



AIDS DRUG ASSISTANCE PROGRAM SUMMIT

ADAPs in Crisis: When will Washington come to the Resue?

Purpose:

The [ADAP Advocacy Association](#) (aaa+) – together with its Lead Sponsor [AIDS Healthcare Foundation](#) (“AHF”) and in coordination with the [Community Access National Network](#) (CANN) and [Housing Works](#) – is hosting its 2011 Annual Conference as an AIDS Drug Assistance Program Summit. This year’s conference theme is “**ADAPs in Crisis: When will Washington come to the rescue,**” which aims to assemble ADAP stakeholders from all of the various constituency groups – including patients, advocates, service providers, health care providers, pharmaceutical companies, allied health professionals, specialty pharmacies and others.

The AIDS Drug Assistance Program is in crisis. The purpose is to identify key action steps to secure additional federal appropriations, programmatic reforms, and available public and private resources to alleviate the ongoing cost-containment strategies that are putting thousands of people living with HIV/AIDS on ADAP wait lists or program disenrollment.



Faced with the “Perfect Storm” that is being fueled by high unemployment, record number of uninsured, state budgetary cutbacks, high cost of medications and inadequate federal funding, there are a historic number of people being denied access to treatment. Without intervention from either the executive or legislative branch, several thousand people living with HIV/AIDS will be at risk of developing Opportunistic Infections (“OIs”), and thousands of others who are HIV-negative will be at greater risk of contracting the virus because their HIV-positive counterparts are more infectious when not taking Highly Active Anti-Retroviral Therapy (“HAART”). The conference provides an excellent opportunity to demonstrate the proven Return on Investment (“ROI”) of ADAPs.

Topics:

- **Health Care Reform Update** – How can key provisions of the new law help?
- **FY2011 ADAP Funding Update** – Where is the additional funding?
- **Ryan White Program Update** – What needs to change to improve access?
- **Welvista Solution Update** – How can private resources plug the gap?
- **ADAP Funding Shortfalls** – How is the ADAP crisis impacting certain sub-populations?
- **ADAP State-Level Funding Solutions** – What can be done?
- **ADAP Advocacy Training** – Tips for self-advocates to educate their lawmakers
- **ADAP Congressional Briefing** – “*End The Crisis; End The Wait*”

Background:

State ADAPs are primarily federally funded under Part B of the Ryan White Comprehensive AIDS Resources Emergency (“CARE”) Act. 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 when President Bill Clinton and Speaker Newt Gingrich were in office.

As of March 24th, there are 7,553 people living with HIV/AIDS in 11 states on ADAP waiting lists – including 31 people in Arkansas, 3,848 people in Florida, 1,221 people in Georgia, 11 people in Idaho, 816 people in Louisiana, 21 people in Montana, 177 people in North Carolina, 303 people in Ohio, 560 people in South Carolina, 563 people in Virginia and 2 people in Wyoming. Overall, 95.54% of these people reside in the south. Additionally, there are people living with HIV/AIDS who are the “invisible” waiting lists because they have been kicked-off the program due to changes in eligibility requirements – including 99 people in Arkansas, 257 people in Ohio, and 89 people in Utah, as well as the 6,500+ people in Florida who have been transitioned off the program.

The ongoing ADAP crisis is being fueled, by in large, because federal spending has been inadequate – despite small budget increases under both President George W. Bush and President Obama since 2005. The federal share of ADAP funding has fallen steadily over the last several years. In FY2003 the federal earmark was 72 percent of the overall ADAP budget. In FY2009, the federal share had fallen to 49 percent of the ADAP budget. ADAPs have long had a strong state-federal partnership; however despite the economic downturn many states have increased funding in FY2010 by an additional \$121 million dollars for a total of \$346.2 million. Pharmaceutical manufacturers have also helped to alleviate fiscal challenges for ADAP by agreeing to lower drug prices and enhance rebates.¹

The problem of growing ADAP waiting lists is exacerbated because we are facing an American HIV/AIDS epidemic of devastating proportion. According to some estimates, the number of people living with HIV/AIDS in the United States was approximately two million by the end of 2010. These numbers are not due to decrease in the near future. In 2006 alone, the Centers for Disease Control & Prevention (“CDC”) estimated that there have been more than 56,000 new HIV infections per year for the last decade. If this was not severe enough, the disease is far from color blind. Currently, the incidence rate of new HIV infection among African American men and women is seven times that of the Caucasian population. Furthermore, racial disparities are echoed regionally as the epidemic has seen its most recent unfettered growth in Southern states, which often times have smaller state budgets and fewer access points to comprehensive care.

¹ The ADAP Coalition, ADAP Need FY2012, January 2011

The ADAP need is being driven by simple factors. As we all know HAART AIDS treatments has dropped U.S. death rates from AIDS by about 75% starting in 1996. Whereas annual AIDS deaths use to run about 40,000 a year, now 15,000 to 17,000, even less in areas of very good medical care.

While dramatic improvements in lifespan and quality of life are almost miraculous, HAART treatments must continue for ADAP patients. Therefore patients living longer will likely require ADAP services for medications longer. There are 200,000 to 300,000 Americans who are unaware that they are HIV+. Extensive multi-million dollar efforts for outreach and HIV testing are going on all over the country, and the CDC now urges routine testing for those at risk for HIV. Funded by churches, foundations, Minority Health Initiatives, pharmaceutical companies and AIDS service groups, these efforts are identifying “hard to reach” populations many of whom lack adequate health insurance. These individuals, when identified, must look to ADAP to cover the costs of their drugs. For most, access to Medicaid is limited. State Medicaid programs typically require disease progression to full-blown AIDS to meet the Social Security definition of disabled. U.S. government treatment guidelines consider progression to full-blown AIDS to be months and years too late for optimum treatments.

While we hope that Congress will pass the Early Treatment for HIV Act (“ETHA”) to allow states the option to provide HIV care and treatments through Medicaid early in the disease process when health benefits are greater and costs are less, for now we are stuck with folks who can’t qualify for Medicaid looking to ADAP for basic coverage. Increases in private sector health insurance costs forces steady streams of HIV+ patients from private health insurance programs to state ADAPs. This is a result of rising costs in premiums and co-payments that become unaffordable, and in some instances by HMO-type providers with drug benefits leaving the market for more profitable locations. These factors together, ensure need for state ADAPs for the coming years. The increasing rate of need will be substantial until key provisions of the **Patient Protection and Affordable Care Act (“PPACA”)** can provide adequate benefits to our entire senior, elderly and disabled populations. As the profile of the American AIDS epidemic has expanded further into communities of color, marginalized populations, rural areas, and particularly to women of color in their child bearing years, ADAPs feel these additional strains from groups which traditionally may work low-paying jobs with inadequate health insurance or no healthcare benefits.

In the past 12 months, 20 state ADAPs have instituted other cost-containment strategies, including **Arizona**: Reduced formulary, **Arkansas**: Reduced formulary, lowered financial eligibility to 200% of FPL, (disenrolled 99 clients in September 2009), **Colorado**: Reduced formulary, **Florida**: Reduced formulary, lower financial eligibility to 300% FPL, transition clients to Welvista from 2/14-3/31/11, **Georgia**: Reduced formulary, implemented medical criteria, continued participation in the Alternative Method Demonstration Project (AMDP), **Idaho**: Capped enrollment **Illinois**: Reduced formulary, instituted monthly expenditure cap, **Kentucky**: Reduced formulary, **Louisiana**: Discontinued reimbursement of laboratory assays, **North Carolina**: Reduced formulary, **North Dakota**: Capped enrollment, instituted annual expenditure cap, lowered financial eligibility to 300% FPL, **Ohio**: Reduced formulary, lowered financial eligibility to 300% of FPL (disenrolled 257 clients), **Puerto Rico**: reduced formulary, **South Carolina**: Lowered financial eligibility to 300% FPL **Utah**: Reduced formulary, lowered financial eligibility to 250% of FPL (disenrolled 89 clients), **Virginia**: Reduced formulary, only distribute 30-day prescription refills, **Washington**: Instituted client cost sharing, reduced formulary (for uninsured clients only), only pay insurance premium for clients currently on antiretrovirals, and **Wyoming**: Reduced formulary, instituted client cost sharing.

Agenda: The following is a *tentative* agenda-at-glance, which is subject to change:

Tuesday, July 5th

Start/End	Function	Topic	Speaker
9:00a – 11:00a	Pre-Conference	TBA	TBA
11:00a	Registration Open	Registration Open	-----
12:30p – 2:00p	Plenary Session LUNCH SERVED	TBA	TBA
2:00p – 3:15p	Plenary Session	TBA	TBA
3:30p – 4:30p	Breakout:	TBA	TBA
3:30p – 4:30p	Breakout:	TBA	TBA
4:30p – 5:30p	Breakout:	TBA	TBA
4:30p – 5:30p	Breakout:	TBA	TBA
5:30p – 6:30p	Plenary Session	TBA	TBA
6:30p – 7:30p	Reception	Networking Reception	

Wednesday, July 6th

9:00a – 10:15a	Plenaryl Session BREAKFAST SERVED	TBA	TBA
10:30a – 11:45a	Breakout:	TBA	TBA
10:30a – 11:45a	Breakout:	TBA	TBA
12:00p – 2:00p	Plenary Session LUNCH SERVED	TBA	TBA
2:15p – 3:15p	Breakout:	TBA	TBA
2:15p – 3:15p	Breakout:	TBA	TBA
3:15p – 3:45p	Break	NETWORKNG	-----
3:45p – 4:45p	Breakout:	TBA	TBA
3:45p – 4:45p	Breakout:	TBA	TBA
5:00p – 6:00p	Plenary Session	TBA	TBA
7:30p – 9:30p	Dinner	1 st Annual ADAP Awards Dinner	TBA

Thursday, July 7th

Start/End	Function	Topic	Speaker
9:00a – 11:00p	Closing Plenary Session BREAKFAST SERVED	TBA	TBA
12:00 – 1:00PM	Hill Visits	Congressional Office Visits to Meet with Legislative Staff about ADAPs	-----
1:00 – 2:30PM	Congressional Briefing	Congressional Briefing	TBA
2:30 – 5:30PM	Hill Visits	Congressional Office Visits to Meet with Legislative Staff about ADAPs	-----

Project Goals:

1. Communicating need for the federal government to adequately fund ADAPs;
2. Facilitating participatory development workshops on Ryan White with key ADAP stakeholders including – patients, advocates, service providers, health care providers, pharmaceutical companies, allied health professionals, specialty pharmacies and others;
3. Developing educational resources on ADAP-related issues;
4. Developing an action plan and set of recommendations for the Office of National AIDS Policy (“ONAP:”) to consider when implementing its National AIDS Strategy (“NAS”);
5. Linking ADAP stakeholders with available resources inside and outside the pharmaceutical industry;
6. Starting national conversation with ADAP stakeholders to raise awareness about the ADAP crisis, generally, and to spread educational components of the event, specifically.
 - a. Disseminating public service announcements about ADAPs.
 - b. Harnessing social media to better engage grassroots advocacy.
 - c. Alerting news media to domestic HIV/AIDS issues – such as ADAP crisis.
7. Initiating conversation about state-level ADAP Advocacy Association affiliates; and
8. Identifying strategies for implementation of the Congressional ADAP Resources & Education (“CARE”) project.

Learning Objectives:

1. To provide information to appropriate ADAP stakeholders on pharmaceutical prescription assistance and co-payment assistance programs, and other resources – including but not limited to HIV specialty pharmacies, Welvista, Patient Advocacy Foundation, etc.
2. To link ADAP stakeholders with relevant, timely and useful resources to alleviate programmatic funding shortfalls by enrolling patients into these programs.
3. To facilitate ongoing dialogue between ADAP stakeholders, pharmaceutical industry and other applicable entities in order to collectively identify practical strategies to improve access to care by removing patients from wait lists.