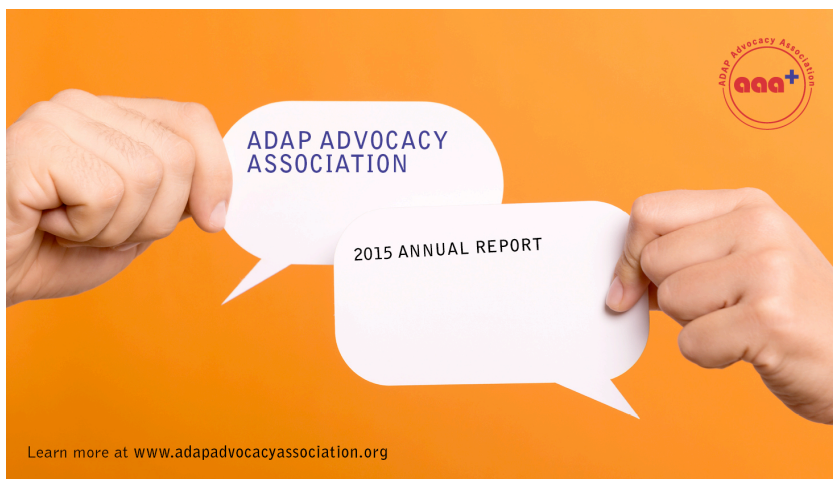# ADAP ADVOCACY ASSOCIATION

aaa+ ®

2015 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:

The Patient Protection and Affordable Care Act ("PPACA"), or the Affordable Care Act ("ACA") continued to unfold in 2015, and its overall impact still yet unknown. Most of the law's major provisions were phased in by January 2014, with other provisions phased in by 2020. The ACA has numerous implications generally on the nation's health care delivery system, but more specifically on the supports and services afforded to people living with HIV/AIDS, under the Ryan White CARE Act. What's more, ongoing Medicaid expansion (or lack thereof) and the implementation of insurance exchanges have impacted nearly all-healthcare providers, as well as their patients.[1]

Unfortunately, people living with HIV/AIDS have experienced some of the unintended consequences of the law – including discriminatory practices limiting their access to care and treatment. As patients have obtained a basic understanding of the ACA's provisions, they have also learned numerous ways to assist with their advocacy to combat such unlawful practices. This was a focal point of the ADAP Advocacy Association's patient education efforts in 2015.

Among them, patients have received guidance from federal agencies on the law's intersection with existing public health programs, especially as it relates to HIV/AIDS and Viral Hepatitis populations. They acquired information about insurance "adverse selection." And thanks to many advocacy and legal organizations, they have developed a greater understanding of potential impact discriminatory practices, as well as non-discrimination protections.

By mid-year the National Alliance of State & Territorial AIDS Directors (NASTAD) released its **2015 National ADAP Monitoring Project Annual Report**. The report represents the most comprehensive annual analysis of the AIDS Drug Assistance Program ("ADAP"), including relevant data on the individuals seeking ADAP services, as well as the services being provided to them. According to NASTAD, among the key findings:[2]

- ADAP enrollment reached its highest level in the program's history, with over 258,000 clients enrolled in FY2013 (April 1, 2013 – March 31, 2014).
- ADAPs reported spending over $110.7 million on insurance purchasing/continuation in June 2014; 61,456 (42%) ADAP clients were covered by such arrangements. By comparison, ADAPs used $27.6 million in June 2013 for insurance purchasing/continuation.
- The majority (63%) of all clients served by ADAPs in June 2014 were reported as virally suppressed, defined as having a viral load that is less than or equal to 200 copies/ml. By comparison, thirty-percent (30%) of all people living with HIV (PLWH) in the U.S. are reported as virally suppressed.

Of particular interest to the ADAP Advocacy Association, ADAPs continued to play a pivotal role in ensuring low-income patients living with HIV/AIDS with little or no health insurance have access to the timely, appropriate care that they deserve. Whereas ADAP enrollment decreased 3% from June 2013 to June 2014 (210,411 patients enrolled and 204,988 patients enrolled, respectively), it nonetheless provided life-saving medications to hundreds of thousands of individuals.[3]

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[1] ADAP Advocacy Association, "Impact of the Affordable Care Act, Medicaid Expansion & Insurance Exchanges on HIV/AIDS & Viral Hepatitis Services," November 6, 2013.

[2] National Alliance of State & Territorial AIDS Directors, "FINDINGS OF THE 2015 NATIONAL AIDS DRUG ASSISTANCE PROGRAM (ADAP) MONITORING PROJECT ANNUAL REPORT," May 12, 2015.

[3] National Alliance of State & Territorial AIDS Directors, "2015 National ADAP Monitoring Project Annual Report, Table 6: Total Clients Enrolled and Served, June 2013 and June 2014," p. 46, May 12, 2015.
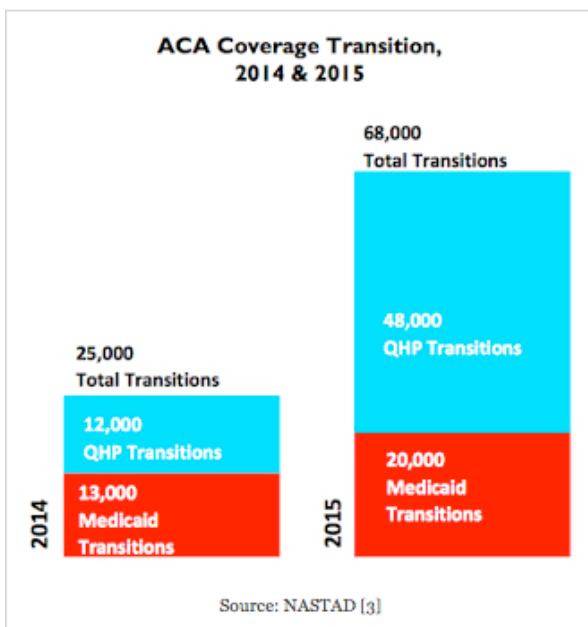
Summarized NASTAD's Executive Director, Murray Penner, upon releasing some important findings on July 24, 2015: "*ADAPs remain at the forefront of adapting HIV care and treatment services to an evolving public health landscape. Supporting clients in public and private insurance coverage under the ACA is a tremendous opportunity to improve the overall health of clients and maximize Ryan White Program resources. These figures represent a huge success for ACA enrollment and implementation, demonstrating the ability of our ADAP and Ryan White Program system of care to transition vulnerable populations to new insurance coverage and keep them engaged in the health system in order to achieve healthy outcomes and ultimately prevent new infections,*"[4]

Penner's statement was in response to ADAPs assisting 68,000 clients living with HIV/AIDS being served by the program gain access to health insurance coverage under the ACA. That figure included 48,000 patients enrolled in a Qualified Health Plan (QHP), funded by ADAP, and an additional 20,000 patients transitioned to Medicaid.[5]

Clearly, ADAPs remained a vital safety net for thousands of people living with HIV/AIDS nationwide, and that fact is unlikely to change into the foreseeable future. Despite robust ADAPs, and overall increased access to care under the ACA (*as demonstrated by this latest news*), systemic challenges remained for patients living with HIV/AIDS last year. Among them, waiting lists and other cost containment measures persist; not to mention new challenges such as marketplace discrimination and roadblocks to the ACA's full implementation.

With the uneven rollout of the ACA's Medicaid expansion, particularly in southern states controlled by Republican governors and/or Republican legislatures, many public health advocates routinely expressed concern over the number of patients potentially falling through the cracks of the new law. This news has major implication for people living with HIV/AIDS, as well as people living with Viral Hepatitis.

ADAP, under Part B of the Ryan White CARE Act, is designed to be the "payer of last resort," meaning that it should only be accessed if there are no other options available to HIV-infected clients. Since the Ryan White CARE Act's inception in 1990, the definition of "last resort" has been continually updated to reflect current Wholesale Acquisition Costs ("WACs") and Average Wholesale Prices ("AWPs") of medications, primarily by adjusting the income threshold in relation the to the Federal Poverty Limit ("FPL"). This is expressed as a percentage of the FPL (e.g. 400% of FPL).

This creates an uneven landscape among the ADAPs nationwide. While a client's annual income may allow them to qualify for benefits in one state or territory, they may not be eligible for coverage in another state. These challenges are likely to continue to confront ADAPs and the patients living with HIV/AIDS served by them, and they continue to fuel some of the uncertainty surrounding the ACA's impact on people living with chronic health conditions, such as HIV/AIDS.

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[4] National Alliance of State & Territorial AIDS Directors, "AIDS Drugs Assistance Program Supports 68,000 People Living with HIV in Gaining ACA Coverage," July 24, 2015.
[5] National Alliance of State & Territorial AIDS Directors, "AIDS Drugs Assistance Program Supports 68,000 People Living with HIV in Gaining ACA Coverage," July 24, 2015.

HIGHLIGHTS:

- Released Annual Report highlighting 2014 accomplishments;

- Increased the size of the organization's list-serve by approximately 2.7 percent;

- Garnered support from twenty-seven (27) corporate entities;

- Renewed strategic partnerships with the **Flowers Heritage Foundation**, **Great Lakes ADA Center**, **Housing Works**, **HealthHIV**, **NeedyMeds**, and **The Partnership for Safe Medicines**.

- Added **sitecues** technology to its comprehensive patient-centric ADAP Directory, http://adap.directory;

- Sponsored Community Access National Network's Congressional Briefing, "**High Out-of-Pocket Costs for Patients Living with HIV/AIDS and/or Viral Hepatitis**" on Capitol Hill;

- Sponsored the "**HIV Advocacy Day**," co-hosted by the North Caroline Harm Reduction Coalition and the North Carolina AIDS Action Network at Winston-Salem State University.

- Hosted an "**Issues facing the AIDS Drug Assistance Program (ADAP) under the Affordable Care Act**" regional summit in Atlanta, Georgia;

- Hosted an "**HIV/HCV Co-Infection**" pre-conference workshops in Washington, DC;

- Hosted its **8th Annual Conference, "A National Conversation about the Ryan White CARE Act and the AIDS Drug Assistance Programs"** in Washington, DC;

- Hosted its **5th Annual ADAP Leadership Awards Dinner**, headlined by former **Congresswoman Donna Christensen, M.D.** (Virgin Islands);

- Hosted online workshop, "**Mandated Mail-Order Pharmacy: Case Studies on Barriers to Care/Treatment**";

- Co-hosted online workshop, "**Harm Reduction: Syringe Exchange Service, Law Enforcement Relations and Legislative Advocacy**";

- Co-hosted online workshop, "**Harm Reduction: Overdose Prevention as an Engagement Tool for HIV & HCV**";

- Seated two new members to its Board of Directors: **Wanda Brendle-Moss** and **Robert Suttle**;

- Funded fifty (50) scholarships;

- Supported Supreme Court amicus brief for *King v. Burwell*;

- Supported thirty-seven (37) national sign-on letters addressing various HIV/AIDS and healthcare initiatives;

- Distributed nine (9) press releases;

- Published twenty-one (21) blogs about ADAP and healthcare-related issues;

- Increased support on Twitter to 3,284 Followers;

- Increased support on Facebook to 2,014 Likes; and

- Increased support on LinkedIn to 312 Connections.

TIMELINE OF EVENTS:

January 22, 2015 – The ADAP Advocacy Association – together with the Community Access National Network (CANN) – announced that it would host its **8th Annual Conference** on **September 25-26, 2015**. The conference was themed as *"A National Conversation about the Ryan White CARE Act and the AIDS Drug Assistance Programs."*

February 9, 2015 – The ADAP Advocacy Association announced that it would host an **ADAP Regional Summit** in Atlanta, Georgia on April 10, 2015. The summit – held in partnership with the AIDS Healthcare Foundation (AHF) and the Community Access National Network (CANN) – focused on specific issues facing the AIDS Drug Assistance Program (ADAP) under the Affordable Care Act.

March 5, 2015 – The ADAP Advocacy Association opened nominations for its 2015 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.

April 15, 2015 – The ADAP Advocacy Association convened its ADAP Regional Summit in Atlanta, Georgia.

July 1, 2015 – The ADAP Advocacy Association announced the appointment of two new members to its Board of Directors: **Wanda Brendle-Moss** of Winston-Salem, North Carolina, who works as a community organizer, and **Robert Suttle** of New York, New York, who is the Assistant Director of the Sero Project.

July 28, 2015 – The ADAP Advocacy Association released it 2014 Annual Report. Although relatively small waiting lists returned under ADAPs, client enrollment continued to expand despite implementation of the Affordable Care Act.

> Download 2014 Annual Report: http://www.adapadvocacyassociation.org/publications.html

August 10, 2015 – The ADAP Advocacy Association announced the recipients for its 2015 Annual ADAP Leadership Awards. The eight leadership awards were presented during the 5th Annual ADAP Leadership Awards Dinner held on Saturday, September 26th, 2015, in Washington, DC.

The award recipients included: ADAP Champion of the Year: **David Poole;** ADAP Emerging Leader of the Year: **Rivkah Meder** of North Carolina; ADAP Corporate Partner of the Year: **Merck;** ADAP Community Organization of the Year: **Georgia Equality** and **Philadelphia FIGHT;** ADAP Lawmaker of the Year: **The Honorable Andrew M. Cuomo, Governor (New York);** ADAP Social Media Campaign of the Year: *HIV Video Minute* by **Josh Robbins;** ADAP Grassroots Campaign of the Year: *Campaign to End AIDS (C2EA)*; and ADAP Media Story of the Year: *Disease Outbreaks Reignite Needle-Exchange Debate by Gabe Johnson, The Wall Street Journal*. In addition, a Lifetime Achievement Award was presented to **The Honorable Donna Christensen**, former Member of Congress (Virgin Islands).

September 25, 2015 – The ADAP Advocacy Association convened its 8th Annual ADAP Conference in Washington, DC. The event was sold out!

September 25, 2015 – The ADAP Advocacy Association announced a new partnership with sitecues by Ai Squared – the makers of the ZoomText family of products. The partnership, which was unveiled at its 8th Annual ADAP Conference, made the organization's website and ADAP Directory easier to see, hear, and use for anyone that could benefit from assistive technology.

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

November 18, 2015 – The ADAP Advocacy Association convened an educational online workshop, "*Mandated Mail-Order Pharmacy: Case Studies on Barriers to Care/Treatment.*" The workshop – held in partnership with the Great Lakes ADA Center and the Community Access National Network (CANN) – reviewed three case studies, each presenting different obstacles presented by mandated mail order pharmacy programs and how best to overcome them.

December 1, 2015 – The ADAP Advocacy Association celebrated the federal theme for World AIDS Day. "*The Time to Act is Now*," embodied the long-standing approach to the successful development, implementation and sustainability of the AIDS-related supports and services afforded to people living with HIV/AIDS over the last three decades. The future of the Ryan White program will depend on greater community and stakeholder collaboration.

SAVE THE DATE

ADAP Advocacy Association
9th Annual Conference

"Magnifying How ADAP Provides Treatment
For People Living With HIV/AIDS"

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Washington, DC
September 23-24, 2016

Learn more at www.**adapadvocacyassociation**.org

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Mylan   OraSure Technologies
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ACKNOWLEDGEMENTS:

In 2015, the ADAP Advocacy Association maintained a strong base of diversified financial support driven by its corporate partners; it was supplemented by its corporate sponsors, programmatic supporters, individual donors, in-kind donations. Funding helps the organization to raise awareness, offer patient educational program, and foster greater community collaboration – 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 online workshops and blogs.

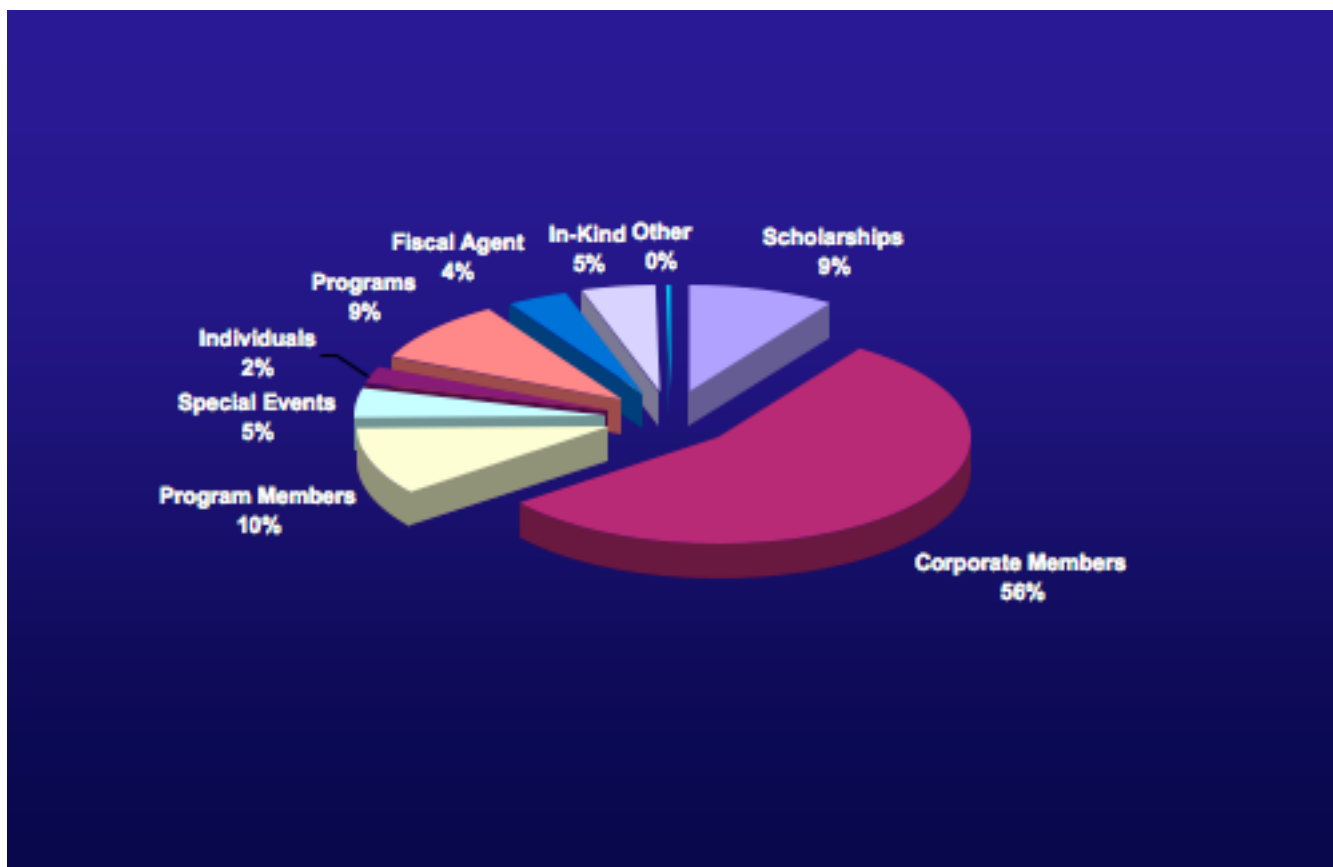The following chart demonstrates the diversity of the organization's funding in 2015:

Figure 1 - 2015 Revenue by Source

CONCLUSION:

The AIDS Drug Assistance Program (ADAP) continued to play a vital role in the delivery of supports and services for people living with HIV/AIDS, despite the ongoing implementation of the Affordable Care Act. Over 68,000 patients obtained ACA insurance coverage, thanks to ADAP's transition assistance. Despite expanded access to care and treatment there remain serious issues confronting underserved populations who rely on programs funded under the Ryan White CARE Act – most notably insurance discrimination.