

## EARLY TREATMENT FOR HIV SUMMIT

### AGENDA-AT-A-GLANCE (Tentative):

**Exhibitors will be strategically placed in/near plenary sessions to maximize networking opportunities!**

### MONDAY

#### 09:30 AM – 11:00 AM Town Hall Meeting on Health Care Reform & National AIDS Strategy

- **Jeff Crowley**, Director of The White House Office of National AIDS Policy (*invited*)
- **Eric Flowers**, President & CEO, Ramsell Holding Corporation (*invited & confirmed*)

#### 12:00 PM – 01:30 PM Opening Plenary Session – “HIV and Health Care Reform” (LUNCH SERVED)

- **Andrea Weddle**, Executive Director of the HIV Medicine Association (*invited & confirmed*)
- **Laura Hanen**, Director of Government Relations for the National Alliance of State and Territorial AIDS Directors (*invited & confirmed*)

<TOPIC> Overview of current state of HIV in the United States, as well as health care coverage and ongoing disparities in access to care. This presentation will bring into context disparities in access to care for people living with HIV/AIDS, provide an overview of federal spending on key health care programs vital to the well-being of people living with HIV/AIDS and recommendations for moving forward with health care reform, in general, and HIV care reform, specifically.

#### 01:45 PM – 03:00 PM Plenary Session – “Impressions of HIV/AIDS in America”

- **Jonathan Rochkind**, Vice President and Director of Research for Public Agenda (*invited & confirmed*)

<TOPIC> A generation after it was first discovered, what do most Americans know about HIV/AIDS? Do they know how it is transmitted and treated? How it can be prevented? How do people feel about people who are living with HIV? Government efforts to combat the epidemic? Participants in focus groups for Public Agenda's "Impressions Of HIV/AIDS In America: Building Public Support For Workable Solutions To End The Epidemic" expressed an interest in learning more about the disease, support for increased education and research, and concern that access to adequate health care may be part of the problem.

To learn more, go to <http://www.publicagenda.org/reports/HIV-AIDS-May-2009>

### **Concurrent Breakout Sessions**

#### 03:15 PM – 04:30 PM **Breakout Session**

##### Breakout 1: Legislative Update – "National & State-Based Access Advocacy Networks"

- **Randy Russell**, President of Healthcare Responses, Inc. (*invited & confirmed*)
- **Charles King**, President & CEO of Housing Works (*invited & confirmed*)

<TOPIC> AIDS advocacy started at the grassroots level some twenty years ago, and while many things about HIV have changed since the 1980s there remains an institutional fortitude in the power of grassroots advocacy. Learn from leading experts about effective national and state-based access advocacy networks, and what you can do to become more involved in the movement to improve early access for HIV diagnosis, access and treatment.

## **Breakout 2 – Awareness & Stigma Update – “Use of Social Networking Sites to Reach People Living with HIV, Other Infectious Diseases”**

- **Robert Breining**, Founder & President of POZIAM (*invited & confirmed*)

<TOPIC> Increasingly, PLWHAs, advocates, public health agencies are harnessing the power of social networking sites to reach people who are living with infectious diseases, including HIV/AIDS. Learn what one site, POZIAM, is doing to revolutionize the way people living with HIV/AIDS communicate with one another, network for the common good and offer support to others who are newly-infected, diagnosed and treated.

Robert Breining started POZIAM because he couldn't just sit back and cope with his HIV diagnosis alone. Confused by all the medical jargon, Robert desperately craved advice and support from other HIV positive people who could relate to him and his condition, which is why he created POZIAM. Feeling disconnected, POZIAM allowed the HIV/AIDS community to come to him in the comfort of his own home. POZIAM is a social networking website for people infected and affected by HIV/AIDS; it is designed so others around the world could share stories, discover similarities, make bonds and form friendships. With close to 1000 members – straight, gay, bisexual, transgender, young, old, men and women – who are bonded by a desire to end society's current stigma surrounding HIV by connecting with others. Robert hopes that POZIAM's slogan, "Finding Your Comfort Zone," will encourage people to feel at ease.

### **04:45 PM – 06:00 PM Breakout Session**

#### **Breakout 1: ADAP Update – “Propose Policy Changes to Secure HIV/AIDS Drugs for the Nations Poor and Uninsured”**

- **Carl Schmid**, Director of Federal Affairs for The AIDS Institute (*invited & confirmed*)
- **William McColl**, Political Director of AIDS Action (*invited & confirmed*)

<TOPIC> The AIDS Institute and AIDS Action announced the release of a new policy paper titled, “The AIDS Drug Assistance Program: Securing HIV/AIDS Drugs for the Nations Poor and Uninsured.” The two organizations examined the AIDS Drug Assistance Program (ADAP) of the Ryan White HIV/AIDS Program and how well it ensures access to HIV/AIDS drugs for people living with HIV in the U.S. ADAPs provide medications and other services to over 158,000 low-income and underinsured people, or about 1 in 4 people receiving HIV/AIDS treatment in the U.S. It is the largest component of the Ryan White Program. Despite a budget of \$1.4 billion in federal and state funds, the authors found that ADAP is not fully meeting the needs of people living with HIV/AIDS with 45 percent of people needing medications not receiving them. Furthermore, there are great disparities between the states in their ADAP coverage.

#### **Breakout 2: Treatment Update – “Disparities in HIV Care & Treatment”**

- **TBA**

<TOPIC> This session will examine the health disparities in treatment and care. According to the Centers for Disease Control & Prevention (CDC), evidenced by men who have sex with men (MSM) accounting for 71% of all HIV infections among male adults and adolescents in 2005, while communities of color are increasingly being disproportionately impacted by the disease.

Blacks had the highest AIDS rate in 2005 with 54.1 cases per 100,000 people, 9.1 times the rate for whites, and accounted for 48% of estimated cases among adults and adolescents diagnosed with AIDS.

06:30 PM – 07:30 PM **Networking Reception**

**TUESDAY**

09:00 AM – 10:30 AM **Plenary Session – “HIV Update: Insight into Early Treatment and Long-Term Complications.” (BREAKFAST SERVED)**

- **Princy N. Kumar, M.D.**, Chief, Division of Infectious Diseases at Georgetown University School of Medicine (*invited & confirmed*)

<TOPIC> Dr. Princy Kumar will discuss the benefits of earlier Antiretroviral treatment. Dr. Kumar will review new data on earlier initiation of HIV treatment, evolution of HIV into a disease of long-term survival and complications of long-term treatment and prevention of these long-term complications.

The importance of earlier anti-retroviral treatment was demonstrated recently by Jonathan Sterne of the University of Bristol (UK) comparing previous studies that followed more than 45,000 HIV-positive people in Europe and North America. Although there are no universal guidelines for when treatment should be started, common practice begins anti-retroviral treatment if CD-4+ T cell counts drop below 250. With the release of the new findings, some are calling for changes to the treatment guidelines (*Kaiser, 04/09/09*). In fact, a study led by Steven Deeks of the University of California-San Francisco further suggests delaying treatment might prevent a patient from reaching a normal CD-4+ T cell count and also experience various health-related complications.

[http://www.kaisernetwork.org/daily\\_reports/print\\_report.cfm?DR\\_ID=57816&dr\\_cat=1](http://www.kaisernetwork.org/daily_reports/print_report.cfm?DR_ID=57816&dr_cat=1)  
[http://www.kaisernetwork.org/daily\\_reports/rep\\_index.cfm?DR\\_ID=57934](http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=57934)  
[http://www.kaisernetwork.org/daily\\_reports/rep\\_index.cfm?DR\\_ID=57935](http://www.kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=57935)  
[http://www.poz.com/articles/early\\_hiv\\_treatment\\_1\\_16536.shtml](http://www.poz.com/articles/early_hiv_treatment_1_16536.shtml)

**Concurrent Breakout Sessions**

10:45 AM – 12:15 PM **Breakout Session**

**Breakout 1: ADAP Update – “What’s an adequate ADAP? What’s an Ideal ADAP?”**

- **Joey Wynn**, QI Director for Broward House (*invited & confirmed*)

<TOPIC> This session will review how ADAPs are varying structured across the nation, with a special emphasis on what constitutes an “adequate” versus “ideal” ADAP. There are 58 ADAPs (for each of the 50 states and eight territories), with total spending of \$1.4 billion (of which \$775 million comes from the federal government), serving nearly 146,000 clients each year. Once designed as the safety net of last resort, ADAPs have had to serve more people than ever before, and this growth shows no signs of slowing down. Yet ADAPs remain vastly underfunded at both the federal and state levels, so their very design and implementation is important.

Every state requires that ADAP clients have HIV. However, that’s pretty much where the similarities end. Some states tie eligibility to CD4 counts, while others do not. All states have income limits, but they vary widely. Medications covered also vary from state to state.

So what would make an “adequate” versus “ideal” AIDS Drug Assistance Program?

## **Breakout 2: Treatment Update – “Personal Experiences on late Dx and Access to Care”**

- **Chuck Middleton**, diagnosed in 2003 *(invited & confirmed)*
- **Lonny LeFever**, diagnosed in 1980 *(invited & confirmed)*
- **Theresa Daugherty**, diagnosed in 2004 *(invited & confirmed)*

<TOPIC> This session will provide real-life testimonials about late diagnosis, access and treatment. These testimonials will put faces behind the statistics and will demonstrate the importance of early treatment.

## **12:30 PM – 02:00 PM Plenary Session –Keynote (LUNCH SERVED)**

- **Greg White**, Senior Director, Policy, Government Affairs, at Johnson & Johnson – *(invited & confirmed)*

<TOPIC> This session will review a broad industry perspective on health care reform, as well as where things stand on health care reform. There are a few HIV-specific provisions in play, but systemic reform will impact mostly all people with HIV, since so many patients rely on the public system now, or are under/uninsured.

## **Concurrent Breakout Sessions**

### **02:15 PM – 03:45 PM Breakout Session**

#### **Breakout 1: Prevention Update – “Routine Testing as Rx for Preventing New Infections”**

- **Tom Myers**, General Counsel & Chief of Public Affairs of the AIDS Healthcare Foundation *(invited & confirmed)*

<TOPIC> AIDS Healthcare Foundation (AHF) is the largest AIDS group in the U.S. and which currently provides more than 14,000 free HIV and STD tests annually in California via its community-based testing programs through AHF’s Public Health Division. Learn about ongoing testing initiatives, as well as the importance of testing as a prevention strategy.

#### **Breakout 2: Treatment Update – “Drug Company Assistance Programs & co-pay assistance for Private Insurance Patients”**

- **Facilitated by: Bill Arnold**, Executive Director of the Community Access National Network *(invited & confirmed)*
- **Ken McCormick**, National Reimbursement Director for Tibotec Therapeutics *(invited & confirmed)*
- **Edward Hamilton**, Consumer Advocate *(invited & confirmed)*

<TOPIC> Do you lack health insurance, but make too much money to qualify for government assistance? Are your prescription co-payments so high that you can’t afford other basic necessities? Have you begun to question whether antiretroviral (ARV) therapy is beyond your financial means? There is another alternative, and it could be one of the best kept secrets in health care: the pharmaceutical industry’s patient and co-payment assistance programs.

[http://www.poz.com/rssredir/articles/hiv\\_pap\\_copayment\\_401\\_16390.shtml](http://www.poz.com/rssredir/articles/hiv_pap_copayment_401_16390.shtml)

<TOPIC> The FPC has recently negotiated with all major HIV drug manufacturers to require them to institute patient drug co-pay programs. The new drug co-pay programs are a direct result of intense work and negotiations between the FPC and representatives of the pharmaceutical industry.

04:00 PM – 05:15 PM Breakout Session

**Breakout 1: Legislative Update – “Why Health Care Reform Needs ETHA”**

- **Seth Koch**, Manager of Policy & Federal Affairs of the Community Access National Network *(invited & confirmed)*

<TOPIC> HIV/AIDS policy measures in the Congress have a history of strong bipartisan and bicameral support, such as the Ryan White CARE Act. This session will provide an overview on the Early Treatment for HIV Act (ETHA) and its importance within the broader healthcare reform debate. While ETHA does expand Medicaid eligibility, it does not expand the long-term cost of funding Medicaid. Rather, it creates significant cost reductions in the long term for State budgets that opt to utilize the program because the biggest opportunity for cost savings in Medicaid over the long term is prevention and early treatment.

Learn more about ETHA: <http://www.campaigntoendaids.org/etha/>

**Breakout 2: Treatment Update – “HIV Access to Care & Treatment in the District of Columbia”**

- **Dr. Shannon Hader** *(invited & confirmed)*

<TOPIC> This session will provide a model demonstration on the importance of early testing, diagnosis, access and treatment. Dr. Hader will review the ongoing situation/developments in the District of Columbia.

**Washington, D.C., Report Finds 3% of City Residents Are Living With HIV**

If you're looking for evidence that the U.S. hasn't done enough to fight HIV inside its own borders, look no further than the capital city itself: A new official report says that 3 percent of Washington, D.C., residents are living with HIV/AIDS, which puts the city on par with many developing countries. "If you really think that you don't know anyone affected with HIV, maybe it's time to think again," said Shannon Hader, director of D.C.'s HIV/AIDS Administration. *(Article from kaisernetwork.org)*

<http://www.thebody.com/content/news/art50853.html?ic=700100>

05:30 PM – 06:30 PM How to Educate Congress

**WEDNESDAY**

10:00 AM Capitol Hill Visits with your Members of Congress