as the launch of the ADAP Advocacy Association's flagship program: The ADAP Directory at http://adap.directory.