March 31, 2006

Bernard M. Branson, MD Associate Director of Laboratory Diagnostics Division of HIV/AIDS Prevention National Center for HIV, STD and TB Prevention Center for Disease Control and Prevention 1600 Clifton Road Atlanta, GA 30333

Re: Coalition Comments on CDC's Draft Revised HIV Testing Guidelines

Dear Dr. Branson:

The undersigned community-based organizations strongly support the underlying purpose of the CDC's *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health Care Settings,* to increase the number and proportion of individuals with unrecognized HIV infection who learn their HIV status as early as possible and gain access to high-quality medical care, support and prevention services. However, we have several concerns regarding the draft guidelines and process for receiving public comments and input:

- CDC has allowed just 15 working days for public comments on sweeping changes to HIV counseling and testing guidelines—this is unacceptable. We urge CDC to extend the deadline for public comments by an additional 60 working days in order to garner input from diverse stakeholders, especially people living with HIV/AIDS and their advocates.
- We are particularly concerned about the proposed abandonment of the need for specific, written, informed consent for HIV testing. Written informed consent need not be a barrier to HIV testing acceptance as proved by the experience of opt-in testing models in Illinois and elsewhere for pregnant women. Specific written consent is a standard and routine part of many other health care services and helps insure that a person is in fact aware that an HIV test will be performed and what its significance is.
- The move to recommend against pre-test prevention counseling in health care settings is disconcerting without understanding whether it will be replaced with adequate pre-test HIV prevention information. HIV testing allows an excellent opportunity to provide HIV prevention information and education, including information about condom use. We can support innovative and much briefer means of providing context-appropriate counseling in various different settings, but to totally disconnect it from screening/testing is to lose a powerful opportunity to spread accurate information about HIV, its risks and its treatment much more widely in the population.
- CDC is correct and should be commended for leaving the decision for testing rightly in the hands of the women, both for prenatal screening and newborn screening. The extra emphasis in CDC's recommendations on screening for all pregnant women throughout pregnancy is the correct approach to further prevention of mother-to-child transmission.
- Routine screening in particularly vulnerable populations, such as incarcerated people, undocumented immigrants and those with limited understanding of English, without additional and specific safeguards is dangerous and unethical. The CDC should set a high standard for understanding and respecting these and other critical, vulnerable groups.
- The provision of fully competent, sensitive counseling and linkage to care and support at the time of delivery of positive HIV test results is critical and we feel insufficiently stressed and elaborated in the draft. It is also incumbent on the CDC to take note of and address the sharp increase in demand for HIV treatment and support services that will follow any successes in expanded screening.

- The new recommendations must be written, disseminated and implemented in a manner which stresses that they are intended to complement not replace current and needed community-based HIV counseling, testing and referral programs targeting communities at particular risk. Linkages between health care institutions and community-based organizations should be specifically encouraged and incentivized.
- CDC must take deliberate steps to engage key stakeholders including people with and at-risk for HIV, testing practitioners, healthcare providers, and others in dialogues about strategies to improve HIV counseling, testing, and knowledge of serostatus. CDC should work closely with key stakeholders to launch nationally significant demonstration projects on new counseling and testing modalities based on principles of human rights, with moral and ethical integrity, as outlined below. Partial steps taken toward this thus far have value, but are insufficient.
- CDC must evaluate current testing practices across various settings to determine compliance with local, state, and federal guidelines, regulations, and laws—failure to fully understand whether and how testing guidelines, regulations, and laws are adopted into clinical practice will undermine the utility of new testing guidelines. New HIV testing protocols are likely to be ethically and effectively implemented only to the extent that they are accompanied by dedicated training programs and adequate resources.

We look forward to your response to our concerns and recommendation for an extended public comments period. To discuss any of the items addressed above, please contact Walt Senterfit (<u>WSenterfit@aol.com</u>), Julie Davids at CHAMP (jdavids@champnetwork.org), David Ernesto Munar at the AIDS Foundation of Chicago (<u>dmunar@aidschicago.org</u>), Diana Bruce at the AIDS Alliance for Children, Youth and Families (<u>dbruce@aids-alliance.org</u>) or Paul Feldman at the Health Privacy Project (<u>pfeldman@healthprivacy.org</u>).

Sincerely,

- 1) Access Community Health Network, Chicago, IL
- 2) ACT UP Philadelphia, Philadelphia, PA
- 3) AIDS Action Baltimore, Baltimore, MA
- 4) AIDS Action Committee of Massachusetts, Boston, MA
- 5) AIDS Action in Mississippi, Jackson, MS
- 6) AIDS Alliance for Children, Youth & Families, Washington, DC
- 7) AIDS Foundation of Chicago, Chicago, IL
- 8) AIDS Law Project of Pennsylvania, Philadelphia, PA
- 9) AIDS Legal Council of Chicago, Chicago, IL
- 10) AIDS Project Los Angeles, Los Angeles, CA
- 11) AIDS Survival Project, Atlanta, GA
- 12) AIDS Taskforce of Greater Cleveland, Cleveland, OH
- 13) AIDS Treatment Activist Coalition, New York, NY
- 14) AIDS Treatment Data Network, New York, NY
- 15) amfAR, The Foundation for AIDS Research, Washington, DC
- 16) American Academy of HIV Medicine, Washington, DC
- 17) American Civil Liberties Union, New York, NY
- 18) Americans for Safe Access/HIV-AIDS Survivors Union, Oakland, CA
- 19) Being Alive: People with HIV/AIDS Coalition of Los Angeles, Los Angeles, CA
- 20) Center for Health and Gender Equity, Takoma Park, MD
- 21) Center for HIV Law and Policy, New York, NY
- 22) Chicago Women's AIDS Project, Chicago, IL

- 23) Community Education Group, Washington, DC
- 24) Community HIV/AIDS Mobilization Project (CHAMP), New York, NY
- 25) FCAN (Families' and Children's AIDS Network), Chicago, IL
- 26) Gay Men's Health Crisis, New York, NY
- 27) Harm Reduction Coalition, New York, NY
- 28) Health People, Bronx, NY
- 29) Health Privacy Project, Washington, DC
- 30) Heartland Health Outreach, Chicago, IL
- 31) HIV/AIDS Law Project, Phoenix, AZ
- 32) HIVictorious, Inc., Madison, WI
- 33) Housing Works, Brooklyn, NY
- 34) Human Rights Campaign, Washington, DC
- 35) INOVA Juniper Program, Springfield, VA
- 36) International Community of Women Living with HIV and AIDS, Washington, DC
- 37) Lambda Legal Defense and Education Fund, New York, NY
- 38) Legal Action Center, New York, NY
- 39) Lifelong AIDS Alliance, Seattle, WA
- 40) National Association of People with AIDS, Washington, DC
- 41) National Minority AIDS Council, Washington, DC
- 42) New Mexico Poz Coalition, Albuquerque, NM
- 43) New York AIDS Coalition, New York, NY
- 44) North Carolina Harm Reduction, Inc., Jamestown, NC
- 45) Ohio AIDS Coalition, Columbus, OH
- 46) Project Inform, San Francisco, CA
- 47) Reproductive Health Technologies Project, Washington, DC
- 48) R.U.1.2? Queer Community Center, Burlington, VT
- 49) Search for a Cure, Boston, MA
- 50) Sexuality Information and Education Council of the United States (SIECUS), Washington, DC
- 51) Sisterhood Mobilized for AIDS/HIV Research and Treatment, Inc., New York, NY
- 52) South Carolina Campaign to End AIDS, Columbia, SC
- 53) Test Positive Aware Network, Chicago, IL
- 54) The Woodhull Freedom Foundation, Washington, DC