



ADAP ADVOCACY ASSOCIATION



2018 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: <http://www.adapadvocacy.org>.



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SUMMARY:

Transparency is a word often used, but equally often abused. A prime example is what transpired with the now defunct National Association of People With AIDS ("NAPWA"). Since the birth of the ADAP Advocacy Association in July 2007, transparency has been a core guiding principle of our organization and its advocacy activities. Our organization takes great pride in the fact that we share an abundance of information — including financial information — about our organization with stakeholders.

Last year, an important question was posed in a report released by Kaiser Health News. The report — *Patient Advocacy Groups Take In Millions From Drugmakers. Is There A Payback?* — and it attempted to "expose Big Pharma's ties to patient groups." It boasted about a national database of 1,215 patient advocacy organizations that received money from the drug companies who KHN tracked in 2015. The ADAP Advocacy Association was not among the organizations in the database, however. Our annual budget is probably so small that it didn't warrant the effort to include us.

We proudly list our supporters on our website, and also make available information about our corporate partnership levels on our website. This information is exactly what we share with any potential funder of our organization, so there is no smoke and mirrors. We also proudly list all of our financial supporters in our Annual Report, which is also available on our website.

The ADAP Advocacy Association receives no taxpayer funding. All of our revenue is generated from individuals, corporations, foundations, and nonprofit organizations.

In 2017, for example, our revenue as reported to the Internal Revenue Service was \$279,392.39; it was derived from numerous sources — including corporate partnerships, awards dinner sponsorships (\$1,000.00), conference registration fees (\$199.00), training fees (\$50.00), exhibit fees (\$1,000.00), scholarship fund donations (ranging from \$5.00 to \$5,000.00), and miscellaneous donations. Approximately 68.61% were donations received from pharmaceutical companies and/or affiliated groups. That means \$87,702.39 of our funding came from non-pharmaceutical sources. As the organization's CEO, one of the goals over the last decade has been achieving greater funding diversification because it is consistent with a sound business model.

That said, our top five pharmaceutical funders last year were Gilead Sciences (12.35%), Merck (11.63%), Janssen Pharmaceuticals (9.31%), ViiV Healthcare (8.59%), and AbbVie (8.05%). Our top five non-pharmaceutical funders were AIDS Healthcare Foundation (4.01%), Community Access National Network (3.76%), Ramsell Corporation (3.58%), Walgreens (3.58%), and Housing Works (1.79%). In total, we garnered the financial support from thirty-three (33) corporate entities (which was our best year to-date).

Our top individual donor was yours truly. Last year, our CEO donated \$16,119.65 back into the organization.

The first few years after we launched the ADAP Advocacy Association, pharmaceutical company donations accounted for approximately 90%+ of our annual revenue. We never once hid this fact. The only non-pharmaceutical revenue came from the Oakland, California-based Ramsell Corporation. Our first pharmaceutical partner was Janssen Therapeutics (then, Tibotec Therapeutics). Today, one in every three dollars is generated from sources outside of the industry.

Over the years, we've approached countless corporations, foundations, and organizations seeking their financial support for our efforts to increase access to care and treatment for people living with HIV/AIDS. Each one had a history of supporting HIV-related initiatives.



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We've been declined by the Elton John Foundation (numerous times). We've been declined by the Ford Foundation (numerous times). The Robert Wood Johnson Foundation declined, as did the Walmart Foundation. Chevron was a strikeout. Kenneth Cole Productions..nope. Macy's was another flop. Target Corporation, too. And the Levi Strauss & Co. and Starbucks (*note: on several occasions Starbucks donated \$5 gift cards for our conference bags*). Now that our pride is wounded sharing only a handful of the letdowns, there should be a clearer picture painted for any remaining doubters about our attempts to achieve funding diversity.

The reality is simple. Without financial support from our pharmaceutical partners, small patient advocacy organizations could not and would not exist...including ours! We're not ashamed or embarrassed by the support from our pharmaceutical partners, or the support from the many other funders either. Ironically, we've been criticized numerous times by other advocacy groups for accepting financial support from the AIDS Healthcare Foundation. We're also proud of the support that their organization has lent us. In fact, we proudly listed every single corporate donor in last year's blog, *10 Years of Accomplishment, Advocacy & Access to Care*.

Some of our non-industry funders have included Bender Consulting Services, Flowers Heritage Foundation, Great Lakes ADA Center, MedData Services, Philadelphia FIGHT, Public Sector Solutions, Southwest Airlines, SunTrust Bank, and Wells Fargo. And yes, we have received considerable support from our pharmaceutical partners — and their support has been equally valued.

In fact, in the 11 years since our Articles of Incorporation were filed in the District of Columbia, not once has a pharmaceutical company demanded or requested a quid pro quo in return for its financial support. Let us repeat...not once!

...demanded support for pending federal or state legislation? Nope.

...nudged us to oppose potentially harmful regulation to the pharmaceutical industry? Never.

...requested allegiances for pro-big Pharma policies? Not even that one.

And let us be equally clear, on occasion the ADAP Advocacy Association has taken a very public stand on issues contrary to our pharmaceutical partners, and again...not once did a single one of them retaliate by withdrawing support. Therefore, speaking alone for our organization there is no direct or implied payback, or conflict-of-interest established by accepting their support.

Respect is earned, and our organization has earned the respect of its funders because they recognize the valuable contributions we make to patient advocacy. And, we will continue to do so. To learn more about our advocacy, educational programs, or community collaboration go to www.adapadvocacy.org.





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HIGHLIGHTS:

- Released its Annual Report highlighting 2017 accomplishments;
- Garnered support from twenty-five (25) corporate entities;
- Renewed strategic partnerships with the **Flowers Heritage Foundation, Great Lakes ADA Center, Housing Works, HealthHIV, NeedyMeds, Partnership for Safe Medicines, Pharmaceutical Research & Manufacturers of America, Professional Association of Social Workers in HIV/AIDS, and RAD Remedy.**
- Added new strategic partnership with **Legacy Health Endowment & Triangle Empowerment Center;**
- Updated its patient-centric ADAP Directory, <http://adap.directory>;
- Sponsored the Community Access National Network's **3rd Annual National Monitoring Report on HIV/HCV Co-Infection;**
- Sponsored the Community Access National Network's Community Roundtable on **Linkages to Care for Current/Former Incarcerated Citizens Living with Hepatitis C – Year Two Update;**
- Sponsored the North Carolina AIDS Action Network's **Annual North Carolina HIV & AIDS Advocacy Conference;**
- Appointed to serve on the Community Access National Network's **340B Commission;**
- Published an infographic and policy paper under its **Correctional Health Project;**
- Hosted an **HIV/AIDS Fireside Chat** retreat in Tampa, Florida to discuss issues facing the HIV Community under the AIDS Drug Assistance Program (ADAP);
- Hosted an **HIV/AIDS Fireside Chat** retreat in Boston, Massachusetts to discuss issues facing the HIV Community under the AIDS Drug Assistance Program (ADAP);
- Hosted its **11th Annual ADAP Conference, Mapping a New Course to Protect the Public Health Safety Net** in Washington, DC;
- Hosted its **Annual ADAP Leadership Awards Dinner**, headlined by **Josh Robbins;**
- Seated three new member to its Board of Directors: **Lyne Fortin, Lisa Johnson-Lett & Theresa Nowlin;**
- Funded sixty-three (63) **advocacy scholarships;**
- Supported forty (40) **national sign-on letters** addressing various HIV/AIDS and healthcare initiatives;
- Distributed eleven (11) **press releases;**
- Published forty-eight (48) **blogs** about ADAP and healthcare-related issues;
- Increased support on social media to **4,801 Twitter Followers** (up from 4,559); and
- Attracted 48,473 unique user sessions were logged on its patient-centric **ADAP Directory** (48.7% increase).



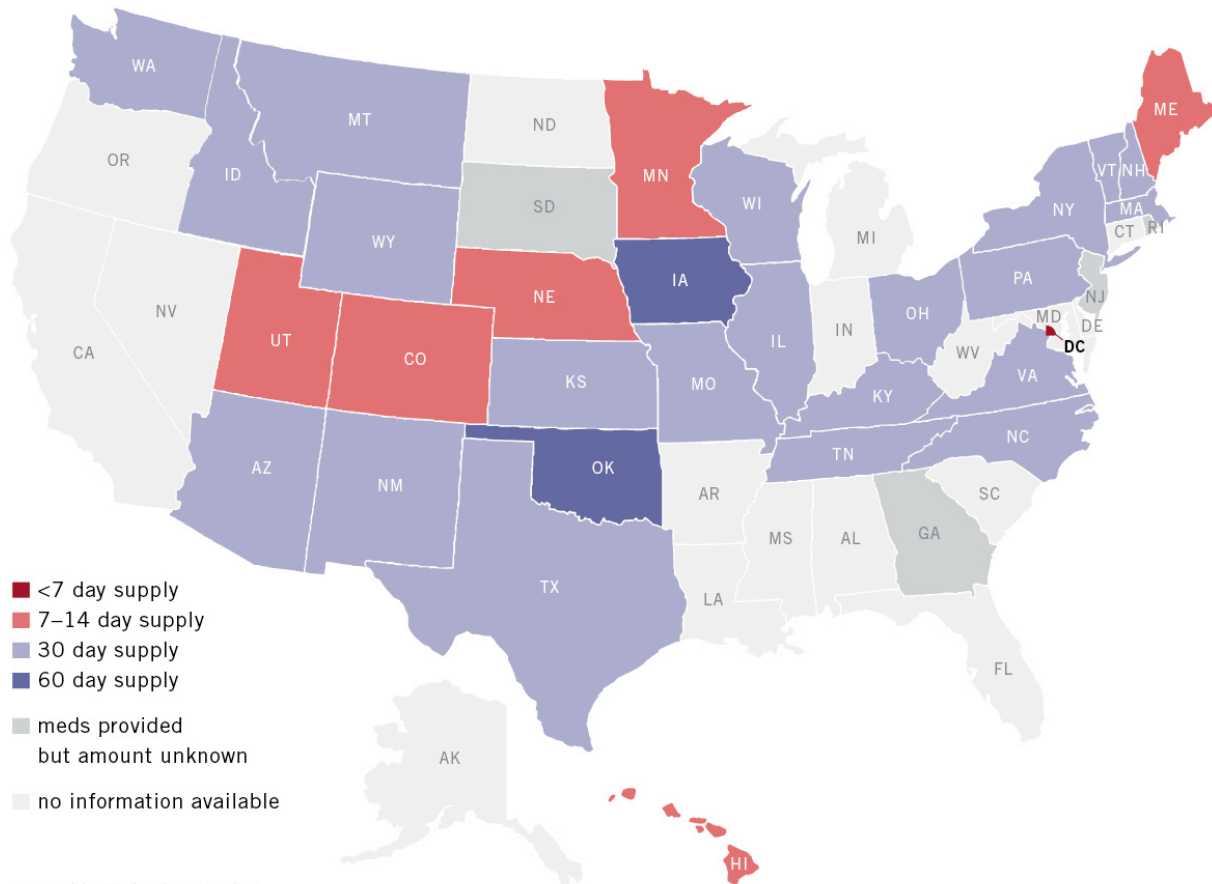
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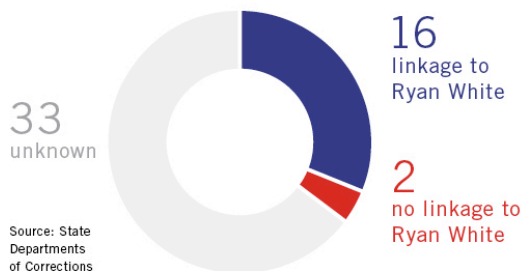
IMPROVING ACCESS to Care Among Formerly Incarcerated Populations Living with HIV/AIDS under the AIDS Drug Assistance Program

HIV MEDS (IN DAYS) SUPPLIED TO INMATES UPON RELEASE BY STATE DEPARTMENTS OF CORRECTIONS



Source: State Departments of Corrections

STATE DEPARTMENTS OF CORRECTION RYAN WHITE LINKAGE



Source: State Departments of Corrections

INCARCERATION RATES & HIV



Source: The Lancet



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TIMELINE OF EVENTS:

January 8, 2018 – The ADAP Advocacy Association – together with the Community Access National Network (CANN) – announced that it would host its **11th Annual Conference** on **September 20-21, 2018**. The conference was themed as "*Mapping a New Course to Protect the Public Health Safety Net.*"

February 1, 2018 – The ADAP Advocacy Association urged an immediate appointment of the Office of National AIDS Policy Director.

February 20, 2018 – The ADAP Advocacy Association – together with the Community Access National Network (CANN) – issued a joint statement on discriminatory proposed healthcare "Conscience Rule" on the "Moral Exemptions & Accommodations for Coverage of Certain Preventive Services Under the Affordable Care Act".

March 7, 2018 – The ADAP Advocacy Association seated two new Board Members, including Lyne Fortin and Lisa Johnson-Lett.



April 8, 2018 – The ADAP Advocacy Association released an infographic as part of its ongoing project, "CORRECTIONAL HEALTH: Improving Access to Care Among Formerly Incarcerated Populations Living with HIV/AIDS under the AIDS Drug Assistance Program." The project raised awareness about issues confronting formerly incarcerated populations living with HIV/AIDS who also access care and treatment (or whom could benefit from such care and treatment) under ADAP, as well as other public health programs.

April 12, 2018 – The ADAP Advocacy Association announced that **Jennifer Vaughan** would deliver the opening keynote at its 11th Annual ADAP Conference.

May 2, 2018 – The ADAP Advocacy Association released its 2017 Annual Report. The report celebrated ten years of promoting and protecting the AIDS Drug Assistance Program.

> Download 2017 Annual Report: <http://adapadvocacyassociation.org/publications.html>

May 17, 2018 – The ADAP Advocacy Association hosted an HIV/AIDS Fireside Chat Retreat in Florida to tackle pressing issues facing the HIV Community.

May 24, 2018 – The ADAP Advocacy Association announced that **Josh Robbins**, a social media strategist, would deliver the keynote at its Annual ADAP Leadership Awards Gala.

June 14, 2018 – The ADAP Advocacy Association opened nominations for its 2018 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 7, 2018 – The ADAP Advocacy Association named to its Board of Directors, **Thersa Nowlin** from Dorchester, Massachusetts..

July 11, 2018 – The ADAP Advocacy Association blasted the Trump Administration's plan to divert Ryan White HIV/AIDS Program funding to Refugee Camps, as reported by *Slate*.



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August 9, 2018 – The ADAP Advocacy Association announced the recipients for its 2017-2018 Annual ADAP Leadership Awards. The leadership awards were presented during the Annual ADAP Leadership Awards Dinner held on Friday, September 21st, 2018, in Washington, DC.



Gary R. Rose
1951-2017

The award recipients included **Gary R. Rose** posthumously for Lifetime Achievement; **Evelyn Foust**, Director of the North Carolina Department of Health & Human Services' Communicable Diseases Branch for "William E. Arnold" Champion; **Tori Cooper**, prevention specialist at Positive Impact Health Centers in Atlanta, GA for Emerging Leader; **Lambda Legal** for Corporate Partner; **Community Research Initiative, Inc.** (Boston, MA) for Community Organization; **Honorable John McCain**, U.S. Senator (AZ) for Lawmaker; **Jennifer's Positive HIV Life**, by Jennifer Vaughan for Social Media Campaign; **Long-Term Survivors Stories Public Service Announcement** by Let's Kick ASS - AIDS Survivor Syndrome for Grassroots Campaign; and **"5 good news stories about the fight against HIV/AIDS"** by Larisa Epatko, published on the PBS News Hour website on 06/13/18 for Media Story.

November 8, 2018 – The ADAP Advocacy Association hosted an HIV/AIDS Fireside Chat Retreat in Massachusetts to tackle pressing issues facing the HIV Community.

December 1, 2018 – The ADAP Advocacy Association recognized World AIDS Day.

UPDATE: ANNUAL ADAP CONFERENCE

The Annual ADAP Conference, which has convened annually since 2007, is being replaced by quarterly HIV/AIDS Fireside Chat Retreats.

The change comes in light of the current political environment and the need for more local engagement to influence federal public policy.



The ADAP Directory

The ADAP Directory is a convenient online resource to locate AIDS Drugs Assistance Program information for all US states and territories.

[LEARN MORE](#)



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CORPORATE SUPPORT:

Corporate Members

Gilead Sciences – Corporate Leader
ViiV Healthcare – Corporate Leader
MagellanRx Management – Gold Member
Theratechnologies – Gold Member
Maxor National Pharmacy – Bronze Member
Walgreens – Bronze Member
Napo Pharmaceuticals – Affiliate Member
Community Access National Network – Associate Member
Patient Advocacy Network Fndn. – Associate Member

Merck – Corporate Leader
AbbVie – Gold Member
Ramsell Corporation – Gold Member
Janssen Therapeutics – Silver Member
ScriptGuideRx – Bronze Member
MedData Services – Affiliate Member
AIDS Alabama – Associate Member
North Carolina AIDS Action Network – Associate Member
Patient Advocate Foundation (PAF) – Associate Member

Strategic Partners

Great Lakes ADA Center
HealthHIV
Legacy Health Endowment
Pharmaceutical Research & Manufacturers of America
RAD Remedy
Triangle Empowerment Center

Flowers Heritage Foundation
Housing Works
NeedyMeds
Professional Association of Social Workers in HIV/AIDS
The Partnership for Safe Medicines

ADAP Directory Founding Corporate Sponsors

AbbVie
Janssen Therapeutics
ViiV Healthcare

Gilead Sciences
Merck
Walgreens

ADAP Scholarship Fund Sponsors

Bender Consulting Services
Community Access National Network
MedData Services

Biotechnology Innovation Organization
Gilead Sciences
PayPal Giving Fund

Annual ADAP Leadership Awards Gala Sponsors

AbbVie
Biotechnology Innovation Organization
Gilead Sciences
MagellanRx Management
Merck
Patient Access Network Foundation (PAN)
ScriptGuideRx
ViiV Healthcare

AIDS Alabama
Community Access National Network
Janssen Therapeutics
Maxor National Pharmacy
Mylan
Ramsell Corporation
Theratechnologies
Walgreens

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

2018 Corporate Partners
