

until it's over
AIDSACTION

AIDS Action is the National Voice on AIDS. We represent 3,200 of the nation's leading community-based AIDS organizations and the millions of Americans they serve. We advocate for fair and effective national AIDS policies that prevent new infections, ensure access to care and fortify the search for a genuine cure.

AIDS Action 1906 Sunderland Place, NW Washington, DC 20036
P 202 530 8030 F 202 530 8031 www.aidsaction.org

Claudia French, Executive Director

Talking About AIDS so America Listens

A HANDBOOK FOR COMMUNICATING
ABOUT TODAY'S EPIDEMIC



COVER PHOTOS

(left to right)

Health and Human Services Secretary **Donna Shalala** (left) talking with **Ravinia Hayes-Cozier** (right) of the Harlem Directors Group

Public opinion researcher **Celinda Lake**

AIDS Action Associate Director of Government Affairs **Julio Abreu** (left) and Director of Government Affairs **Jeff Jacobs** (right) testifying before a Congressional appropriations committee

AIDS Action Executive Director **Daniel Zingale** briefing Vice President **Al Gore**

Tavis Smiley, Black Entertainment Television anchor and AIDS Action advisor

CONTRIBUTORS

John Barnes
Michael Bento
Steven Fisher
Jamie Fox
Peter D. Hart Research Associates, Inc.
Celinda Lake
Lake Sosin Snell Perry and Associates
Mike McKay
Vicki Shabo
Tavis Smiley
Gloria Smith
Daniel Zingale

This handbook was made available through a generous gift from the Gill Foundation.

Global AIDS and sex education research data provided by the Children's Research and Education Institute.

Design: Audrey Denson

“AIDS Action knows the modern fight against AIDS requires a communications effort rivaling that of the best political campaigns. Just like the smart candidate stays in touch with the pulse of the people, fighting today's AIDS epidemic requires the same strategy.”

Gloria Smith, Executive Director, Columbus AIDS Task Force

“Reaching out and listening to the diverse voices of the American people – Republicans and Democrats, people of faith, black and white – is how AIDS Action is helping to shape a winning message in the war on AIDS.”

Tony Braswell, AID Atlanta

“The AIDS epidemic is evolving as fast as America's media infrastructure. Adhering to a carefully researched and dynamic communications strategy is the best way today's AIDS advocates can have a voice in our diverse and competitive media culture.”

Tavis Smiley, Host, BET Tonight,
Black Entertainment Television

Talking About AIDS so America Listens

Tear out this card and use
it whenever you talk about
AIDS.

until it's over
AIDS ACTION

AIDS Action 1906 Sunderland Place, NW Washington, DC 20036

P 202 530 8030 F 202 530 8031 www.aidsaction.org

Claudia French, Executive Director



PROTECTING A NEW GENERATION FROM AIDS

“ The AIDS epidemic is quickly becoming a crisis of America's youth.

“ Today, half of the 40,000 new HIV infections each year are among people under 25.

“ While America's investment in AIDS care and research is paying off through lower death rates, our divestment from HIV prevention is creating a new epidemic for a new generation of Americans.

“ We have to stop this new epidemic so that AIDS doesn't ravage a new generation of Americans the way it did the last generation.

“ We need targeted prevention efforts that are effective at reaching the diversity of communities and people at risk for HIV and AIDS.

AMERICA'S COMMUNITY AIDS SERVICE ORGANIZATIONS - THE FRONTLINES IN THE NATION'S WAR ON AIDS

“ From the smallest church basements in the heartland to the largest urban facilities serving thousands of clients, each one of America's AIDS service organizations is a command post in the nation's war on AIDS.

“ America's community-based AIDS service providers are the frontlines in the fight against HIV and the new epidemic of infections among young people.

“ With federal health officials estimating that 300,000 Americans are HIV-positive and don't know it, local AIDS service providers are the leading organizations working to bring people into testing and counseling.

AIDS AND DRUGS: TWIN EPIDEMICS

“ With half of all HIV infections attributed directly or indirectly to substance abuse, getting dirty needles off our streets, getting people into substance abuse treatment and making the battle against illegal drug use more effective must be a top national prevention priority.

“ Needle exchange programs are proven to prevent the spread of HIV without increasing drug use. They are also a useful way to get people into substance abuse treatment.

“ It is a national tragedy that people who want to end their addiction are frequently told to stand in line.

“ We need treatment on request for anyone addicted to harmful or illegal substances.

A GREAT AMERICAN WAR ON DISEASE

“ America achieved world dominance in the 20th century through a determined and unwavering national commitment to fighting and defeating the forces that threatened peace, democracy and human rights in America and throughout the world.

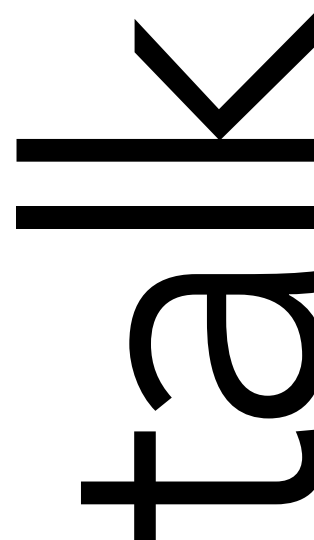
“ While the 20th century was about protecting the American people from enemies abroad, the 21st century must be also be about protecting the American people from enemies from inner-space - the deadliest viruses, bacteria and invaders of the human cell.

“ Last year, 2,000,000 Americans died from deadly diseases, more than all the wars in our nation's history. Today, cancer, heart disease, diabetes and AIDS may be the greatest threat to the health and well-being of the American people and the world.

“ The AIDS epidemic is spreading so fast in Africa that it threatens to bring down entire nations.

“ This is a war we are already beginning to win. Breakthroughs in heart disease, diabetes, AIDS and cancer research all provide hope that we will one day defeat these deadly diseases.

AIDS DOs	AIDS DON'Ts
Say "men, women and children living with HIV."	Don't call people affected by HIV "AIDS sufferers," "AIDS victims" or "AIDS orphans."
Talk about the diversity of people affected by HIV and the need to target efforts to prevent new infections and provide treatment.	Don't call AIDS a "gay" disease.
Say that everyone shares responsibility to fight the spread of HIV – local communities, national leaders, parents, physicians, schools and individuals.	Don't say that if people become infected with HIV, it's their own fault. And don't concede the value of responsibility to our adversaries.
Say that we need to fight all diseases in America and that every disease is unique and in need of a unique response.	Don't say AIDS is "special."



Talking About AIDS So America Listens

Since the first days of the epidemic, AIDS has been as much a communications and political struggle as a medical and scientific one.

Indeed, America's war on AIDS began only after we found a message that resonated with the American people, one that appealed to our nation's best sense of compassion. As a result, reason and rationality triumphed over fear and ignorance.

Today, the AIDS epidemic has shifted for better and for worse. While new life-prolonging drugs have ended the automatic death sentence of an HIV diagnosis, the decline in death has contributed to a sense that the epidemic is somehow over. In addition, there is a growing misperception that people with AIDS somehow receive "special" treatment.

To combat these new crises of complacency and misunderstanding, AIDS Action launched a groundbreaking and unique public opinion project, focusing on finding messages that re-engage the American

people, national leaders and AIDS-affected communities in the fight against a changing but continually dangerous epidemic.

More than simply a polling project, we sat down with ordinary Americans from Milwaukee to Atlanta to gain a sense of their concerns, their fears and their hopes about the fight against AIDS.

While many issues generate varying degrees of concern, AIDS Action's data-driven research has found that none is more compelling than the need to stop the 20,000 new HIV infections among young Americans each year.

Even more important, our research found that the youth prevention message increases concerns about other fronts in the fight against AIDS such as treatment, research and fairness issues.

Protecting a new generation from AIDS – a moral and societal imperative to save a new generation of young people at risk for HIV as well as a message that reinvigorates the American people in the fight against AIDS.

This handbook will help you talk about AIDS in ways that the American people and decision-makers understand and with messages that engage them and can achieve policy results. Please use this guide whenever you talk to the media, government decision-makers or your community allies.

Communications – one of our most valuable tools in the fight to end AIDS.

Sincerely,
Daniel Zingale
Executive Director

talk

“The prevention message tested strongest across the board. African Americans, unmarried parents, unmarried mothers, all mothers, and people with young kids, as well as with younger women and single people were especially responsive.”

Public Opinion Researcher Celinda Lake

Rules of the Game

Talking about AIDS doesn't have to be complicated. Navigating an epidemic with controversial political, medical, social and policy implications means that knowing how to talk about AIDS can make the difference in a fair and effective war on AIDS.

There are several basic guidelines to follow when talking about AIDS:

AIDS DOs

Use terms like “men, women and children living with HIV” or “children orphaned by AIDS.”

Talk about the diversity of people affected by HIV and the need to target efforts to prevent new infections and provide treatment.

Say that everyone shares responsibility to fight the spread of HIV – local communities, national leaders, parents, physicians, schools and individuals.

Say that we need to fight all diseases in America and that every disease is unique and in need of a unique response.

AIDS DON'Ts

Don't call people affected by HIV “AIDS sufferers,” “AIDS victims” or “AIDS orphans.”

Don't call AIDS a “gay” disease.

Don't say that if people become infected with HIV, it's their own fault. And don't concede the value of responsibility to our adversaries.

Don't say AIDS is “special.”

ing.

When talking to the press or the public, **talk in terms that ordinary Americans understand**, especially how AIDS policies will affect people in your local community or the nation.

Speak

The Facts: The Clinton Administration agrees with the science that needle exchange programs reduce HIV infection among injecting drug users but nonetheless refuses to provide federal funding to support such programs.

The Message: *It's like saying, 'we acknowledge the world is not flat yet we refuse to give Columbus the money for the ships.'*

The Facts: Under current Medicaid policy, low-income people with HIV do not qualify for benefits unless they have been diagnosed with full-blown AIDS, when treatment is less effective and more expensive.

The Message: *If automobile regulations followed the Medicaid model, airbags would only be required in cars that have already crashed.*

The Facts: The federal government is considering HIV tracking proposals that require states to collect the names of all people with HIV. At the same time, there are no plans to ensure better access to care and treatment that can delay the onset of illness.

The Message: *It's like the Titanic all over again: we're counting up all the passengers but not providing enough lifeboats.*

The Facts: The AIDS epidemic continues to affect millions of Americans and the new protease drugs are only a stop-gap measure. We must remain vigilant and continue to fund research and build public support in our search for a cure.

The Message: *AIDS isn't over. If we act like it is, it never will be.*

Protecting A New Generation From AIDS

The AIDS epidemic is quickly becoming a crisis of America's youth. Today, half of the 40,000 new HIV infections each year are among people under 25.

The advent of new protease drugs in the mid-1990s ended the automatic death sentence previously associated with an HIV diagnosis. But the new AIDS drugs that gave the gift of prolonged life have also resulted in a misperception of "cure," "end" and "over."

At the same time, risky behavior has increased and, consequently, so have HIV infections. Equally disturbing, during the same period that infections have increased, there have been no new national investments in prevention.

There is no national voice contradicting some members of a new generation of sexually active young people who think having HIV means simply taking a few pills each day.

At the same time President Clinton calls for an intensive effort to find a medical vaccine for HIV, national support for HIV prevention is stagnant. In fact, the last ambitious national prevention effort occurred in the mid-1980s, when many of today's sexually active young people were too young to even read.

From the streets of Harlem to the barrios of Los Angeles, our nation's AIDS leaders all agree that, until there's a cure, prevention is our only vaccine.

Reinvigorating national HIV prevention is not only a moral imperative, but also a political one. Prevention is the one issue that generates the most support for a strengthened national fight against AIDS.

AMERICANS STRONGLY SUPPORT SEX EDUCATION TO FIGHT AIDS

Americans were presented with two arguments about sex education:

- Supporters of sex education say that at a time when young people are being exposed to a lot of misinformation about sex, it's important that they are able to get accurate scientific information about sex and issues that involve their health such as drugs, pregnancy, AIDS, and other sexually transmitted diseases.
- Opponents say that sex education should be done in the home in accordance with the parents' own values, and not in schools where it may encourage children's curiosity and experimentation.

Americans who said supporters were more convincing: 55%

Americans who said opponents were more convincing: 27%

Other: 18%

"The window into this issue is youth. The salience of AIDS is heightened dramatically when voters think about the potential impact of HIV and AIDS on their kids and youth in general."

Celinda Lake

VOICES OF THE AMERICAN PEOPLE

"They show some person just standing there with a black screen behind them going 'Have Safe Sex.' Kids don't watch it. They're not doing commercials that are catching the eyes of teenagers."

White Milwaukee woman

"Education is the only vaccine for now."

White Milwaukee man

"I think a lot of them think they're going to live forever. I mean you're 16 – you don't think of mortality."

Atlanta African American woman about youth and AIDS

"Support what we need to do in order to make children aware of what's going on. If we need to gear more programs to our kids, we need funding to do that."

African American woman in Atlanta

"We've got to take care of the people who have it now, but we have to instruct generations to come on how to prevent from acquiring it."

White Milwaukee man, about the balance between care and prevention

POLLING DATA

- YOUTH HIV PREVENTION RESONATES MORE STRONGLY THAN ANY OTHER AIDS ISSUE

71% — Americans who say that HIV prevention is a convincing reason for an increased national investment in the fight against the AIDS epidemic overall.

71

- AMERICA WANTS YOUTH HIV PREVENTION TO PARALLEL TEEN SMOKING FIGHT

Americans were asked if a youth-focused presidential effort on HIV prevention is as important as a youth-focused anti-smoking campaign.

84% — HIV prevention equally or more important than smoking

10% — HIV prevention less important than smoking

10

84

- HIV PREVENTION REINVIGORATES CONCERN AMONG AIDS-COMPLACENT AMERICANS

Those who were less concerned about AIDS today than five years ago were informed that HIV infections are on the rise with half of them among young people.

81% — New HIV infections increased concern

10% — New HIV infections made no difference in concern

10

81



TALKING POINTS: PROTECTING OUR KIDS FROM AIDS

“ Every hour, two young Americans become newly infected with HIV.

“ While America’s investment in AIDS care and research is paying off through lower death rates, our divestment from HIV prevention is creating a new epidemic for a new generation of Americans.

“ For many young people who were too young to witness the devastation AIDS wrought in the first 15 years of the epidemic, condoms and safe sex are simply a “retro-eighties thing” book-ended between C. Everett Koop and Nancy Reagan’s wagging finger.

“ “Just say no” just doesn’t work – young people need to know what they *can* do, not only what they *can’t*.

“ We must provide young people at risk with the unvarnished **truth** about HIV as well as the sober facts about the new AIDS treatments. AIDS drugs cost \$40 a day – condoms cost a dollar.

“ Investing in prevention not only saves lives, it saves money. The 40,000 new HIV infections each year add \$6.2 billion in lifetime treatment costs to the nation’s health care bill.

“ We have to stop this new epidemic so that AIDS doesn’t ravage a new generation of Americans the way it did the last generation.

JUST THE FACTS

“ Half of the 40,000 new HIV infections in America each year are among young people.

“ Every hour, two young Americans become newly infected with HIV.

“ HIV infection rates are growing faster among adolescent women than any other group.

“ Before they reach the age of 18, more than half of females and three-fourths of males have had sexual intercourse.

“ Nearly 90% of young people don’t even think they are at risk for HIV despite the fact that they comprise half of all new infections.

America’s CBOs: Leading the War on AIDS

December 8, 1941 – The day after the gravest threat to American existence emerged off the shores of Hawaii, imagine if President Roosevelt had refused to acknowledge the attack, utter the words “Pearl Harbor” or mobilize troops to defend the American people.

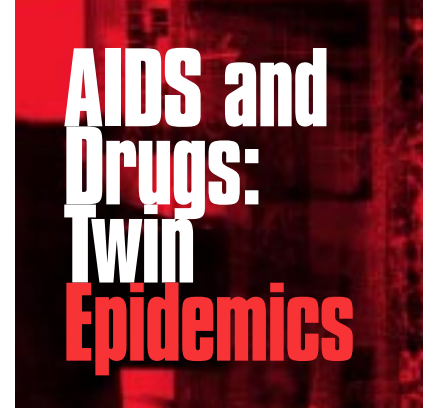
That’s just what happened 40 years later when AIDS first appeared in America.

We witnessed a President who wouldn’t acknowledge the attack, wouldn’t utter the word “AIDS” and wouldn’t mobilize public health forces to defend the American people.

Responding to desperate Americans faced with a frightening new disease, community leaders built an emergency health care infrastructure that served as the foundation for America’s response to AIDS.

Today, community-based AIDS service organizations continue to be the frontlines in the fight to slow new infection rates, to educate young people about protecting themselves from HIV and to provide services that bring people at risk into testing, counseling and treatment.

From the smallest church basements in the heartland to the largest urban facilities serving thousands of clients, each local AIDS service organization is a command post in America’s war on AIDS.



TALKING POINTS

- ⌘ America's community-based AIDS service providers are the frontlines in the fight against HIV and the new epidemic of infections among young people.
- ⌘ Local AIDS service providers are the leading organizations working to bring people into testing and counseling that stops new infections.
- ⌘ These AIDS organizations provide care and treatment that save lives and can act as a testing incentive to people at risk for HIV who are unaware of their HIV status.
- ⌘ Today's local AIDS organizations are the primary source of targeted prevention advertising and other information that give young people and other groups at risk the tools to prevent HIV infection.

JUST THE FACTS

America's community-based AIDS service organizations provide a variety of services designed to slow the progression of HIV in people who are infected. They provide services and information that get people at risk into testing and provide counseling that helps people with HIV protect the health of others.

These organizations provide services at the lowest cost possible to the diverse populations affected by AIDS, from targeted prevention campaigns to treatment services tailored to meet the needs of people in local communities.

Testing – The Centers for Disease Control and Prevention (CDC) estimates that there are 300,000 Americans who have HIV and don't even know it. Community-based AIDS service providers bring at-risk people into test-

ing and counseling so this emotionally difficult test can be performed in the easiest and most comfortable setting.

Counseling – Pre- and post-test counseling encourage those who are infected to inform past and current sex partners and provide information about access to new treatment options.

Care and Treatment – With more people living with HIV than ever before, AIDS service organizations provide access to services that help people adhere to the complex regimen of AIDS drugs so they stay healthy.

Nutrition – Access to a proper and healthy diet is critically important to the success of the drug treatments. AIDS service organizations provide low-income Americans with HIV access to nutrition counseling as well as to the food itself.

With half of all HIV infections attributed directly or indirectly to substance abuse, getting dirty needles off our streets, getting people into substance abuse treatment and making the battle against illegal drug use more effective must be a top national prevention priority.

The twin epidemics of drug abuse and AIDS are hitting communities of color particularly hard. Where people of color once made up 30% of all AIDS cases, they make up 57% of all cases today, with injecting drug use a leading cause of infection.

America's battle against illegal drugs has largely been about interdicting drugs and vilifying drug users. The best way to stop drug abuse and to interdict the flow of illegal narcotics is to reduce demand by working to bring drug users into treatment that ends addiction.

Substance abuse treatment is woefully underfunded in America with waiting lists and inadequate access. We need full funding of treatment centers so that those who want to end their addiction have the tools to do so.

While we continue to fight the battle against illegal drugs, we have to take HIV out of the equation. Needle exchange programs are scientifically proven to reduce HIV infection among injection drug users and prevent the cycle of indirect infections to their loved ones, including their children.

Drugs and alcohol cloud judgment and increase the likelihood of unsafe activity.

“If it reduces AIDS and doesn’t increase drug abuse, I don’t mind. I wouldn’t go walk in a parade for it, but it’s not really bothering me...”

(White college-educated man, Milwaukee)

ORGANIZATIONS THAT SAY NEEDLE EXCHANGE PROGRAMS STOP HIV WITHOUT INCREASING DRUG USE

- The National Institutes of Health
- The Clinton Administration
- The American Medical Association
- The American Public Health Association
- The American Bar Association



TALKING POINTS

“ Illegal drugs and alcohol are all direct or indirect accomplices to the AIDS epidemic. We need a strong fight against illegal drug use in this country that helps people break the cycle of addiction. Until we win this battle against drugs, let’s take HIV out of the equation.

“ Needle exchange programs are proven to prevent the spread of HIV without increasing drug use. They are also a useful way to get people into substance abuse treatment.

“ People who want to end their addiction are frequently told to stand in line. We need treatment on request for anyone addicted to harmful or illegal substances.

“ Without needle exchange programs, women and children are the first casualties in the fight against drug abuse.

“ Maintaining the current needle exchange ban railroads America’s most vulnerable families on a fast track to AIDS.

“ Our failure to get dirty needles off our streets increases the HIV infection rate among those most likely to depend on Medicaid for health care access.

“ Ironically, Medicaid does not provide treatment for HIV infection until a beneficiary develops full-blown AIDS, when treatment is less successful and more expensive.

**AIDS:
A Shared
Responsibility**

Celinda Lake on the public opinion data:

Responsibility is a word that AIDS Action’s focus group participants mentioned often and in several different contexts. Our central finding about “responsibility” is that the AIDS community need not fear it. Participants used “responsibility” to describe:

- society’s role in helping sick people, including people with AIDS, regardless of their own personal biases against “lifestyle choices”
- the role of individuals to help protect themselves and others
- government’s role in AIDS research, as well as treatment and care for people living with HIV and AIDS
- government’s role in education and prevention

The term “shared responsibility” resonated as a description of the compact that should exist between society and government and people affected by HIV and AIDS.

Prevention dominated the sense of shared responsibility, under the notion that everyone has a responsibility to educate children and young people about HIV.

“I don’t think there is a primary role [for educating kids]. I think it is a shared role.”

(White college-educated woman, Atlanta)



TALKING POINTS

“ The success of a new era of prevention depends upon shared **responsibility**, not finger pointing or blame, but commitment from all sectors of society — public and private, individuals and communities — to fight the spread of HIV.

“ Our nation’s leaders have a **responsibility** to fund and support community-based and national prevention efforts so that those at risk have the tools they need to avoid HIV infection.

“ Local communities have a **responsibility** to provide those at risk with the unvarnished truth about how HIV is spread.

“ Individual responsibility means that those who are HIV-positive or at risk for HIV have a **responsibility** to protect their own health and the health of others.

“ Personal **responsibility** doesn’t occur in a vacuum. People need to know the facts and have tools to protect themselves and others.

“ For four years, the federal government has made no new investments in HIV prevention. The first step toward more personal **responsibility** is a nation that encourages it.

Talking
About
AIDS

A GREAT AMERICAN WAR ON DISEASE

A NEW IMPERATIVE FOR MEDICAL RESEARCH

“ America achieved world dominance in the 20th century through a determined and unwavering national commitment to fighting and defeating the forces that threatened peace, democracy and human rights in America and throughout the world.

“ While the 20th century was about protecting the American people from enemies abroad, the 21st century must also be about protecting the American people from enemies from inner-space – the deadliest viruses, bacteria and invaders of the human cell.

“ Last year, 2,000,000 Americans died from deadly diseases, more than all the wars in our nation’s history. Today, cancer, heart disease, diabetes and AIDS may be the greatest threat to the health and well-being of the American people and the world.

“ This is a war we are already beginning to win. Breakthroughs in heart disease, diabetes and cancer all provide hope that we will one day defeat these deadly diseases.

“ A visionary nation – Republicans and Democrats – came together during the last 15 years to overcome fear and ignorance by declaring war on AIDS and investing in research, care and treatment and, as a result, today we have the first life-prolonging AIDS drugs.

“I think there’s a lot of research being done and I think that they already have developed some... drugs that will keep (HIV disease) where it’s at... Like if you’re HIV positive, you may not develop AIDS if you have the money to spend on drugs.”

(White college-educated woman, Atlanta)

AN INTERNATIONAL HOLOCAUST

“AIDS is the world’s deadliest infectious disease with about 2.28 million deaths worldwide in 1998. Nearly 95% of all people infected with HIV live in developing countries. In the year 2000, 40 million people worldwide will be infected with HIV.

“With staggering infection rates internationally, AIDS is a disease that threatens to bring down entire nations. Early in the 21st century, one in four adults will have contracted HIV in numerous African countries.

“Just as we have made an commitment internationally to fight evil regimes in Europe and elsewhere, we should make the same commitment to fight an evil virus that threatens the people of Africa and other developing regions of the world.

“While AIDS drugs have cut the death rate in much of the developed world, their high cost makes them unavailable to most developing nations, where the vast majority of men, women and children with HIV live.

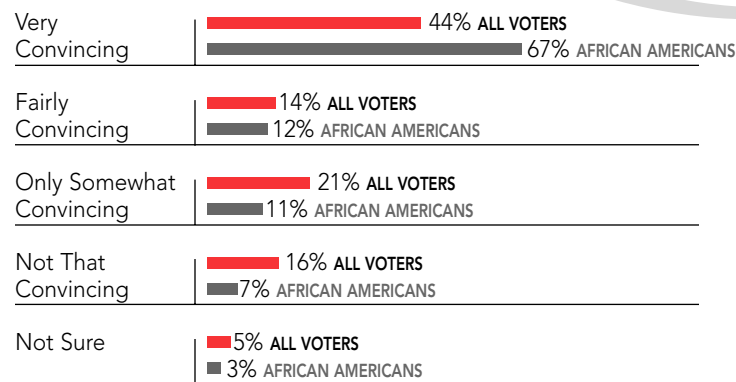
“We need better prevention efforts and an intense search for a vaccine if we want to begin to stem the tide against HIV internationally.

“According to Peter D. Hart Research Associates, a majority of Americans (54%) support increased United States assistance to help fight AIDS in Africa, including an overwhelming majority of African-Americans (83%).

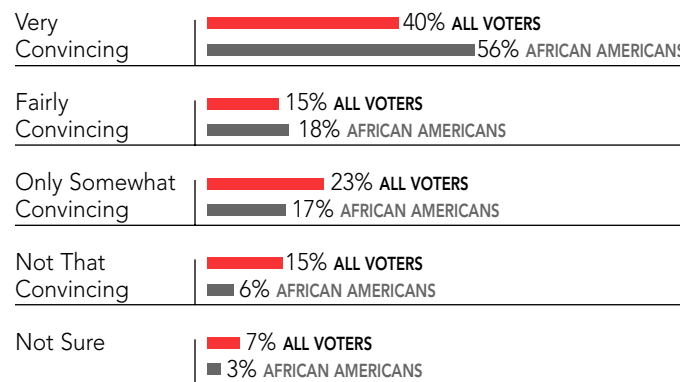
AMERICANS STRONGLY SUPPORT INTERNATIONAL AIDS EFFORT

Percentage of Americans who found the following global AIDS messages **convincing**:

“We all live on one planet, and the whole world benefits from fighting the spread of AIDS - if the epidemic has spread that much in Africa, we are fooling ourselves if we think that it won't affect the U.S. - it will, unless we do something now.”



“The AIDS epidemic is creating millions of orphans that are overwhelming the capacities of orphanages and churches, and filling the streets of many African cities. An estimated forty million children will lose a parent to AIDS by 2010.”



“I wouldn’t take the AIDS test... I don’t want to be blackballed or on the black list...”

(White college educated man, Milwaukee)

TESTING – A NEW NATIONAL IMPERATIVE

⌘ There are 300,000 HIV-positive Americans who aren’t even aware of their status, putting their health and the health of others at risk.

⌘ All people at risk for HIV must be encouraged to get tested so they can know their status and take steps to protect their own health and the health of others.

⌘ HIV testing must be made safe, swift and simple.

⌘ Anonymous testing must be made available in every corner of the nation as it provides the best incentive to get people at risk into testing so they can protect their own health and the health of others.

⌘ Mandatory testing betrays the American people’s strong opposition to forced medical testing and would only drive people at risk for HIV underground.

⌘ Enacting mandatory partner notification would also act as a testing disincentive, driving people away from the counseling that is the best way to give people the tools to inform others about their status.

NEW AIDS DRUGS – THE TRUTH

⌘ The current generation of AIDS drugs don’t work for everyone and aren’t a cure for anyone.

⌘ These drugs cost as much as buying a new car every year, require an oppressive pill-taking regimen and their long-term effectiveness is unknown.

⌘ While we need to continue to search for a genuine cure, we need a parallel effort to stop HIV infections in the first place.

⌘ Young people need to know that AIDS drugs cost \$40 a day and condoms cost one dollar and are proven to stop HIV and save lives.

⌘ The overpricing of AIDS drugs by pharmaceutical manufacturers makes these drugs readily available only to the wealthiest and best-insured Americans.

“If you’ve got a drug and it works, let’s get it tested, let’s get it out there and bring the cost down. I think they need to really get into the cost issue, because you’ve got these great drugs, but nobody can afford them.”

(African-American woman, Atlanta)

HEALTH CARE THAT’S FAIR

⌘ Under current Medicaid policy, an HIV-positive individual qualifies for benefits, including access to protease inhibitor drugs that can prevent the progression of HIV disease, only when they are diagnosed with full-blown AIDS.

⌘ In essence, the federal government is telling low-income HIV-positive Americans that they can’t receive AIDS-preventing drugs until they develop AIDS. If automobile safety regulations followed this model, air bags would only be required in cars that have already crashed.

⌘ While the protease drugs have been responsible for a halving of AIDS deaths, the real story is that this figure would be significantly lower if an entire class of Americans were not being denied access to today’s state of the art treatment and care.

listen



“ Nowhere does the Medicaid absurdity make itself more apparent than in the African American community where AIDS remains the number one killer among those age 25-44.

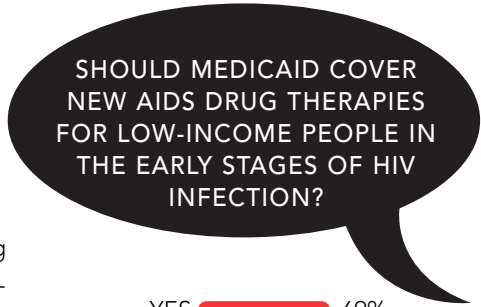
“ Reinventing Medicaid to cover healthier HIV-positive Americans would save lives and save money.

“ Every major study of protease cocktails has proven that early treatment provides the best route for preventing the onset of illness.

“ Moreover, the cost of providing drugs early would offset the exorbitant hospitalization and other medical costs that AIDS treatment incurs.

“ But Reinventing Medicaid would not just prevent AIDS, it would help prevent HIV infection in the first place by bringing HIV-positive people into treatment programs that provide education about preventing transmission to others.

AMERICA SUPPORTS HEALTH CARE THAT'S FAIR



YES 69%

NO 20%

Reporters usually cover several issues and cannot be expected to be AIDS experts. It's important to inform members of the media about the current state of the AIDS epidemic.

Don't Confuse AIDS and Gay

Many continue to think of AIDS as a gay disease. In AIDS Action's focus groups, some participants referred to AIDS as a 'gay and lesbian disease' despite the fact that lesbian sexual activity is among the least risky of all behaviors.

While HIV and AIDS today still affect gay men disproportionately, including gay men of color, the epidemic is expanding quickly among women and young people. African Americans comprise 57 percent of all AIDS cases today. And despite a drop in death among white men and women, AIDS is the leading cause of death among young black and Latino men and women.

Issues like needle exchange and inadequate access to health care largely affect communities of color and low-income Americans. And the fight against global AIDS is overwhelmingly heterosexual.

“In the initial beginning, I think it was more homosexuals [who] were affected by [AIDS]... But I think over the past few years heterosexuals and then the black – the females were also affected because, supposedly, the man was infecting the black female without her knowing it, more so than anything.”

(African American woman, Atlanta)

People with HIV Are Just That

“Person (people) living with HIV” and “men, women and children with HIV” are the most appropriate ways to describe those living with HIV disease.

“AIDS babies,” “AIDS orphans,” “AIDS victims,” and “AIDS sufferers” are among the commonly misused phrases used to describe people living with HIV. These phrases are offensive to people living with HIV as they de-emphasize humanity and prejudice the state of people’s conditions.

HIV and AIDS – The Difference in the Details

HIV is the virus that causes AIDS. As HIV slowly ravages the body’s immune system, HIV disease progresses.

AIDS is the final stage of HIV disease. Its technical definition – defined by the federal government – is a T-Cell (the most basic element of the immune system) count of less than 200 and the presence of one or more opportunistic infections.

While AIDS is commonly used as a catch-all phrase to describe the epidemic, **HIV and AIDS should be used appropriately** in medical descriptions. (e.g. never say that someone transmitted AIDS to another person.)

“**HIV disease**” is the most appropriate way to describe the continuum of HIV and AIDS.

Needle Exchanges Aren’t Giveaways

Needle exchange programs allow drug users to exchange one used syringe for one clean one. Despite misperceptions to the contrary, they do not simply give out syringes to anyone who wants one. They remove HIV-tainted needles from our streets and communities.

The Clinton Administration, The Department of Health and Human Services, the National Institutes of Health and America’s leading scientists all say that needle exchange programs are effective in reducing HIV infection without increasing drug use.

Needle exchanges also bring people into substance abuse treatment and HIV testing that can give people the tools to protect others from infection.

Why does AIDS have its own federal health care funding stream?

The Ryan White CARE Act was established in 1991 as a partnership between the federal government and local community health leaders to fortify the fight against AIDS in ways that meet the diverse needs of local communities. There is no single, uniform national approach to fighting AIDS. A local approach is the best national approach.

America’s community-based AIDS service organizations are at the frontlines in the epidemic of this deadly and communicable disease. They are providing prevention information, testing, counseling and treatment that protect the health of everyone at risk for and living with HIV.

Why is spending per AIDS death higher than other diseases?

America should never pit the dying against the dying or the suffering against the suffering. Every year, 2 million people die from disease, more than all the wars in our history. We must make a great American war on disease – all diseases – a top national priority of the 21st century.

America’s leading scientists all believe in continued investments in AIDS research. While AIDS deaths are dropping, more people are living with HIV today than ever before. Even worse, infection rates are so high in some parts of the developing world, AIDS threatens to bring down entire nations.

Everyone dreads the call from a loved one about a grandparent’s colon cancer diagnosis. But nothing is worse than a seventeen-year-old son or daughter informing a parent about his or her infection with HIV.

I'm not homophobic and I have sympathy for those addicted to drugs. But why should we spend money on a disease that can be easily prevented if people just acted responsibly?

Young people make mistakes. Human beings make mistakes. No one deserves to pay for those mistakes with their lives. No one deserves AIDS.

Personal responsibility is an important part of our fight against AIDS but it doesn't occur in a vacuum.

We have a shared responsibility to make sure every American, especially our kids, knows the unvarnished truth about how HIV is spread and how they can protect themselves and others.

An HIV-positive student has enrolled at the local public school and now he wants to participate in sports. Isn't he putting other young people at risk for HIV?

Our young people are at risk for HIV – at the rate of two new infections every hour. But infections aren't occurring on the softball field or the volleyball court. Focusing attention on settings

where HIV is not being transmitted undermines efforts to stop transmission *where it is occurring.*

Local jurisdictions should be educating young people about activities that are affecting their generation at a rate of two infections an hour instead of spending time on activities that are not resulting in HIV infection.

A local man is accused of having unsafe sex with multiple partners. What can we do to stop this man? Shouldn't we enact laws to stop people like him?

Anyone who is HIV positive and willingly exposes someone else to HIV is acting irresponsibly and is already subject to prosecution under laws such as reckless endangerment.

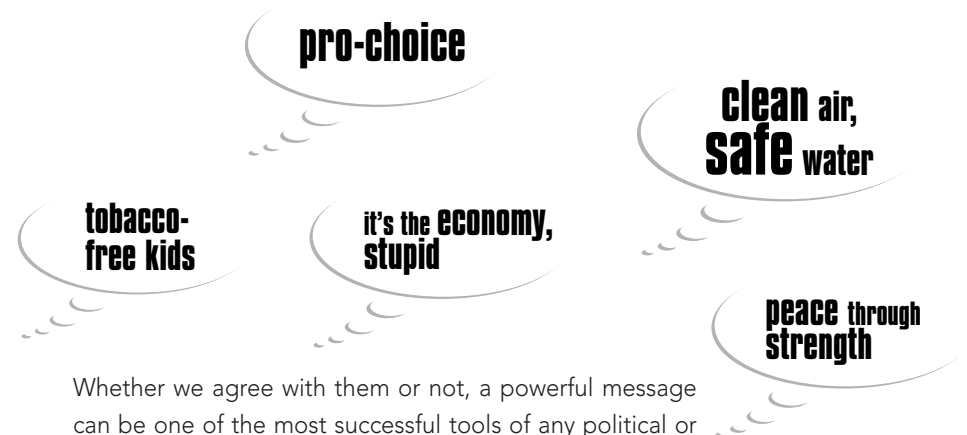
Passing laws specifically designed to punish people with medical conditions like HIV disease is unnecessary and will only scare people at risk for HIV aware from testing, fueling new infections and worsening the epidemic.

appendix



It's the first thing you learn in Politics 101:

No cause wins without a compelling message that resonates with the voters.



Whether we agree with them or not, a powerful message can be one of the most successful tools of any political or advocacy campaign. But messages succeed only when they're carefully researched, simple to understand and integrated into a broad campaign.

Successful message campaigns have helped elect presidents, pass laws, defeat bills and reinvigorate the debate around seemingly moribund advocacy movements.

The same can hold true in the fight to end AIDS.

FINDING A MESSAGE

Finding a winning message involves a methodical and complex process. AIDS Action has commissioned Lake Sosin Snell and Perry, one of America's leading public opinion strategy firms to assist us in this continuing project.

There are two primary tools used to research and uncover resonant advocacy messages.

FOCUS GROUPS – Carefully chosen individuals in groups of demographic and geographic diversity provide qualitative and incisive research into the political pulse of the American people. AIDS Action sat down with ordinary Americans from Atlanta to Milwaukee to gain a better sense of their attitudes and concerns about AIDS.

POLLING – Qualitative polling data can test messages and uncover attitudes among a scientific sample that reflects the views of the entire nation. AIDS Action tested themes from focus groups to determine the most resonant messages around AIDS.

STAYING ON MESSAGE

The successful use of a message strategy means integrating that message into as much of your communications as possible. Staying on message is just as important as finding the one that works. A well-researched advocacy message is your silver bullet – the one issue that moves the most voters and drives interest about an advocacy movement.

For example, talking about AIDS treatment programs as an incentive for HIV testing appeals to the public's support for testing as a component of prevention and, consequently, increases support for treatment programs.

ALL SHIPS RISE

An advocacy campaign built around a specific message strategy reinvigorates concern around any broad advocacy movement.

An AIDS message focused on youth prevention engages the American people more than any other issue and will not only build support for increased prevention but, because it's the one AIDS issue that resonates most strongly, it stimulates concern about AIDS overall, thus building support for care, research and discrimination issues.

learn

WINNING WITH A SUCCESSFUL MESSAGE: A CASE STUDY

PROBLEM

For decades, anti-tobacco advocates fought cigarette smoking as a broad public health measure. And for decades, those advocates were frustrated by slow progress and political reluctance to enact anti-smoking laws.

RESEARCH

After careful public opinion research, anti-tobacco advocates found that Americans had mixed feelings about government dictating what they could and couldn't do, regardless of the health consequences. But they did find that Americans were overwhelmingly concerned about youth smoking and tobacco companies that stalked children.

OUTCOME

A campaign built around the message of tobacco-free kids brought tobacco companies to their knees and ignited a national debate about smoking, resulting in new laws that banned smoking and advertising in many public places. As the result of a well-researched message campaign focused on the one smoking issue that moved voters most strongly, the tobacco advocates achieved their original goal of enacting laws to ban smoking in public places.

Organizations Contributing to AIDS Action

(AIDS Action board members in bold)

A Better Place, New York, NY
A Loving Spoonful, Vancouver, BC
Access Network, Hilton Head, SC
Action AIDS, Inc., Philadelphia, PA
African Services Committee, New York, NY

AID Atlanta

Aid for AIDS of Nevada

AIDS Action Committee, Boston, MA
AIDS Activities Coordinating Office, Philadelphia, PA
AIDS Committee of Toronto, Ontario
AIDS Community Alliance, Lancaster, PA
AIDS Community Services, Buffalo, NY
AIDS Consortium of Southeast Michigan
AIDS Coordinator's Office - City of Los Angeles
AIDS Council of Northeastern New York, Inc.
AIDS Delaware

AIDS Education and Training Centers

AIDS Foundation of Chicago
AIDS Foundation of Miami Valley, Dayton, OH
AIDS Healthcare Foundation, Los Angeles, CA
AIDS Help, Inc., Key West, FL
AIDS Housing Corporation, Boston, MA
AIDS Housing of Washington, Seattle
AIDS Ministries/AIDS Assist, South Bend, IN
AIDS National Interfaith Network, Washington, DC
AIDS Network, Madison, WI

AIDS Nutrition Service Alliance, Washington, DC

AIDS Outreach Center, Fort Worth, TX

AIDS Program Albany Medical Center, NY

AIDS Project Los Angeles

AIDS Project, Inc., Portland, ME
AIDS Research Alliance, Los Angeles, CA

AIDS Resource Center of Wisconsin

AIDS Resources, Information & Services - Santa Clara
City., San Jose, CA
AIDS Response Seacoast, Portsmouth, NH
AIDS Rochester, Inc., NY
AIDS Service Agency of North Carolina
AIDS Service Center, Pasadena, CA
AIDS Services Center, Bethlehem, PA

AIDS Services Foundation of Orange County,

Irvine, CA
AIDS Services of Dallas
AIDS Survival Project, Atlanta, GA

AIDS Task Force of Alabama
AIDS Task Force of Greater Cleveland
AIDS Task Force Richmond, IN
AIDS Task Force, Inc., Fort Wayne, IN
AIDS Treatment Initiatives, Atlanta, GA
AIDS Vancouver, BC
AIDS Volunteers Of Cincinnati
AIDS Walk Kansas City
AIDS/HIV Services Group, Charlottesville, VA
AIDServe Indiana, Inc.
Albany Medical Center/Food Positive, NY
All Souls AIDS Task Force, New York, NY
American Academy of Family Physicians, Kansas City, MO
American Association of Health Plans, Washington, DC
American Federation of Labor - Congress of Industrial
Organizations, Washington, DC
American Federation of State, County and Municipal
Employees, Washington, DC
American Nurses Association, Washington, DC
American Psychological Association, Washington, DC
Amigos Volunteers in Education Services, Houston, TX
ANGELS Foundation, Macon, GA
ARIS of Santa Clara, San Jose, CA
ARMS Clinic, Dallas, TX
Asian Pacific Islander Coalition for HIV/AIDS, Jackson
Heights, NY
Bailey House, Inc., New York, NY
Bering Omega Community Services, Houston, TX
Berks AIDS Network, Reading, PA
Bienestar Health Services, Inc., Los Angeles, CA
Bill's Kitchen - Rio Piedras, PR
Bill's Kitchen - San Juan, PR
Billy DeFrank Lesbian and Gay Community Center, San
Jose, CA
Boston Living Center
Boulder County AIDS Project
Boulder County Health Department
Bronx Community Works Ltd.
Broward House, Inc., Fort Lauderdale, FL
Cambridge Cares About AIDS, Inc., MA
Care Coordination Team, Wichita, KS
CARES, Kalamazoo, MI
CARETEAM, Myrtle Beach, SC
Catholic Charities of San Mateo, CA

Catholic Charities of The Archdiocese of San
Francisco
CBAF, Inc., Corpus Christi, TX
Central City Lutheran Mission, San Bernardino, CA
Central Florida AIDS Resources, Inc.
Central Ohio Ryan White Consortium
Chase-Brexton Health Services, Inc., Baltimore, MD
Chester County AIDS Support Services, Coatesville, PA
Chicago House & Social Service Agency, Inc.
Chicken Soup Brigade, Seattle, WA
Clark County Health Department, Jeffersonville, IN
Coalition of Labor Union Women, Washington, DC
Coastal Bend AIDS Foundation, Inc.,
Corpus Christi, TX
Colorado AIDS Project
Columbia University School of Public Health - New
York/Virgin Islands AIDS ETC
Columbus AIDS Task Force
Community AIDS Resource, Inc. (CARE RESOURCE),
Coral Gables, FL
Community Family Planning Council, New York, NY
Community Health Awareness Group, Detroit, MI
Community Health Law Project, Bloomfield, NJ
Community Healthcare Network Inc., New York, NY
Community Prescription Services, Inc., New York, NY
Community Research Initiative, Brookline, MA
Community Response, Inc., Oak Park, IL
Community Servings, Roxbury, MA
Comprehensive AIDS Program, West Palm Beach, FL
Comprehensive AIDS Resource Education,
Long Beach, CA
Comprehensive Care Center, Nashville, TN
Connecticut AIDS Residence Coalition
Connecticut Positive Action Coalition
Country Doctor Community Health Centers,
Seattle, WA
Crusader Clinic, Rockford, IL
D.C. Care Consortium
Damien Ministries, Washington, DC
Democratic National Committee, Washington, DC
Department of Health and Mental Hygiene,
Baltimore, MD
Desert AIDS Project, Inc., Palm Springs, CA
Diablo Valley AIDS Center, Concord, CA

Dolores Street Community Services,
San Francisco, CA
Doorways, Interfaith Residence, St. Louis, MO
Douglas County AIDS Project, Lawrence, KS
Elizabeth Glaser Pediatric AIDS Foundation, Santa
Monica, CA
Emory University School of Medicine -
Southeast AIDS ETC
Episcopal Church - Washington Office, DC
Escambia AIDS Services and Education, Pensacola, FL
Exponents, Inc.- Arrive Project, New York, NY
Face To Face/Sonoma County AIDS Network,
Santa Rosa, CA
FACT/AIDS Task Force of Greater Cleveland
Fenway Community Health Center, Boston, MA
Florida AIDS Action Council
Florida AIDS Consortium
Food & Friends, Washington, DC
Food for Friends, New Orleans, LA
Food for Life Network, Miami, FL
Food for Thought, Forestville, CA
Food Outreach, St. Louis, MO
Fraternity House, Inc., Escondido, CA
Friends for Life AIDS Resource Center, Memphis, TN
Gay Men's Health Crisis, New York, NY
Glendale Memorial Hospital and Health Center, CA
God's Love We Deliver, New York, NY
Good Samaritan Project, Kansas City, MO
H.C.C., Washington, DC
Harlem Directors Group
Health Education Resource Organization (HERO),
Baltimore, MD
Health Horizons of East Texas, Inc.
Hemophilia Association of New Jersey
Hetrick-Martin Institute, New York, NY
HIV Resources, Ft. Lauderdale, FL
HIVCO, Elk Grove Village, IL
Ho' Omana' Olana - Gregory House Programs,
Honolulu, HI
Hospice Foundation of America, Miami, FL
Hotel Employees and Restaurant Employees
International Union, Washington, DC
Housing Assistance, Kansas City, MO
Human Rights Campaign, Washington, DC

Hyacinth AIDS Foundation, New Brunswick, NJ
 Iniciation Comunitaria, San Juan, PR
 Interfaith AIDS Ministry of Greater Danbury, CT
 International AIDS Empowerment Project, El Paso, TX
 International AIDS Vaccine Initiative Inc., New York, NY
 Jerusalem House, Inc., Atlanta, GA
 John XXIII AIDS Ministry, Monterey, CA
 Kentuckiana People With AIDS Coalition, Inc.
 Kitchen Angels, Santa Fe, NM
 LA County Health Department
 Laguna Shanti, Laguna Beach, CA
 Lansing Area AIDS Network, MI
 Latino/as Contra Sida, Hartford, CT
 Life Force: Women Fighting AIDS, Brooklyn, NY
 Los Angeles Gay & Lesbian Services Center
 Los Angeles Shanti Foundation
 Louisiana State University Medical Center -
 Delta Region AIDS ETC
 Mama's Kitchen, San Diego, CA
 MANNNA of Southern NJ
 Marin AIDS Project, San Rafael, CA
 Maui AIDS Foundation, Wailuku, HI
 McDowell Healthcare Center, Phoenix, AZ
 Medical and Health Research Association of New York City
 Mercy Mobile Health Program, Atlanta, GA
 Metropolitan AIDS Neighborhood Nutrition Alliance
 (MANNNA), Philadelphia, PA
 Metropolitan Residential Services, Columbus, OH
 Mid Toronto Community Services, Ontario
Minnesota AIDS Project
 Momentum AIDS Project, New York, NY
 Moveable Feast - Baltimore, MD
 Moveable Feast - Fall River, MA
 Moveable Feast - Lexington, KY
 Nashville Cares
 National AIDS Fund, Washington, DC
 National Catholic AIDS Network, San Francisco, CA
 National Education Association, Health Information
 Network, Washington, DC
 National Native American AIDS Prevention Center,
 Washington, DC
 National Rural Health Association, Washington, DC
Nebraska AIDS Project
 New Mexico AIDS Services

**New York HIV Health and Human Services Planning
 Council**

New York State Department of Health - AIDS Institute
NO/AIDS Task Force, New Orleans, LA
 North Central District AIDS Coalition, Lock Haven, PA
 North County Health Services, San Marcos, CA
 North Jersey Community Research Initiative
 Northeast Florida AIDS Network
Northwest AIDS Foundation, Seattle, WA
 Office of AIDS Programs and Policy, Los Angeles, CA
 Open Arms of Minnesota
 Open Hand Chicago
 Other Options, Bethany, OK
 Outer Cape Health Services, Inc., Truro, MA
 Palmetto AIDS Life Support Services, Columbia, SC
 Peninsula AIDS Foundation, Newport News, VA
 People of Color AIDS Coalition, St. Petersburg, FL
 People With AIDS Coalition of Houston
 Persad Center, Pittsburgh, PA
 Phoenix Body Positive
 Pierce County AIDS Foundation, Tacoma, WA
 Pima County AIDS Program, Tucson, AZ
 Pittsburgh AIDS Task Force
 Planned Parenthood Action Fund, New York, NY
 Planned Parenthood Federation of America, Inc.,
 Washington, DC
 Program for Wellness Restoration, Houston, TX
 Project Angel Food, Los Angeles, CA
 Project Angel Heart, Denver, CO
 Project Food, Paris,
 Project Open Hand Atlanta
 Project Open Hand Columbus
 Project Open Hand San Francisco
 Project Outreach, Guyana, South America
 Project Response, Ft. Pierce, FL
 PWA Coalition of Broward County, Fort Lauderdale, FL
 R.A.I.N. Regional AIDS Interfaith Network, Charlotte, NC
 Rhode Island Project AIDS
 Saint Joseph's Mercy Care, Atlanta, GA
 San Francisco AIDS Foundation
 Second Helping, Gainesville, FL
 Service Employees International Union, Washington, DC
 Service To AIDS Victims Endowment Foundation,
 Kansas City, MO

Sierra AIDS Council, Angels Camp, CA
 Simon House, Detroit, MI
 South Jersey AIDS Alliance
 South Louisiana Human Resource
 Southern Arizona AIDS Foundation
 Southern Colorado AIDS Project
 Southern Tier AIDS Program, Johnson City, NY
 Special Delivery San Diego
 Special Health Resources of East Texas
 Spokane AIDS Network, WA
 St. Francis Medical Center, Morton, IL
 St. Louis Effort For AIDS
 St. Luke's Episcopal Hospital, Houston, TX
 Staten Island AIDS Task Force
 Students That Care, Inc., Stony Creek, CT
 T.O.U.C.H. of Rockland County, Inc.,
 Congers, NY
 Tampa AIDS Network
 Tapestry Health Systems, Northampton, MA
 Tarrant County AIDS Interfaith Network, Inc.,
 Fort Worth, TX
 Tarzana Treatment Center, Inc., CA
 TERROS Behavioral Health Center, Phoenix, AZ
 Test Positive Aware Network, Chicago, IL
 The AIDS Council Of Greater Kansas City
The Assistance Fund, Houston, TX
 The Center for AIDS Services, Oakland, CA
 The Damien Center, Indianapolis, IN
 The Food Chain, London,
 The Free Medical Clinic of Greater Cleveland
 The Hektoen Institute for Medical Research, L.L.C.,
 Chicago, IL
 The Momentum AIDS Project, Inc., New York, NY
The Montrose Clinic, Houston, TX
 The Open House, Cleveland Heights, OH
 The University of Texas Health Science Center -
 AIDS ETC for Texas and Oklahoma

The Xchange Point, Cleveland, OH
Treatment Action Group, New York, NY
 Tulsa CARES, OK
 Union of American Hebrew Congregations,
 New York, NY
 United States Conference Of Mayors, Washington, DC
 United Way Of Central Carolinas, Inc.
 Universidad de Puerto Rico - Puerto Rico AIDS ETC
 University of Colorado Health Science Center -
 Mountain Plains Regional AIDS ETC
 University of Illinois at Chicago - Midwest AIDS ETC
 University of Kansas School of Medicine AIDS ETC
 University of Massachusetts - New England AIDS ETC
 University of Medicine and Dentistry of New Jersey -
 New Jersey AIDS ETC
 University of Michigan HIV/AIDS Treatment Program
 University of Nevada School of Medicine
 University of Pittsburgh - Pennsylvania AIDS ETC
 University of Southern California School of Medicine/
 University of San Francisco - Pacific AIDS ETC
 University of Texas Medical Center
 University of Washington - Northwest AIDS ETC
 University of Wyoming
 Urban Coalition for HIV/AIDS Prevention Services
 Victory Programs, Boston, MA
 Virginia Commonwealth University -
 Mid-Atlantic AIDS ETC
 Volunteers of America - Kentucky and Tennessee
 WAM Foundation, Inc., Houston, TX
 Washington State Department of Health
 Wayne State University - Great Lakes to Tennessee
 Valley AIDS ETC
 Wellness House of Michigan
Western Colorado AIDS Project
 Western North Carolina Community Health Services Inc.
Whitman-Walker Clinic, Inc., Washington, DC

To add your voice to AIDS Action,
 call 202-530-8030 ext 3078
 or go to www.aidsaction.org.

