

AIDSWatch

AIDSWatch 2008 Report

Focusing on the Domestic Epidemic

April 28 – 30, 2008 • Washington, DC



TAEP



NATIONAL ASSOCIATION OF
PEOPLE WITH AIDS

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I. AIDSWatch 2008 Summary

Once again, AIDSWatch was the largest constituent-based Federal HIV/AIDS advocacy and education event of the year. Over 400 participants, including people living with HIV/AIDS, their families, friends, care providers, and other advocates arrived at our nation's capital to educate their Senators and Representatives on the most pertinent issues facing persons living with HIV/AIDS in the United States.

This year, the National Association of People with AIDS (NAPWA) joined with the Treatment Access Expansion Project (TAEP) to produce an AIDSWatch focused on domestic HIV/AIDS issues. Among other issues, AIDSWatch participants from across the country met with legislators to advance efforts to increase access to care and treatment, remove the federal ban on needle exchange, repeal the HIV entry and immigration ban, and secure adequate funding of HIV care, prevention, research, housing, mental health and substance abuse programs.

As always, many of our national partner organizations, and the clients they serve, actively participated in the planning, funding and support of AIDSWatch 2008.

Left: Robert Greenwald prepares AIDSWatch participants to discuss 2008 priorities on the hill.

Center: NAPWA President & CEO Frank J. Oldham Jr. with Congresswoman Maxine Water (D-CA).

Right: David Ernesto Munar introduces Senator Richard Durbin (D-IL)



II. AIDSWatch 2008 Platform

Our AIDSWatch 2008 platform called for renewed attention to domestic HIV/AIDS issues and the development of a coordinated, results-oriented national strategy to address the domestic HIV/AIDS epidemic.

AIDSWatch participants met with members of Congress to promote laws and policies that improve health outcomes, reduce health disparities, and create an effective public health response to HIV/AIDS. After several years of level-funding of many AIDS programs, despite significant increases in the number of people living with HIV in the United States, participants sought increased support of HIV/AIDS care, prevention, research, housing, substance abuse and mental health programs. They also sought the elimination of abstinence-only-until-marriage education programs that have proven to be largely ineffective, provide inaccurate information and stigmatize persons living with HIV/AIDS.

This year, participants asked for Congress's urgent attention to the following legislative and appropriations priorities:

Legislative Priorities

- Pass the Early Treatment for HIV Act (ETHA) to expand Medicaid coverage for low-income, HIV-positive people before they are disabled by AIDS. (S. 860; H.R. 3326)
- Help HIV-positive Medicare recipients afford their Part D prescription drug coverage by allowing ADAP expenditures to count toward out-of-pocket costs. (S. 1103; H.R. 2058)
- Impose moratoria to prevent the implementation of harmful Medicaid rule changes. (S. 2819; H.R. 5613)
- Pass the Microbicide Development Act (MDA). (S. 823; H.R. 1420)
- Lift the federal ban on funding for syringe exchange programs.
- Repeal the entry and immigration ban against HIV-positive foreign nationals.

Appropriations Priorities

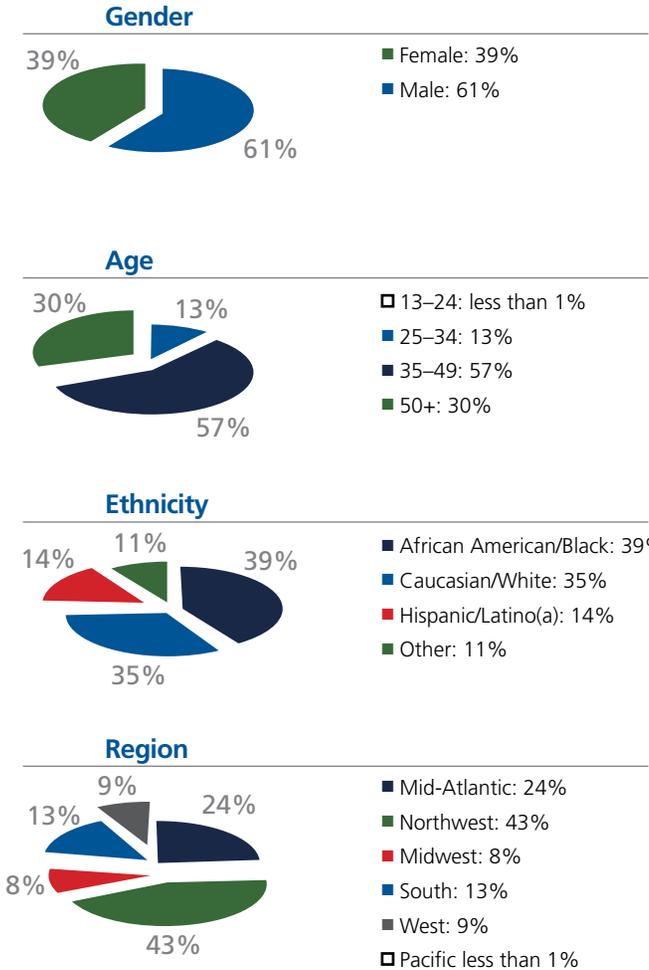
- Ryan White Programs
+ \$614.5 million
Expand access to care and treatment programs.
- Centers for Disease Control and Prevention (CDC)
+ \$608 million
Increase funding for domestic HIV prevention programs.
- Housing Opportunities for People with AIDS (HOPWA)
+ \$169.9 million
Expand housing accessibility.
- Minority AIDS Initiative (MAI)
+ 223 million
Address HIV's disproportionate impact on communities of color.
- National Institutes of Health (NIH)
+ \$450 million
Advance treatment research efforts.
- Substance Abuse and Mental Health Services Agency (SAMHSA)
+337 million
Improve access to services and new treatments.
- Eliminate funding for abstinence-only education programs.

III. AIDSWatch Participant Demographics and Training Session

The AIDSWatch 2008 training day began with a discussion of the urgent need for a renewed Congressional focus on domestic HIV/AIDS issues, followed by an in-depth review of our legislative and appropriations priorities. In each training session, educators, advocates and consumers worked together to provide an overview of the key issues involved in each AIDSWatch priority.

Presenters also demonstrated a mock Hill visit “role play” with Advisory Committee members playing the role of Congressional staff and consumers demonstrating how to conduct an effective Hill visit and advocate for our legislative and appropriations priorities. After each role play training participants met in small groups and conducted their own mock Hill visits. All of the training sessions reinforced the consistent message to participants that “real life” testimonials add meaning and relevance to our AIDSWatch priorities and provide significant value to members of Congress and their staff.

AIDSWatch 2008 drew interest from more than 400 people living with HIV/AIDS, service providers, community leaders, and other AIDS advocates. This year’s event attracted diverse participation that crossed ethnic, gender, age, and regional lines, including the following:



Above: Senator Richard Durbin (D-IL) talks about the hard-fought fight and what is needed to move forward.

Training Feedback

“ I thought the training would overwhelm the client participants, but I was wrong... participants did an excellent job of taking their personal stories and connecting them to specific policy issues ... clients were outstanding ... and highlighted issues for Congressional staff in a way that made the issues very human and very real. ”

– AIDSWatch 2008 Participant

IV. AIDSWatch 2008 Congressional Hill Visits

AIDSWatch 2008 participants conducted 197 meetings with members of Congress and their staff. Over 400 participants, largely people living with HIV and AIDS, managed the Capitol Hill matrix to request an increased and coordinated focus on the domestic HIV/AIDS epidemic, including our legislative and appropriations agenda. Carrying packets of materials that addressed the AIDSWatch priorities, participants met with Hill staff to discuss specific policy goals and objectives. At the same time, AIDSWatch advocates told their personal stories and described how support of AIDS programs affects their lives.

Total Number of Hill Visits

The chart below outlines the number of Hill visits conducted by AIDSWatch participants:

| State | Number | State | Number |
|------------------|--------|-------|--------|
| AL | 7 | MS | 4 |
| CA | 23 | MO | 3 |
| CT | 8 | NC | 4 |
| DC | 1 | NV | 5 |
| FL | 9 | NJ | 13 |
| GA | 11 | NY | 23 |
| HI | 4 | OH | 4 |
| IA | 5 | PA | 6 |
| IL | 15 | RI | 4 |
| KY | 2 | TX | 3 |
| MD | 5 | VA | 9 |
| MA | 12 | WA | 3 |
| MI | 2 | WI | 1 |
| MN | 9 | WV | 2 |
| Total 197 | | | |

In offices where the member of Congress and their staff were unavailable for an in-person meeting, AIDS advocates delivered our AIDSWatch materials highlighting our legislative and appropriation priorities.



Left: From left to right Michael Emanuel Rajner; National Community Organizer, National Association of People with AIDS; Jason Kennedy; State Policy Coordinator, The AIDS Institute; Congresswoman Ileana Ros-Lehtinen, R-Miami; David Brakebill; Key West Florida. Ileana has recently joined the Congressional LGBT Equality Caucus.



Center: POZ Editor-in-Chief Regan Hoffman talks about her former fear of people knowing she is living with HIV.



Right: Congresswoman Donna Christian-Christensen (D-VI) joins AIDS advocates in wearing a t-shirts urging greater attention to "AIDS at Home"

V. Additional AIDSWatch Activities and Outcomes

In addition to the AIDSWatch training and Congressional Hill visits, this year's AIDSWatch offered participants a multitude of opportunities to engage with other community stakeholders as well as network with colleagues from across the country.



Above: Youth participants are among those asking for a coordinated results-oriented response to the domestic epidemic. From the left; Juan Quinonez, Ronald Cheney, Robert Felix.

AIDS At Home Rally

This year's AIDSWatch event coincided with the kickoff of NAPWA's 25th anniversary receptions. These receptions, which will take place throughout the country in 2008 and 2009, offered an opportunity to celebrate NAPWA's heritage and a glimpse at NAPWA's vision for the future. Twenty-five years of AIDS has taught our community many lessons. NAPWA is committed to working toward a coordinated and effective response to the domestic HIV/AIDS epidemic by drawing from past successes and learning from missed opportunities.

With the support of the Campaign to End AIDS (C2EA) and DC Fights Back, this year's AIDSWatch proceeding included a rally on Capital grounds to bring attention to the need for a coordinated national strategy to address the domestic HIV epidemic. This year's rally included messages of endurance and hope from Senator Durban (D-IL), and Congresswomen Maxine Waters (D-CA) and Donna Christian-Christensen (D-VI). Congresswoman Maxine Waters promised "to fight AIDS until the day she died." People living with HIV and AIDS added a personal tenor with their stories of struggling to access care and working hard to increase access to information and services.

PLWA Meeting H.E.L.P. Committee Staff

For the second year in a row, NAPWA offered opportunities for persons living with HIV/AIDS to meet with key congressional leadership in the reauthorization of the Ryan White Treatment Modernization Act of 2006. (The Act is scheduled to sunset in September 2009.) Participants had the opportunity to share their experiences with Ryan White services. Ryan White beneficiaries discussed the gap caused in care and treatment when service availability changes after relocation and the need to relocate for access to services. They also identified populations who remain outside of care because

they are not poor or sick enough. This is one of many opportunities NAPWA is extending to persons with HIV/AIDS around the country to provide personal testimony on how to improve access to care and treatment services under Ryan White programs. NAPWA will be hosting regional meetings throughout 2008 and beyond to reach those persons living with HIV/AIDS who might not be able to access national meetings and events.

Congressional Briefing on Latinos and AIDS

Bienestar held its 3rd Annual Congressional Briefing on Latinos and AIDS in Washington, DC on April 29th. This year's panel discussion focused on the HIV/AIDS Travel and Immigration Exclusion Policy as well as the impact of HIV/AIDS in US Immigration Detention Centers. Invited presenters included Congresswomen Hilda Holis

(D-CA), Barbara Lee (D-CA), Lucille Roybal-Allard (D-CA) and Maxine Waters (D-CA). This year's briefing also attracted a diverse audience of community leaders from the National Minority AIDS Council (NMAC); National Alliance of State and Territorial AIDS Directors (NASTAD); the Centers of Disease Control and Prevention (CDC); the US Department of Health and Human Services (DHHS) - Office of HIV/AIDS Policy; and the Florida Department of Health. The National Association of People with AIDS (NAPWA) joined NMAC and NASTAD as proud sponsors of this event.

The Women's Collective and NAPWA collaborated on a Microbicides Meet and Greet Dinner for AIDSWatch 2008 on April 29, 2008.

During three days of AIDSWatch events, advocates from across the country attended advocacy trainings, participat-

ed in networking events, and made visits to their Congressional representatives.

A small but lively group attended the dinner. MAP presented microbicides basics, the recent incorporation of microbicides language into PEPFAR, and policy recommendations for advocates who would be attending Congressional representative meetings.

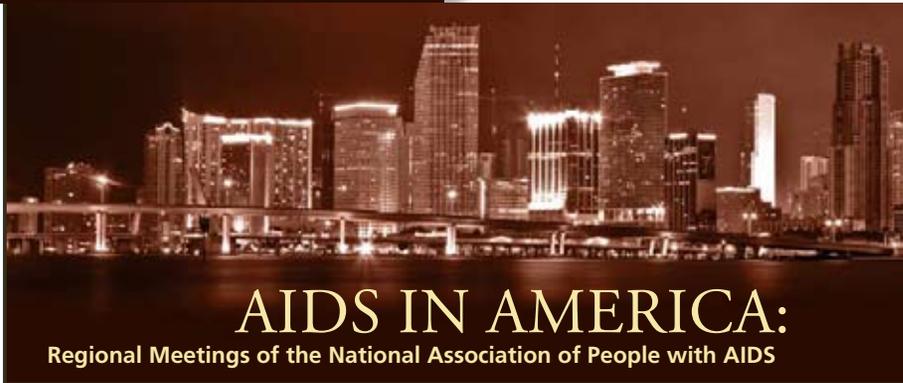
The discussion that followed centered on the inclusion of HIV-positive women in clinical trials and the concerns that peers have about clinical trial ethics.

Several attendees emphasized the importance of the highest possible ethical standards in clinical trials, especially in Africa. MAP is currently researching ways for US advocates to link with others internationally on inclusion of women living with HIV at all phases of clinical trials, from planning to roll out of new products.



VI. AIDSWatch Momentum Continues with "AIDS in America" Regional Meetings

Traditionally, NAPWA has held national conferences such as Staying Alive as a means of extending outreach to our constituency. Over the past two decades, the face of the AIDS epidemic in America has changed, funding has decreased, constituent needs have developed, new technological and treatment-oriented initiatives have arisen, and the "AIDS movement" has been re-shaped. Recognizing these needs, NAPWA has decided to take a new approach to constituent outreach by holding Regional Meetings across the nation beginning in 2008. These Regional Meetings will engage constituents on the local level to ensure that their voices assist in creating a national HIV/AIDS strategy. In addition, these meetings will offer an opportunity for people living with HIV/AIDS to institute local grassroots initiatives that support our national strategy. Advocacy will focus on both national and regional priorities and encourage constituents to remain engaged with congressional members throughout the year. An additional goal is to support and develop new community advocates who are actively engaged in efforts to secure support for life-saving care, treatment, and support for persons living with HIV/AIDS.



AIDS in America: NAPWA will provide its unique perspective of the state of HIV/AIDS at home as a domestic crisis.

Program Summary: The 2008 Regional Meeting model has the advantage of being responsive to particular issues in a local community around stigma, access to care, and health legislation education. NAPWA will achieve these goals through plenary sessions, panel presentations, small group workshops, and formal and informal networking sessions. The 2008 Regional Meeting model is a different way for a national AIDS organization to conduct business: by reaching out to local regions and making sure that their voices and concerns are recorded in a timely and accurate manner.

Costs: Registration \$35 per person. Registration covers one year NAPWA membership, and the day's lunch, refreshments and evening social. Go to www.napwa.org to register.

No travel, hotel or registration scholarships are available. All participants are expected to cover the cost of participating on their own.

Location: Andreas School of Business Building, 11300 NE Second Avenue, Miami Shores, FL 33161

Miami, FL • July 23, 2008 at Barry University • 9 a.m.– 6 p.m.

The National Association of People with AIDS is YOU.

Come to the NAPWA Meeting in your region to:

- Learn the latest advances in treatment from the point of view of other positive people!
- Discuss your services locally!
- Find out what you can do about local AIDS policy and advocacy!
- Articulate your regional issues so that NAPWA can bring them to national service and policy tables!
- Get the chance to meet other positive people in your area!
- Be part of the National Association of People with AIDS!

Whether you are living with HIV/AIDS, a service provider, or an ally, make your voice heard with NAPWA.

Statement from the Advisory Committee of People with AIDS (1983)

The Denver Principles “We condemn attempts to label us as ‘victims,’ a term which implies defeat, and we are only occasionally ‘patients,’ a term which implies passivity, helplessness, and dependence upon the care of others. We are ‘People With AIDS.’”

Go to www.napwa.org or call NAPWA toll free: 866-846-9366 to register today!



VII. AIDSWatch 2008 Advisory Committee

In 2008, NAPWA and TAEP continued the AIDSWatch tradition of collaboration by inviting our national partners and the clients they serve to participate in all aspects of the AIDSWatch planning process. Through the diligent work of the Advisory Committee a comprehensive AIDSWatch platform was developed along with up-to-date and accurate briefing materials.

AIDSWatch Principle Coordinator: Kali Lindsey

- *Vice-President of Federal Government Affairs,*
National Association of People with AIDS
- *Director of Federal Government Affairs,*
Treatment Access Expansion Project

AIDSWatch Principle Advisor: Robert Greenwald

- *Director,* Treatment Access Expansion Project
- *Director,* Health Law Clinic, Harvard Law School

If you have any further questions about the 2008–2009 AIDS in America regional meetings or concerning AIDSWatch 2009, contact Kali Lindsey via e-mail klindsey@napwa.org or phone 240-247-1019.

Participants of the AIDSWatch 2008 Advisory Committee included:

AIDS Action

Rebecca Haag, Donna Crews, William McColl, and Ronald Johnson

AIDS Alliance for Women, Youth, and Families

Diana Bruce

AIDS Foundation of Chicago

David Ernesto Munar

American Psychological Association

Daniel Dawes

High Noon Communications

Becky Sachs and Scott Sanders

Housing Works & Campaign to End AIDS (C2EA)

Christine Campbell and Larry Bryant

National Alliance of State and Territorial AIDS Directors (NASTAD)

Ann Lefert

National Association of People with AIDS (NAPWA)

Stephen Bailous and Michael Emanuel Rajner

National Minority AIDS Council (NMAC)

Ravinia Hayes-Cozier

San Francisco AIDS Foundation

Ernest Hopkins

Southern AIDS Coalition

Kathie Hiers

The AIDS Institute

Carl Schmidt and Jason Kennedy

Treatment Access Expansion Project (TAEP) & Harvard Law School

Health Law Clinic

Amy Rosenberg

AIDSWatch 2008 Sponsors



- AIDS Foundation Chicago
- Alphawood Foundation
- American Psychological Association
- Broadway Cares /Equity Fights AIDS
- CAEAR Coalition
- Gay Men's Health Crisis
- National Alliance of State and Territorial AIDS Directors
- National Minority AIDS Council



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