

# **Federal HIV Testing Initiatives Can Only Succeed with Expanded Healthcare, Patient and Provider Education**

September 21, 2006

The undersigned regional and national organizations released today this statement in response to new guidelines by the U.S. Centers for Disease Control and Prevention (CDC) on HIV testing in healthcare settings:

## **We support the routine offer of HIV testing**

Expanding the offer of voluntary HIV counseling and testing services in healthcare settings is good public health policy. Routinely offered HIV testing will help reach more individuals who may be unaware of their HIV-positive status as well as those who are HIV-negative but engaging in high-risk behaviors. Encouraging individuals to learn their status will help slow the spread of HIV and assist those who are HIV-positive live healthier, longer lives.

## **We support CDC's recommendation that HIV testing remain voluntary and free of coercion**

Mandated or coercive testing strategies threaten to alienate people with or at risk for HIV—the very individuals whose involvement is pivotal to successful efforts against the epidemic. By merely encouraging testing, and ensuring it is readily available and properly explained, most people will recognize its benefits and accept testing on their own volition. The new CDC guidelines' recommendation of reliance on a patient's general consent to medical services without a requirement to document the offering of the test and the right of the patient to refuse without penalty does not, especially in the context of hectic and understaffed clinics and emergency rooms, constitute voluntary, consensual testing. Non-consensual testing violates individuals' basic human rights to consent to their own medical procedures.

## **We strongly disagree with CDC recommendations to eliminate pre-test counseling and informed, written consent to testing**

An expanded focus on testing without counseling and written, informed consent will put people at risk for testing without their prior knowledge or approval—a clear violation of medical ethics and human rights.

De-linking counseling from testing is also highly problematic for many vulnerable populations. For example adolescents and young people, who are at particularly high risk of stigma and rejection from family and friends when disclosing their HIV status and who are often dependent on adults to access health care services and reimbursement, may not be fully prepared for the consequences of an HIV diagnosis in the absence of counseling and written, informed consent.

Pre-test counseling and informed, written consent to testing open conversations about HIV/AIDS between patients and providers and help dispel commonly held myths that perpetuate high-risk behaviors and stigmatizing attitudes. Open and honest communication about HIV/AIDS and the behaviors that can (and cannot) transmit HIV are instrumental to progress against the epidemic. Accurate education about HIV/AIDS must be expanded on a scale equal to or greater than the expansion of HIV testing.

**We support efforts to develop new, innovative strategies to expedite counseling and informed written consent to HIV testing**

We urge CDC to develop, pilot, and disseminate new models that offer clients much briefer means to receive context-appropriate HIV counseling in various settings. We also support the development of innovative ways to speed the attainment of written informed consent to testing. Testing conducted without these important components, however, will forgo critically important opportunities to educate at-risk individuals about HIV prevention. Several of the undersigned organizations have examples of such initiatives in use across the country and urge CDC to use the opportunity to learn about and implement our best practices.

**We call on CDC to address the needs of HIV-negative individuals at high risk of infection and people without regular access to healthcare**

We are gravely concerned that high-risk HIV-negative individuals will fail to receive the education and support they need to remain HIV free under testing procedures that exclude counseling and informed written consent. Without any counseling or attempts to link people into risk-reduction services, these high-risk negatives may be misled into falsely believing that a negative test result means that they are not at risk for HIV, thereby increasing their risk. The fact that not all populations with high rates of undetected HIV will encounter a clinical setting where they may be offered an HIV test must also be taken into consideration in attempts to reduce racial disparities in early diagnosis of HIV, and strategies to reach them must be adequately promoted and funded.

**We strongly object to the limited degree of input solicited from community stakeholders in the development of these guidelines and the secrecy with which CDC advanced and finalized them**

In March 2006, CDC developed and quietly circulated a draft of its revised HIV testing guidelines, sidestepping the typical public posting process in the *Federal Register* that generally allows 60 or more days for public comment. Instead, CDC sent its draft revised guidelines to a select group of individuals and allowed just 15 working days for the selected interested parties to register their opinions. While CDC did solicit input from clinicians and other medical providers, we believe efforts to involve people living with HIV, community advocates, social workers, outreach workers, local administrators of HIV services, and other workers responsible for conducting HIV testing were wholly insufficient. CDC has demonstrated a pattern

of secrecy and poor engagement of stakeholders in regards to HIV prevention policy. Reviving our nation's lagging HIV prevention efforts will require new, collaborative relationships that engage and involve AIDS community members.

**We call on CDC to involve greater numbers of people living with HIV, community stakeholders, and clinicians in efforts to strengthen HIV testing promotion and acceptance in the U.S.**

We agree that testing modalities can and should be improved to account for changes in technology, the growth and diversity of the epidemic, and the need to reach more people with HIV testing, prevention, and care services. We also believe CDC should take a leadership role in developing and widely disseminating proven models to deliver voluntary HIV counseling and testing services in ways that expedite counseling and the attainment of informed, written consent to testing. Federal initiatives to expand the offer of HIV testing, however, must be guided and informed by the experiences of people living with HIV/AIDS, community-based organizations, and HIV clinicians who are at the forefront of the fight against the epidemic.

**We believe that the effects and impact of routine offering of HIV tests in healthcare settings must be carefully documented and analyzed**

The effectiveness, costs, barriers, correlates of relative success and possible unintended consequences of these guidelines must be documented and characterized in whatever form these recommendations are promoted and implemented. Key questions must be answered such as how many new cases of infection are diagnosed in this way compared to other strategies, what proportion of people with newly recognized HIV are successfully linked to ongoing care and which populations are most receptive to routinely offered screening tests. The CDC must call for adequately funded operation research to track and report on the outcome and impact of these recommended practices both in themselves and as compared to alternate uses of the same resources.

**We believe testing promotion alone will not reverse the escalation of HIV/AIDS in the U.S.**

In the absence of fully accessible HIV care, treatment, and support services, and a more robust HIV prevention agenda, federal efforts to expand HIV testing promotion will ultimately fail at decreasing HIV-related morbidity, mortality, and new infections. The federal government must match its support for HIV testing with proven prevention and care strategies to adequately address the size and complexity of HIV/AIDS in the U.S. today. All testing, prevention, and care measures also must include targeted approaches to meet the needs of those at greatest risk of infection and transmission, as well as those at risk of not seeking care once diagnosed.

**We believe funding for new testing initiatives should be in addition to existing program funding**

Expanding support for the routine offer of HIV testing should not shift funds away from more targeted, community-based testing or HIV prevention programs. Indeed, Congress must appropriate a minimum \$1 billion annually for HIV prevention programs in order to begin to reduce the number of new HIV infections that occur annually in the U.S. In addition, the CDC should make clear that it expects the costs of offering routine HIV testing and counseling in healthcare settings to be borne by insurers and other payers already covering the costs of the care being sought.

**Endorsing organizations:**

1. ACT UP Philadelphia
2. African American Health Alliance (AAHA)
3. AIDS Action in Mississippi
4. AIDS Alliance for Children, Youth and Families
5. AIDS Foundation of Chicago
6. AIDS Legal Council of Chicago
7. AIDS Network, Madison, WI
8. AIDS Survival Project
9. American Medical Student Association (AMSA)
- 10.amFAR, The Foundation for AIDS Research
- 11.Brothers Uplifting Brothers, Inc., Merrillville, IN
- 12.Center for Health and Gender Equity (CHANGE)
- 13.Community HIV/AIDS Mobilization Project (CHAMP)
- 14.East Bay AIDS Advocacy Foundation
- 15.Ebony Sisters Campaigning for AIDS Prevention Education (ESCAPE)
- 16.Gay Men's Health Crisis (GMHC)
- 17.Harm Reduction Coalition
- 18.Heartland Health Outreach
- 19.HIV/AIDS Alliance of Michigan
- 20.HIV Law Project
- 21.Housing Works
- 22.Lambda Legal
- 23.Minnesota AIDS Project
- 24.National Minority AIDS Council (NMAC)
- 25.New Mexico POZ Coalition
- 26.New York State Black Gay Network
- 27.Ohio AIDS Coalition
- 28.Pediatric AIDS Chicago Prevention Initiative
- 29.Project Inform
- 30.Sexuality Information and Education Council of the United States (SIECUS)
- 31.The AIDS Institute (TAI)
- 32.The Well Project
- 33.The Woodhull Freedom Foundation