



AIDS DRUG ASSISTANCE PROGRAM SUMMIT

ADAPs in Crisis: Moving Beyond Waiting Lists & Improving Access to Care

Background:

AIDS Drug Assistance Programs (ADAPs) are in a state of emergency, with no signs of improvement. According to the National Alliance for State and Territorial AIDS Directors (NASTAD), wait lists have tripled by state and increased by over 1,000% by count since the beginning of 2009; additionally, other cost containment measures – such as capped enrollment, reduced formularies and restricted eligibility – have only exacerbated the crisis.

High unemployment has fueled more people desperately trying to access appropriate health care – including enrollment in the AIDS Drug Assistance Programs. Furthermore, state budget cuts in AIDS programs to the tune of \$167 million have truly shaken ADAPs nationwide – but especially in the states that were forced to institute waiting lists. In 2000, Congress appropriated seventy-two (72%) of the federal ADAP earmark; a number which fell to fifty-four (54%) in 2009. This severe drop in the federal commitment to ADAP – in addition to the high unemployment and state budget cuts – has largely been the catalyst for the most recent spike in HIV patients placed on wait lists. It is anticipated that at least twelve additional states will have to implement some form of cost containment measure in the upcoming months, including wait lists. In light of the present predicament, as well as the historical programmatic challenges and funding shortfalls, ADAP stakeholders need a coordinated effort to move beyond the wait list crisis and improve access to care for all people living with HIV/AIDS.

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 will be 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.

The good news is that with the advent of new medicines, people living with HIV/AIDS are able to live full and productive lives. The bad news is that it is increasingly difficult for people living with HIV/AIDS to afford their medications. Life saving medications can cost a single patient up to \$20,000 per year. This is compounded by the fact that nearly three quarters of all people with HIV/AIDS are either uninsured or dependent on public insurance. This makes strengthening our public HIV/AIDS healthcare system of critical importance – but in the meantime our efforts should concentrate on eliminating the wait lists.

Purpose:

The ADAP Advocacy Association (aaa+) – in coordination with the Community Access National Network (CANN) and Housing Works – is hosting its 2010 Annual Conference as an AIDS Drug Assistance Program Summit. This year's conference theme is "**ADAPs in Crisis: Moving Beyond Wait Lists & Improving Access to Care**," 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 purpose is to identify key action steps to secure additional federal appropriations, programmatic reforms, available private resources and other remedies to move beyond ADAP wait lists and improve access to care for all people living with HIV/AIDS.

The AIDS Drug Assistance Programs have been plagued by perpetual funding shortfalls – both at the federal and state levels – which led to waiting lists and other cost containment measures. These measures have historically restricted access to care for an-already under-served population and in some cases, even death of HIV/AIDS patients waiting to access their life-saving medications. But the reality is that ADAPs need more than just adequate funding to provide the needed services to the people the program is intended to serve; among them, better coordination of services, elimination of duplicative services, identification of short-term strategies – such as enrollment in Patient Assistance Programs, identification of long-term strategies – such as passage of the Early Treatment for HIV Act (ETHA), and overall improvement of health disparities.

While the ongoing ADAP crisis represents a serious challenge facing HIV/AIDS patients, there remain other opportunities (i.e., health care reform, drug rebates, patient assistance programs, etc.) that taken together can help to develop a successful strategy for ending the ADAP waiting lists immediately, as well as in the future.

Topics:

The 2010 Annual Conference "**AIDS Drug Assistance Program Summit: ADAPs in Crisis: Moving Beyond the Waiting List & Improving Access to Care**" will offer informative, practical and useful presentations and updates by leading industry experts on the following:

- **Health Care Reform Update** – How can key provisions of the new law help?
- **FY2010 ADAP Emergency Supplemental Update** – Where is the additional \$126 million?
- **Ryan White Program Update** – What needs to change to improve access?
- **Patient Assistance Programs (PAPs)** – How can private resources plug the gap?
- **Specialty HIV/AIDS Pharmacy Programs** – What are their role in improving access?
- **Benefits Coordination Programs** – How can they help more people receive care?
- **Housing as Health Care** – Can affordable housing be linked to improved health outcomes?
- **ADAP Advocacy Training** – Tips for self-advocates to educate their lawmakers
- **ADAP Congressional Briefing** – "*End The Crisis; End The Wait*"

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

Monday, July 5th

Start/End	Function	Topic	Speaker
12:00 – 2:00PM	Plenary Session LUNCH SERVED	Health Care Reform – The Good...The Bad & The Ugly	Randy Allgaier, Shanti Robert Greenwald, Treatment Access Expansion Pjt TBA
2:00 – 3:15PM	Plenary Session	ADAPs Under Siege – What Caused this Crisis?	William Arnold, CANN Kevin Dedner, Arkansas DOH Laura Hanen, NASTAD Robin Webb, A Brave New Day Claude Martin, Acadiana CARES
3:30 – 4:30PM	Breakout: Legislative Update	Early Treatment for HIV Act (ETHA)	Seth Koch, CANN
3:30 – 4:30PM	Breakout: Access Update	Specialty Pharmacies & Consumer Choice	Tim Murrill, Ramsell Holding Corp. Glen Pietrandoni, Walgreens Steven Duncan, Diplomat Pharmacy Vernon Watson, MOMS Pharmacy
4:30 – 5:30PM	Breakout: Legislative Update	Robbing Peter to Pay for Paul's HIV Care	Randy Allgaier, Shanti Christine Campbell, Housing Works Jesse Fry, Advocate Roy Hayes, ACT Up Philly
4:30 – 5:30PM	Breakout: Access Update	Puerto Rico on the Brink: Update on the Crisis in Puerto Rico	Anselmo Fonseca, Pacientes de SIDA pro Politca Sana
5:30 – 6:30PM	Plenary Session	Help4U Demonstration	Eric Flowers, Ramsell Holding Corp.
6:30 – 7:30PM	Reception	Networking Reception	

Tuesday, July 6th

9:00 – 10:15AM	Plenary Session BREAKFAST SERVED	Medical Update: How are Treatment Guidelines Impacted by ADAP Crisis	Jeffrey Stephens, M.D., Professor of Medicine & Physician of Infectious Disease, Mercer University
10:30 – 11:45AM	Breakout: Housing Update	Housing as Health Care	Nancy Bernstine, National AIDS Housing Coalition Kathie Hiers, AIDS Alabama
10:30 – 11:45AM	Breakout: ADAP Update	ADAPs under America's New Health Care System – What's in Store for PLWHAs	Emily McCloskey, The AIDS Institute
12:00 – 2:00PM	Plenary Session LUNCH SERVED	Access to Wellness: Solutions to Improve Access & Affordability to Medicines and Medical Products	Andrew Weber, Johnson & Johnson
2:15 – 3:15PM	Breakout: Housing Update	Why Housing Matters: Housing = Adherence	Christine Campbell, Housing Works Kathie Hiers, AIDS Alabama Ginny Shubert, Shubert Botein & Associates
2:15 – 3:15PM	Breakout: Access Update	Stretching Program Dollars: Creative Solutions in Cost Containment	Cynthia Jones, Health Management Services Arika Pierce, Health Management Services
3:15 – 3:45PM	Break	NETWORKING	-----
3:45 – 4:45PM	Breakout: Housing Update	Housing Roundtable: Identifying Solutions & Improving Access	Christine Campbell, Housing Works Nancy Bernstine, National AIDS Housing Coalition Kathie Hiers, AIDS Alabama Ginny Shubert, Shubert Botein & Associates
3:45 – 4:45PM	Breakout: ADAP Update	Innovative Solutions to Help ADAP Patients	Ken Trogdon, Welvista Jeffrey Lewis, Heinz Family Philanthropies
5:00 – 6:00PM	Plenary Session	Update on HIV Primary Care, Community Health Centers, and the HIV Medical Home Movement	Brian Hujdich, HealthHIV

Wednesday, July 7th

Start/End	Function	Topic	Speaker
9:00 – 11:00AM	Closing Plenary Session BREAKFAST SERVED	Panel Discussion / Debate on TLC+	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 Hosted by Sen. Richard Burr (NC) <ul style="list-style-type: none"> • What happens to me without Medication • Waiting Lists – How we got here and how we can fix it • Challenges facing the states • Feeling the brunt of the waiting lists in the South • Why interrupted treatment is detrimental • Making “patient-centered care” a priority 	Nick Rhoades, Iowa ADAP Waiting List Patient Kathie Hiers, AIDS Alabama Laura Hanen, NASTAD Lorraine Wells, Florida ADAP Director Stephen Jeffrey, MD, Mercer University
2:30 – 5:30PM	Hill Visits	Congressional Office Visits to Meet with Legislative Staff about ADAPs	-----

Project Goals:

1. 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;
2. Developing educational resources on ADAP-related issues;
3. 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);
4. Linking ADAP stakeholders with available resources inside and outside the pharmaceutical industry; and
5. Starting national conversation with ADAP stakeholders to raise awareness about the ADAP crisis, generally, and to spread educational components of the event, specifically.

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.
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.