



ADAP ADVOCACY ASSOCIATION



2016 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, health care, government, patients, pharmaceutical companies and other stakeholders to raise awareness, offer patient educational program, and foster greater community collaboration.

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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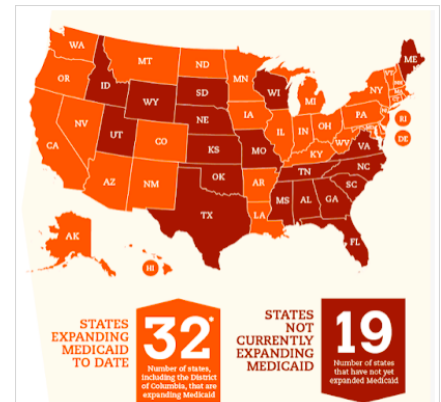
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SUMMARY:

In 2016, a considerable amount of attention focused on the future of the AIDS Drug Assistance Program (ADAP) in Medicaid non-expansion states, especially since the Affordable Care Act ("ACA") was designed to expand both. According to Families USA, there are currently 19 non-expansion states...mostly situated in the South, and rural states in other parts of the country.

One of the most troubling unintended consequences of the ACA has been exacerbated health disparities in the South, evidenced by only three southern states having expanded their Medicaid programs (Arkansas, Louisiana, and West Virginia). Yet the South is arguably the area of the country that needs greater access to care and treatment, and not less.



Source: Families USA

On February 1st, an analysis released by the National Alliance of State & Territorial AIDS Directors (NASTAD) revealed some interesting findings on ADAPs. The **2016 National ADAP Monitoring Project Annual Report** tracked state-by-state programmatic changes, emerging trends, and latest available data on the number of clients served, expenditures on prescription drugs, among other things. It is widely recognized by stakeholders has the most comprehensive analysis of ADAP-related information and data, and NASTAD's work provides an essential advocacy tool. The report focused on two main areas, including:

- A Model for Optimizing HIV Outcomes Within an Evolving Health System
- 3 Ways ADAP is Improving Health Outcomes

Overall the 2016 National ADAP Monitoring Project Annual Report yielded some very compelling data on the success of the program nationwide in 2015. Some key points were:

- Over 139,000 clients were served, representing a 5% decrease overall from the previous year;¹
- The total ADAP drug expenditures were \$130,921,720;²
- Drug rebates accounted for \$1.016 billion, or 45% of the overall ADAP budget, representing an increase of 6% from the previous year;³
- ADAP remained the primary payer for individuals whose insurance cost-sharing responsibilities (e.g., premium, deductible and co-payment) are a barrier to purchasing and maintaining insurance;⁴
- A majority (72%) of all clients served by ADAPs were reported as virally suppressed, which represents a 12% increase over the previous year;⁵ and
- A majority of ADAPs paid premiums (84%), deductibles (83%) and prescription co-payments/co-insurance (90%) on behalf of eligible clients.⁶

Download the report at <https://www.nastad.org/resource/national-adap-monitoring-project-2016-annual-report>.

¹ National Alliance of State & Territorial AIDS Directors, "2016 National ADAP Monitoring Project Annual Report," February 1, 2016, p. 3.

² National Alliance of State & Territorial AIDS Directors, "2016 National ADAP Monitoring Project Annual Report," February 1, 2016, p. 3.

³ National Alliance of State & Territorial AIDS Directors, "2016 National ADAP Monitoring Project Annual Report," February 1, 2016, p. 4.

⁴ National Alliance of State & Territorial AIDS Directors, "2016 National ADAP Monitoring Project Annual Report," February 1, 2016, p. 5.

⁵ National Alliance of State & Territorial AIDS Directors, "2016 National ADAP Monitoring Project Annual Report," February 1, 2016, p. 3.

⁶ National Alliance of State & Territorial AIDS Directors, "2016 National ADAP Monitoring Project Annual Report," February 1, 2016, p. 3.



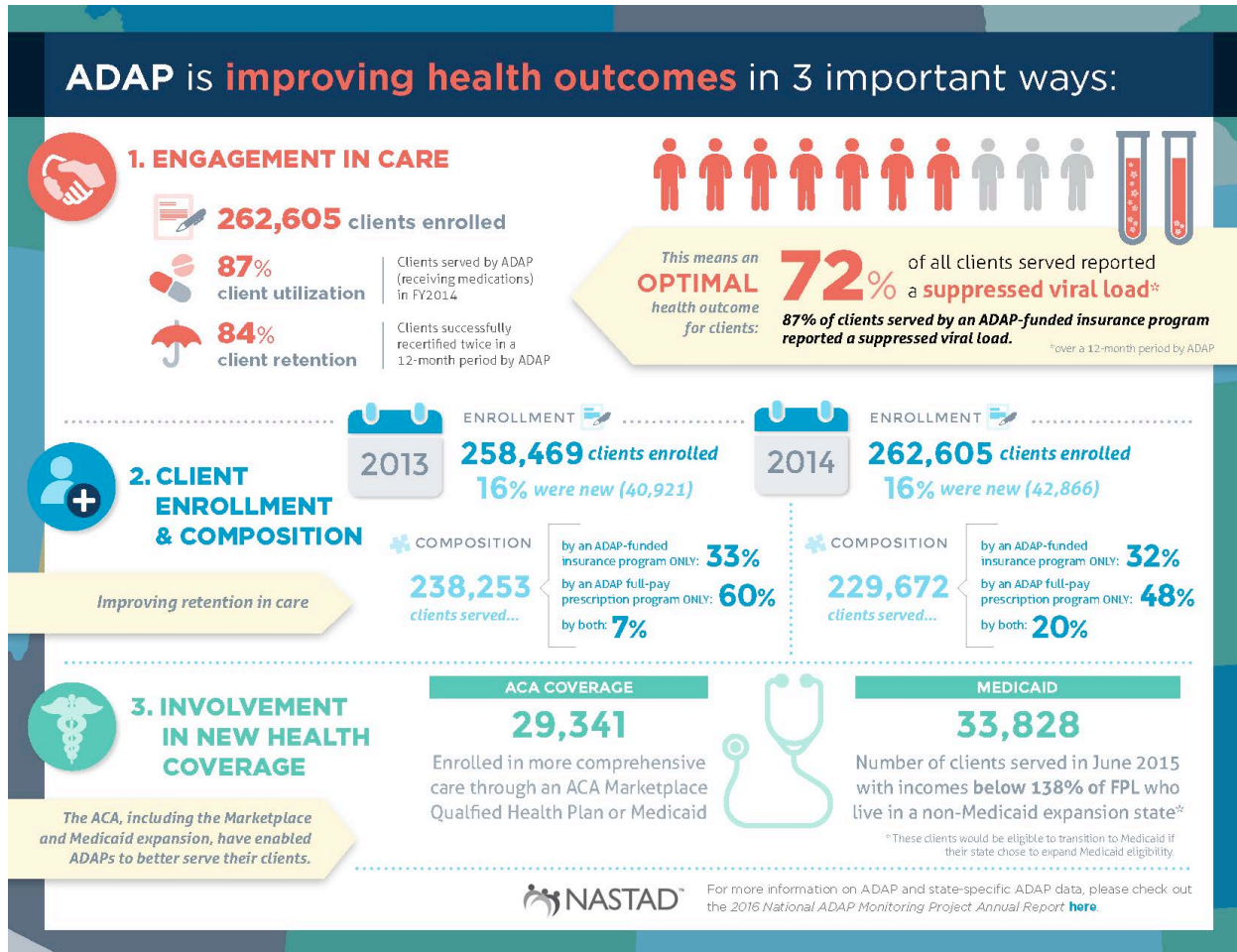
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Accompany the report was an infographic (seen herein), which NASTAD used to convey the important message behind how ADAPs are improving health outcomes.



The election results from November 8th shifted the national conversation, and left many HIV/AIDS stakeholders concerned about the future of the Ryan White CARE Act (including ADAPs), as well as the ACA in the new age of Donald J. Trump's "Make America Great Again." It became evident that the public safety net was in danger.

Ever since Trump's electoral win on November 8th, he has promised to repeal (and replace) the ACA and thereby remove protections afforded to people living with HIV/AIDS; he has tapped a staunch anti-ACA congressman to lead the U.S. Department of Health & Human Services ("HHS") and thus threaten Medicaid expansion; he has deemed fit to select a man with no knowledge about housing policy to lead the U.S. Department of Housing & Urban Development ("HUD") and thereby potentially threatening important housing programs for our community (namely the Housing Opportunities for People with AIDS program, or HOPWA); and yet still he has not once uttered the words "HIV" or "AIDS" since coming down that escalator in Trump Tower on June 16, 2015. The aforementioned are all red flags, but they don't even address his selection of the man who will be a heartbeat away from the Oval Office – a man who once proposed cutting AIDS-related funding and diverting it to conversion therapy. In other words, it stands to reason that the HIV/AIDS community is anxious about what lies ahead.



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HIGHLIGHTS:

- Released its Annual Report highlighting 2015 accomplishments;
- Increased the size of the organization's listserv by approximately 0.9 percent;
- Garnered support from thirty-one (31) 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 an **ADAP Eligibility Calculator** to its patient-centric ADAP Directory, <http://adap.directory>;
- Launched its **340B Services Caucus** for the patient perspective on the 340B Drug Pricing Program;
- Sponsored the Community Access National Network's **Annual National Monitoring Report on HIV/HCV Co-Infection**;
- Sponsored the Community Access National Network's Community Roundtable on **Hepatitis C & Aging**;
- Launched its **Transgender Health Project: Improving Access to Care Among Transgender Men & Women Living with HIV/AIDS under the AIDS Drug Assistance Program (ADAP)**;
- Hosted an ADAP Regional Summit on **Issues facing the AIDS Drug Assistance Program (ADAP) under the Affordable Care Act** in Birmingham, Alabama;
- Hosted its **9th Annual ADAP Conference, Magnifying How ADAP Provides Treatment For People Living With HIV/AIDS** in Washington, DC;
- Hosted its **6th Annual ADAP Leadership Awards Dinner**, headlined by **Murray Penner**, Executive Director of the National Alliance of State & Territorial AIDS Directors (NASTAD);
- Hosted online workshop, **Use of Tesamorelin among HIV Patients with Abdominal Fat Accumulation**;
- Hosted online workshop, **Ending the AIDS Epidemic in New York: Lessons Learned from Linkages to Care**;
- Hosted online workshop, **Improving Access to Care Among Transgender Men & Women Living with HIV/AIDS under the AIDS Drug Assistance Program**;
- Seated two new members to its Board of Directors: **Hilary Hansen** and **Jen Laws**;
- Funded fifty-four (54) scholarships;
- Supported thirty-one (31) national sign-on letters addressing various HIV/AIDS and healthcare initiatives;
- Submitted public comment to HRSA calling for an **Update to the Guide for HIV/AIDS Clinical Care**;
- Distributed thirteen (13) press releases;
- Published thirty-one (31) blogs about ADAP and healthcare-related issues;
- Increased support on Twitter to 3,979 Followers (up from 3,284);
- Increased support on Facebook to 2,341 Likes (up from 2,014); and
- 21,245 user sessions were logged on its patient-centric ADAP Directory during the year.



Ryan White Clinics for **340B** Access

FIGHTING TO PRESERVE THE BENEFITS OF THE 340B PROGRAM

PURPOSE AND GOALS

RWC-340B members work together to advocate for the interests of fellow 340B Ryan White providers. This includes active lobbying in state and federal arenas, as well as fostering ongoing relationships with Senators and Representatives. Our members work together to provide extensive training and assistance on how to deliver a unified message.

ABOUT RWC-340B

RWC-340B is a coalition of HIV/AIDS medical providers receiving support under the Ryan White CARE Act. It was organized in 2013 by a group of providers seeking ways to preserve the benefits of the 340B program.

OUR STRUCTURE

- RWC-340B is led by a board, executive committee and various ad hoc committees.
- All members have equal representation on the board.
- All members are encouraged to be involved with committees within the organization and outside lobbying efforts.

RWC-340B is a 501(c)(4) non-profit corporation.

This Year and Beyond

We anticipate significant activity in Congress, including ACA Repeal and Tax Reform. We are prepared to stand up for fellow providers and your patients.

Growth

Since its inception, RWC-340B has expanded to 24 organizations located in 23 states and Washington, DC.

Join RWC-340B

RWC-340B is only as strong as its members. There is strength in numbers so we must unite to protect our patients. Visit our website for more information.

www.rwc340b.org



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TIMELINE OF EVENTS:

January 21, 2016 – The ADAP Advocacy Association – together with the Community Access National Network (CANN) – announced that it would host its **9th Annual Conference** on **September 23-24, 2016**. The conference was themed as "*Magnifying How AIDS Drug Assistance Programs Provides Treatment For People Living With HIV/AIDS.*"

January 28, 2016 – The ADAP Advocacy Association launched its patient-centric **340B Services Caucus**. The Caucus came in response to the ongoing debate over the 340B Drug Pricing Program, which requires drug manufacturers to provide outpatient drugs to eligible health care organizations at significantly reduced prices.

February 10, 2016 – The ADAP Advocacy Association announced that it would host an **ADAP Regional Summit** in Birmingham, Alabama on April 15, 2016. The summit – held in partnership with AIDS Alabama, 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.

April 15, 2016 – The ADAP Advocacy Association convened its ADAP Regional Summit.

May 10, 2016 – The ADAP Advocacy Association opened nominations for its 2016 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 24, 2016 – The ADAP Advocacy Association released its 2015 Annual Report. The report also highlighted ADAPs assisting 68,000 clients living with HIV/AIDS being served by the program gain access to health insurance coverage under the Affordable Care Act.

> Download 2015 Annual Report: <http://adapadvocacyassociation.org/publications.html>



June 8, 2016 – The ADAP Advocacy Association announced that **Dr. Mike Magee**, President of Positive Medicine Inc., would deliver the opening keynote at its 9th Annual ADAP Conference.

July 7, 2016 – The ADAP Advocacy Association announced the agenda topics for its 9th Annual ADAP Conference.

July 18, 2016 – The ADAP Advocacy Association announced the appointment of two new members to its Board of Directors: **Hilary Hansen**, Director, Alliance Development with Merck, and **Jen Laws**, an HIV and transgender health advocate.

August 3, 2016 – The ADAP Advocacy Association launched a new project to improve access to care and treatment for transgender men and women living with HIV/AIDS. The project – "Improving Access to Care Among Transgender Men & Women Living with HIV/AIDS under the AIDS Drug Assistance Program (ADAP)" – aimed to raise awareness about issues confronting transgender men and women living with HIV/AIDS who also access care and treatment (or whom could benefit from such care and treatment) under ADAP, as well as provide useful resources and tools to the communities serving them.

September 6, 2016 – The ADAP Advocacy Association announced the recipients for its 2016 Annual ADAP Leadership Awards. The eight leadership awards were presented during the 6th Annual ADAP Leadership Awards Dinner held on Saturday, September 24th, 2016, in Washington, DC.



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The award recipients included the ADAP Champion: **Carl Schmid of The AIDS Institute**; ADAP Emerging Leader: **Alex Smith of AIDS Alabama**; ADAP Corporate Partner: **Prudential**; ADAP Community: **North Carolina AIDS Action Network (NCAAN)**; ADAP Lawmaker: **The Honorable Carl Sciortino, Massachusetts House of Representatives (2005-2014)**; ADAP Social Media Campaign: **HEAL Blog by Marcus Hopkins of the Community Access National Network (CANN)**; ADAP Grassroots Campaign: **Legalized Needle Exchange, by the North Carolina Harm Reduction Coalition (NCHRC)**; and ADAP Media: **“Sex 58,000 Times With Undetectable Partners = Zero HIV Transmission,” by JD Davids, TheBody.com.**

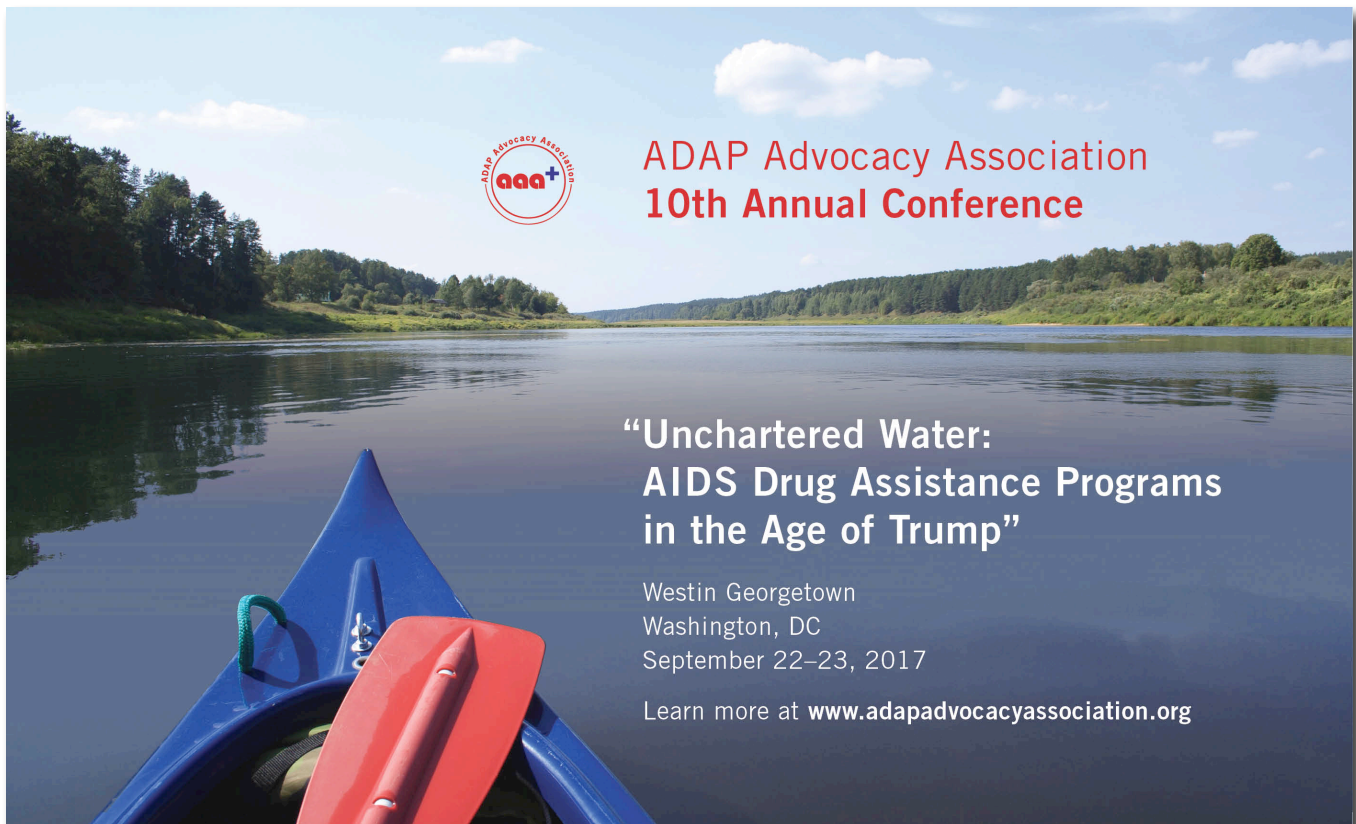
September 13, 2016 – The ADAP Advocacy Association announced its keynote speaker for its 6th Annual ADAP Leadership Awards Dinner would be **Murray Penner**, Executive Director of the National Alliance of State & Territorial AIDS Directors (NASTAD).




September 23, 2016 – The ADAP Advocacy Association launched its **ADAP Eligibility Calculator – powered by PillPack – on its flagship ADAP Directory**. The new user-friendly, patient-centric tool is designed to provide additional information about possible eligibility for the AIDS Drug Assistance Programs (ADAP) for consumers, care providers and other stakeholders.

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

December 1, 2016 – The ADAP Advocacy Association celebrated World AIDS Day by urging President-Elect Donald J. Trump to continue the fight against HIV/AIDS. “Don’t Turn Your Back on AIDS” – an awareness campaign using art launched several years ago in Oakland, California by the Flowers Heritage Foundation – embodies the message being sent to the incoming 45th President of the United States.



The banner features a scenic view of a river with a blue kayak in the foreground. The ADAP Advocacy Association logo is in the top left. The main text is in red and white, and the title is in white. The location and date are listed below the title, and a website link is at the bottom.

 **ADAP Advocacy Association
10th Annual Conference**

**“Uncharted Water:
AIDS Drug Assistance Programs
in the Age of Trump”**

Westin Georgetown
Washington, DC
September 22–23, 2017

Learn more at www.adapadvocacyassociation.org

REALITIES OF IMPORTATION

WHAT YOU THINK HAPPENS IN CANADA



If medicines at Canadian pharmacies are fine, this website for a Canadian pharmacy is safe too.



Canadian government inspects medicines being shipped out of Canada.



WHAT ACTUALLY HAPPENS IN CANADA



Medicines from online pharmacies can come from anywhere, regardless of what the website says.



The Canadian government does NOT inspect medicines being shipped out of Canada – whether they originate in Canada or elsewhere.



Allowing medicines to be imported from Canada risks patients being hurt by counterfeit and dangerous medicines.



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CORPORATE SUPPORT:

Corporate Members

Gilead Sciences – Corporate Leader
ViiV Healthcare – Corporate Leader
Janssen Therapeutics – Gold Member
Theratechnologies – Gold Member
HealthHIV – Silver Member
Duane Reade Pharmacy – Bronze Member
The Macsata-Kornegay Group, Inc. – Bronze Member
AIDS Alabama – Associate Member
Patient Advocacy Network Foundation (PAN) – Associate Member
Philadelphia FIGHT – Associate Member

Merck – Corporate Leader
AbbVie – Gold Member
Ramsell Corporation – Gold Member
Bristol Myers-Squibb – Silver Member
Community, A Walgreens Pharmacy – Bronze Member
MedData Services – Bronze Member
Walgreens – Bronze Member
Community Access National Network – Associate Member
Patient Advocate Foundation (PAF)

Strategic Partners

Great Lakes ADA Center
Housing Works
The Partnership for Safe Medicines

Flowers Heritage Foundation
NeedyMeds

ADAP Directory Founding Corporate Sponsors

AbbVie
Janssen Therapeutics
ViiV Healthcare

Gilead Sciences
Merck
Walgreens

ADAP Scholarship Fund Sponsors

Bender Consulting Services
Gilead Sciences
MedData Services

Community Access National Network
Housing Works
Napo Pharmaceuticals

Annual ADAP Leadership Awards Gala Sponsors

AbbVie
AIDS Healthcare Foundation
Bristol-Myers Squibb
Gilead Sciences
Merck
Patient Access Network Foundation (PAN)
Ramsell Corporation
Turing Pharmaceuticals
Walgreens

AIDS Alabama
Biotechnology industry Organization (BIO)
Community Access National Network
Janssen Therapeutics
Mylan
Philadelphia FIGHT
The Macsata-Kornegay Group, Inc.
ViiV Healthcare

Individual Donors

Thank you to people like you, who continue to support us with your small, medium, and large tax-deductible donations!

Program Scholarships Funded: 54



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2016 Corporate & Strategic Partners
