

June 12, 2009

Reference Committee E
American Medical Association House of Delegates
515 N. State Street
Chicago, IL 60654

To the Staff of Reference Committee E:

We, the undersigned, are writing to express our concern over Resolution 517 before the American Medical Association House of Delegates. The Resolution, proposed by the North Carolina Delegation, supports mandatory HIV testing for all pregnant women who have not received testing before labor. The proposal calls for the elimination of informed consent in testing when all evidence demonstrates that mandatory testing is unnecessary, counterproductive to the goal of HIV prevention, and violative of patient rights.

Significant research demonstrates that consent and pre-test counseling are not barriers to testing.¹ At the recent 2008 National Summit on HIV Diagnosis, Prevention and Access to Care, a number of health care providers from busy hospital and clinic settings reported high rates of HIV testing uptake in expanded rapid test programs that included not only streamlined pre-test counseling and written documentation of consent.² Providing information about testing is *more* likely to encourage pregnant women to accept testing, rather than deter it.³ A number of successful models around the country demonstrate that it is readily possible to increase HIV testing without abandoning safeguards that ensure that testing is informed and voluntary. Massachusetts, which requires written informed consent for all HIV testing, has virtually eliminated perinatal transmission, with 0 cases in 2006.⁴

¹ See, e.g., Kaiser Family Foundation, Kaiser Public Opinion Spotlight, *Attitudes about Stigma and Discrimination Related to HIV/AIDS* (2006), at <http://www.kff.org/spotlight/hivUS/index.cfm> (concluding that the primary reason people reported not getting tested was because they didn't think they were at risk, not because of a signed consent form); J. Omi, New York City Health and Hospitals Corporation, *Integration of HIV Testing Within Medical Care in a Large Public Hospital System*, Nov. 2008 Slide presentation, 2008 National Summit on HIV Diagnosis, Prevention and Access to Care (Nov. 19, 2008), at http://www.hivforum.org/storage/hivforum/documents/HIV%20Summit/Presentations/1120_tr_a_3_01_aberg_trac k.pdf (concluding that “[w]ritten informed consent has not been a significant barrier to achieving exceptional increases in the number of unique patients testing for HIV”).

² See, e.g., A. Hilley, J. Bell-Merriam, S. Criniti, E. Aaron & S. Garg, *Implementing Routine HIV Testing in the Emergency Department of an Urban University Hospital*, Nov. 2008 Poster presentation (Poster 101), 2008 National Summit on HIV Diagnosis, Prevention and Access to Care (Nov. 19-21, 2008), at http://www.hivforum.org/storage/hivforum/documents/HIV%20Summit/2008%20National%20Summit%20Posters/101_aaron.pdf; Omi, (2008), *supra* note 1.

³ Surveys about pre-natal HIV testing confirm that providing greater information about HIV testing and the benefits of testing is more likely to encourage people to accept testing. See, e.g., R. Kropp *et al.*, Unique Challenges to Preventing Perinatal HIV Transmission Among Hispanic Women in California: Results of a Needs Assessment, AIDS EDUCATION & PREVENTION 17, 22 (2005); M.I. Fernandez *et al.*, Acceptance of HIV Testing During Prenatal Care, 115 PUBLIC HEALTH REPORTS 460-468 (2000).

⁴ Massachusetts STD, HIV/AIDS and Viral Hepatitis Surveillance Report: 2007, Massachusetts Department of Health 9 (2007).

Other successful models of expanded testing that retains necessary safeguards are:

- The “Expanded HIV Testing Initiative” undertaken by the New York Health and Hospitals Corporation (HHC), which, as the largest municipal health care delivery system in the United States, involves nearly 5 million annual visits and 19,000 patients with HIV infection in care.⁵ New York law requires pretest and post-test counseling and written proof of consent. As the CDC knows from its close tracking of this initiative, HHC has substantially increased the number of individuals tested for HIV since 2006. The target was 150,000 per year. In FY 2008, the HHC documented 160,900 tested. In addition, the number of positive HIV tests has more than doubled since FY 2004, to 1,863 in FY 2008.⁶ In fact, in a November, 2008 summary of expanded testing activities across the country, the CDC reported the most impressive statistics from New York. While New York has successfully adapted and streamlined pre-test and post-test counseling, with patient documentation of informed consent, to the needs of individuals presenting for care, the CDC noted negligible testing increases generally across the country and in many states with no such patient protections.⁷
- Kaiser Permanente (KP)—the nation’s largest HMO, and a leading integrated health care system of 30 medical centers, 431 medical offices, and 12,000 physicians—provides a compelling refutation of the position that counseling and informed written consent are a time-consuming barrier to HIV diagnosis and care. KP’s philosophy is that HIV testing is a process that includes an antibody test with pre-test and post-test counseling, patient education, procedures to handle newly identified cases, convey test results, and discuss risk behavior, sexuality, and STD testing. Counseling and the frequency of testing are determined individually. Ninety percent of KP’s HIV patients are in care within 120 days of diagnosis, and their mortality rate is lower than the national average.⁸
- Authors of one study found that routinely recommending HIV counseling and testing can be feasible and effective in an emergency department setting, despite the time constraints present in that setting, and concluded that emergency room testing can be increased by streamlining counseling and providing some information in writing, as well as by involving non-physician staff in counseling.⁹

⁵ J. Omi (2008), *supra* note 1.

⁶ B. Branson, Centers for Disease Control and Prevention, *Overview of Routine/Expanded HIV Testing in the US*, Slide presentation, 2008 National Summit on HIV Diagnosis, Prevention and Access to Care (Nov. 19, 2008); *see also* NYC Health and Hospitals Corporation, *Rapid Testing and More Routine Testing Reaches Patients Not Commonly Known to Be at Risk, Including More Women and Teens*, Oct. 3, 2006, at <http://www.nyc.gov/html/hhc/html/pressroom/press-release-20061003.shtml> (reporting HHC increased the number of patients tested in HHC hospitals by 63% in 2006).

⁷ B. Branson (2008), *supra* note 6.

⁸ Information provided at the 2006 National Summit on Opportunities for Expanding HIV Diagnosis, Prevention, and Access to Care in the United States (Nov. 29-30, 2006) by Dr. Michael Horberg, Kaiser Permanente’s Director of HIV/AIDS Policy, Quality Improvement, and Research, at <http://www.hivlawandpolicy.org/resourceCategories/view/10>. With over 16,000 active HIV positive patients in care, including more than 200 patients 19 years old or younger, Kaiser Permanente (KP) is the second largest provider of HIV care in the U.S. *Id.*

⁹ R. Rothman, Current Centers for Disease Control and Prevention Guidelines for HIV Counseling, Testing, and Referral: Critical Role of and a Call to Action for Emergency Physicians, 44 ANNALS OF EMERGENCY MEDICINE 31 (2004).

The fact is, it is health care providers' failure to offer a test, rather than informed consent, that remains a barrier to eliminating mother-to-child transmission. A 2002 CDC report stated that, "increases in pre-natal HIV testing rates . . . were probably associated with a greater likelihood that (women) were offered HIV testing during prenatal care."¹⁰ The vast majority of women who are offered HIV testing agree to it, and those who do not generally cite institutional barriers, such as scheduling.¹¹ This indicates that 100% testing rates could be best achieved by eliminating institutional barriers, rather than informed consent.¹²

Numerous medical and public health authorities reject mandatory HIV testing of pregnant women. In April 2009, the U.S. Public Health Service Task Force Perinatal Guidelines Working Group issued a revised version of its Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States. The Guidelines strongly affirm the right of pregnant women to control medical decision-making, and state that "Coercive and punitive policies are essentially counterproductive in that they may undermine provider-patient trust and could discourage women from seeking prenatal care and adopting health behaviors that optimize fetal and neonatal well-being."¹³ Similarly, the American College of Obstetrics and Gynecologists calls mandatory testing "problematic," "difficult to defend ethically," and "inappropriate," noting that, "mandatory testing may compromise the ability to form an effective physician-patient relationship at the very time when this relationship is critical to the success of treatment."¹⁴ Mandatory testing also conflicts with the Centers for Disease Control's *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings*, which explicitly states that, "HIV testing must be voluntary and free from coercion. No woman should be tested without her knowledge."¹⁵

We would applaud any efforts to increase HIV testing rates among pregnant women by requiring health care providers to *offer* testing to all pregnant women. Interestingly, however, we've received information that North Carolina has implemented mandatory testing because half of all physicians were not complying with the existing requirement to offer testing to pregnant women. This is a disturbing breach of physician responsibility that clearly needs to be addressed. It also raises a question of why the failure of one mandate means that we should simply add another mandate—

¹⁰ Centers for Disease Control and Prevention, *HIV Testing Among Pregnant Women—United States and Canada, 1998-2001*, 51 MMWR Weekly 1013-1016 (Nov. 15, 2002), available at <http://www.cdc.gov.mmwr/preview/mmwrhtml/mm5145a1.htm>; *see also* HIV Testing: Pregnant Women and Newborns, HIV Law Project 2 (2009).

¹¹ M. I. Fernandez et al, The Perinatal Guidelines Evaluation Project. Acceptance of HIV testing during prenatal care, 115 Public Health Reports 460-468 (Sep.-Oct. 2000); *see also* HIV Testing: Pregnant Women and Newborns, *supra* note 10 at 2.

¹² *See* HIV Testing: Pregnant Women and Newborns, *supra* note 10 at 2.

¹³ U.S. Public Health Service Task Force, Perinatal HIV Guidelines Working Group, *Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-Infected Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in the United States*, Apr. 29, 2009, at 1.

¹⁴ American College of Obstetrics and Gynecologists, Committee Opinion 389 (2007).

¹⁵ Centers for Disease Control and Prevention, *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings*, 55 MMWR RR-14 (Sept. 22, 2006).

particularly one that compromises the physician-patient relationship, decreases the quality of care patients receive, and violates their right to informed consent. The most reasonable response to this problem is to create or enforce existing mandates that physicians offer HIV testing to pregnant women. The North Carolina delegation's proposed resolution, however, seems to indicate an inappropriate willingness to accept physicians' neglect of their mandated responsibility to offer HIV testing and to discuss care with their patients—a minimum component of proper medical care.

We urge the AMA to reject Resolution 517, and to instead focus on interventions with proven success at decreasing perinatal transmission rates—offering voluntary testing to all pregnant women, as well as increasing HIV education and counseling for all patients.

Sincerely,

The Center for HIV Law and Policy

AIDS Foundation of Chicago

The AIDS Institute

AIDS Law Project of Pennsylvania.

AIDS Taskforce of Greater Cleveland

American Civil Liberties Union AIDS Project

American Civil Liberties Union Reproductive Freedom Project

Community HIV/AIDS Mobilization Project (CHAMP)

HIV/AIDS Legal Services Alliance (HALSA)

HIV Law Project

Human Rights Watch

Lambda Legal

Legal Action Center

National AIDS Fund

National Association of People With AIDS (NAPWA)

U.S. Positive Women's Network

Women Organized to Respond to Life Threatening Disease (WORLD)

Women's Initiative to Stop HIV (WISH-NY)