

8.1 Routine Universal Screening for HIV

Physicians' primary ethical obligation is to their individual patients. However, physicians also have a long-recognized responsibility to participate in activities to protect and promote the health of the public. Routine universal screening of adult patients for HIV helps promote the welfare of individual patients, avoid injury to third parties, and protect public health.

Medical and social advances have enhanced the benefits of knowing one's HIV status and at the same time have minimized the need for specific written informed consent prior to HIV testing. Nonetheless, the ethical tenets of respect for autonomy and informed consent require that physicians continue to seek patients' informed consent, including informed refusal of HIV testing.

To protect the welfare and interests of individual patients and fulfill their public health obligations in the context of HIV, physicians should:

- (a) Support routine, universal screening of adult patients for HIV with opt-out provisions.
- (b) Make efforts to persuade reluctant patients to be screened, including explaining potential benefits to the patient and to the patient's close contacts.
- (c) Continue to uphold respect for autonomy by respecting a patient's informed decision to opt out.
- (d) Test patients without prior consent only in limited cases in which the harms to individual autonomy are offset by significant benefits to known third parties, such as testing to protect occupationally exposed health care professionals or patients.
- (e) Work to ensure that patients who are identified as HIV positive receive appropriate follow-up care and counseling.
- (f) Attempt to persuade patients who are identified as HIV positive to cease endangering others.
- (g) Be aware of and adhere to state and local guidelines regarding public health reporting and disclosure of HIV status when a patient who is identified as HIV positive poses significant risk of infecting an identifiable third party. The doctor may, if permitted, notify the endangered third party without revealing the identity of the source person.
- (h) Safeguard the confidentiality of patient information to the greatest extent possible when required to report HIV status.

AMA Principles of Medical Ethics: I,VI,VII

Background report(s):

CEJA Report 3-A-16 Modernized *Code of Medical Ethics*

CEJA Report 3-A-10 Amendment to E-2.23 "HIV Testing"

CEJA Report 4-I-07 Amendment to E-2.23 "HIV Testing"

CEJA Report C-A-92 Confidentiality of HIV Status on Autopsy Reports

CEJA Report B-I-86 Statement on AIDS

REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 3-A-10

Subject: Amendment to E-2.23, “HIV Testing”
(Resolution 517, A-09)

Presented by: John W. McMahon, Sr., MD, Acting Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Madelyn E. Butler, MD, Chair)

1 MANDATORY HIV TESTING DURING LABOR

2
3 This report is submitted in response to Resolution 517 (A-09, HIV Testing During Labor),
4 introduced by North Carolina Delegation, which asked the American Medical Association (AMA)
5 to support state policies that seek mandatory rapid HIV testing for “all pregnant women in labor
6 with no record of an HIV test during the current pregnancy.” Because mandatory HIV testing—i.e.,
7 testing without specifically informing the patient or permitting refusal of testing—is not consistent
8 with current AMA policies, the Council on Ethical and Judicial Affairs (CEJA) was asked to
9 review the proposed policy. Based on its review of the most up-to-date epidemiologic data
10 available, with assistance from the Council on Science and Public Health, and of the ethical
11 analysis that informs current policies, CEJA concludes that there are currently no compelling
12 reasons to issue new policy specifically relating to intrapartum testing for HIV that recommends
13 mandatory HIV testing. CEJA recommends that existing House policies be reaffirmed and that
14 editorial changes as noted below be made to clarify CEJA Opinion E-2.23, “HIV Testing.”
15

16 BACKGROUND

17
18 The primary goal of rapid HIV testing during labor is to identify HIV+ women whose serostatus
19 was not previously known so that appropriate interventions can be offered to reduce the risk of
20 mother-to-child transmission of HIV. Without intervention, the risk for perinatal transmission is 14
21 to 25 percent in developed countries.¹ Transmission rates vary with the prevalence of different risk
22 factors, including breastfeeding, premature birth, nutritional deficiencies, obstetrical practices, and
23 maternal viral load.² According to the most recent data available, between 100 and 200 infants are
24 infected with HIV each year in the United States, with perinatal transmission the commonest route
25 of infection.³ While it is generally believed that intrapartum vertical transmission accounts for the
26 greater number of perinatal infections,² the picture is complicated by the fact that it can be difficult
27 to determine which children acquire HIV in utero and which acquire the infection during labor and
28 delivery.⁴ Risk of intrapartum vertical transmission is also affected by whether the woman received
29 antiretroviral therapy (ART) prenatally.
30

31 Prevention of mother-to-child transmission is most effective when ART is initiated during
32 pregnancy and continued through delivery for the mother and administered to the newborn after

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1 birth and is the standard of care recommended by the American Academy of Pediatrics (AAP), the
2 American College of Obstetricians and Gynecologists (ACOG), and the American Academy of
3 Family Physicians (AAFP) along with scheduled cesarean delivery (when indicated) and avoidance
4 of breastfeeding.⁵⁻⁷

5
6 ART can significantly reduce HIV infection in newborns. In one population of high-risk women, a
7 three-part regimen of prenatal, intrapartum, and postnatal ART was shown to reduce mother-to-
8 child transmission from 19.4 percent to 3.3 percent.⁸ Abbreviated regimens were also found to be
9 highly effective, reducing transmission to 9.4 percent when ART was administered intrapartum and
10 postnatally (i.e., approximately 60% reduction) and to 11.9 percent when ART was administered to
11 the newborn only (50% reduction).

12
13 As Resolution 517 (A-09) notes, the main risk factor for mother-to-child transmission of HIV is the
14 pregnant women's lack of awareness of their HIV status. In the U.S., approximately 25 percent of
15 HIV+ individuals do not know their HIV status.³ Uptake of HIV testing among pregnant women
16 differs depending on the testing approach used, with "opt-in" testing proving less effective than
17 "opt-out" testing. Under the "opt-in" approach, in which the woman is provided HIV counseling
18 and must give specific consent to be tested, testing rates have ranged from 25 to 83 percent. In
19 comparison, testing rates under the opt-out approach, in which the woman is told that HIV testing
20 will be included among standard prenatal tests unless she specifically declines to be tested, have
21 ranged from 71 to 98 percent.^{1,9-11} In light of these findings, in 2006 the Centers for Disease
22 Control and Prevention (CDC) updated its guidelines to recommend routine opt-out HIV screening
23 for all pregnant women and the offer of opt-out screening with a rapid HIV test for women whose
24 status is unknown at the time of labor.¹²

25 26 CURRENT AMA POLICY

27
28 Historically, the AMA has opposed mandatory HIV testing for the general population and has
29 recognized only a very limited number of circumstances in which it may be appropriate.¹³ Current
30 House policy recommends routine, voluntary screening for all pregnant women¹⁴ and consideration
31 of rapid HIV testing of newborns with the mother's consent when maternal HIV status is not
32 known.¹⁵ While recognizing that "treatment of HIV-infected pregnant women with appropriate
33 antiretroviral therapy can reduce the risk of transmission of HIV to their infants," policy affirms
34 that "[t]he final decision about accepting HIV testing remains the responsibility of the woman."¹⁴
35 Policy similarly affirms that authority to accept or reject recommended ART for herself or her
36 infant remains with the woman.¹⁴ Existing policy further recommends that where safe alternative
37 nutrition is available, all HIV-positive women should be counseled not to breastfeed or donate
38 breast milk.¹⁶

39
40 Current ethics policy likewise provides that physicians should seek patients' informed consent
41 prior to HIV testing and should respect a patient's refusal to be tested.¹⁷ This policy parallels the
42 CDC's opt-out policy in regard to universal HIV testing. It permits nonvoluntary testing only in
43 very limited circumstances.

44 45 ETHICAL CONSIDERATIONS

46
47 Decisions about HIV testing carry significant implications for core ethical values, including
48 physicians' commitments to respect for patient autonomy and the primacy of patient well-being.¹⁸
49 The potential benefits of mandatory HIV testing of women in labor must be carefully balanced
50 against the harms to such core values that could result from condoning testing without consent.

1 Mandatory HIV testing for any targeted population, including women in labor, is ethically
2 justifiable only when the expected benefits outweigh the anticipated harms.

3 Respect for patient autonomy is one of the cornerstones of medical ethics; it is a foundation of the
4 patient-physician relationship and underlies physicians' ethical obligation to seek informed consent
5 for medical interventions. Mandating HIV testing without patient consent (or informed refusal)
6 would undermine physicians' ability to uphold this core value and is in conflict with existing
7 policies supporting patients' rights to self-determination and voluntary consent for medical
8 interventions.^{19,20} Moreover, to serve the intended public health goal of mandatory intrapartum
9 testing, physicians must not simply perform HIV testing without consent or after refusal, but also
10 be prepared to administer ART to both the woman and to the newborn against the woman's wishes.

11
12 Further, in promoting the interests of the soon-to-be-newborn over those of the woman in labor,
13 mandatory intrapartum HIV testing would contravene physicians' duty to regard responsibility to
14 the patient as paramount.²¹ It is not consistent with modern ethics to allow beneficence-based
15 decision-making on the behalf of the fetus/newborn trump the autonomous decision of the pregnant
16 woman. Physicians have a duty to minimize risks of harm to not just the fetus or newborn, but to
17 the woman in labor as well and should appreciate the risk of social and psychological harm to the
18 woman.²² In the U.S., misconceptions about HIV/AIDS are still widespread²³ and fear of social
19 stigma remains a concern.^{1,24} And even if a rapid test result ultimately proves to be a false positive,
20 the patient is likely to experience some psychological trauma.¹ This trauma may be particularly
21 severe for women with limited income and access to health care, as is often the case among HIV-
22 positive women.²⁵

23
24 Mandatory HIV testing also carries significant ethical implications for appropriate implementation.
25 We concur with the observation of the (then) Council on Scientific Affairs in its 2001/2002 report
26 on universal screening of pregnant women for HIV that identifying HIV-positive individuals also
27 ethically requires that they be provided appropriate follow-up in medical care and social services.²
28 The report further notes that difficult questions would arise regarding whether a individual
29 identified as HIV-positive through mandatory screening could be forced to submit to ART, which
30 is complex and requires active participation by patient and physician, as well as what ethical and
31 legal consequences should follow if the individual refuses therapy. Opt-out policies are widely
32 endorsed by key institutions, including the CDC,¹² AAFP,⁷ AAP,⁵ and ACOG.²⁷ States too have
33 consistently supported voluntary testing, in opt-out or opt-in policies. Of the 27 states that have
34 statutes addressing prenatal HIV testing, 19 have provisions specific to testing during labor of
35 women with unknown or undocumented HIV status.²⁸ Of states that address intrapartum testing
36 specifically, 16 have adopted opt-out policies, while three require that physicians offer the test and
37 receive opt-in consent. With the exception of North Carolina, where a newly enacted statute
38 appears to permit testing without a woman's consent, none have adopted mandatory HIV testing
39 for women in labor.

40 41 CONCLUSION

42
43 Given these considerations and in light of data both on the current rate of mother-to-child
44 transmission of HIV as well as the success rate of opt-out universal HIV testing, we conclude that
45 mandatory rapid HIV testing of woman in labor is a disproportionate response to the goal of
46 protecting the interests of fetuses and infants at risk for HIV infection.

47
48 In CEJA's view, a more ethically appropriate approach would seek to build on the successes of opt-
49 out policies that have already achieved high screening rates. Such efforts may include enabling
50 health care professionals to proactively overcome barriers, such as differences in language,

1 misperceptions about risk status, lack of time for counseling and testing, and state regulations
2 requiring separate written informed consent.^{12,29} Other policies that increase the availability and
3 accessibility not only of HIV testing, but also of subsequent counseling and treatment may further
4 encourage women to learn their HIV status. And at an individual level, physicians should strongly
5 recommend HIV testing to all pregnant women, including those who go into labor without knowing
6 their serostatus. Studies indicate that physician encouragement has a positive influence on a
7 woman's decision to get tested.¹²

8
9 RECOMMENDATIONS

10
11 CEJA does not find that there are compelling reasons to issue new AMA policy supporting
12 mandatory rapid HIV testing for women in labor with unknown serostatus. The Council therefore
13 recommends that the following be adopted in lieu of resolution 517 (A-09), and that the remainder
14 of this report be filed.

- 15
16 1. That our AMA reaffirm Policy H-20.918, "Maternal HIV Screening and Treatment to Reduce
17 the Risk of Perinatal HIV Transmission", in lieu of Resolution 517 (A-09).
18
19 2. That Opinion E-2.23, "HIV Testing," be amended as follows:

20
21 Physicians' duties to promote patients' welfare and to improve the public's health are fostered
22 by routinely testing their adult patients for HIV. Physicians must balance these obligations with
23 their concurrent duties to their individual patients' best interest by following the guidelines
24 below:

- 25
26 (1) In order to protect patients, avoid injury to third parties, and promote public health,
27 physicians should support routine universal screening for HIV with opt-out provisions.
28 ~~Physicians should support routine HIV testing procedures in order to protect patients,~~
29 ~~avoid injury to third parties, and promote public health.~~
30
31 (2) Although ~~While~~ medical and social advances may have minimized the need for specific
32 written consent prior to HIV testing, the ethical tenets of respect for autonomy and
33 informed consent require that physicians should continue to seek patients' informed
34 consent to undergo any form of medical treatment, including refusal of HIV testing.
35 Given the potential benefits to a patient (and the patient's intimate others) of knowing
36 his/her HIV status, it is appropriate for physicians to make efforts to persuade reluctant
37 patients to be screened. Physicians should, however, respect the decision of a patient
38 who "opts out." Unless required by law, patients' consent to HIV testing does
39 not need to be documented in writing (unless required by law), although, However, the
40 conversation concerning testing should be documented in the patient's chart. It is
41 justifiable to test patients without prior consent only in limited cases where the harms
42 to individual autonomy are offset by significant benefits to known third parties. Such
43 exceptions include testing for the protection of occupationally-exposed health care
44 professionals or patients.
45
46 (3) Physicians must work to ensure that patients identified as being HIV positive receive
47 appropriate follow-up care and counseling.
48
49 (4) Physicians must comply with all applicable disease reporting laws while taking
50 appropriate measures to safeguard the confidentiality of patients' medical information
51 to the extent possible.

- 1 (5) Physicians must honor their obligation to promote the public's health by working to
2 prevent HIV-positive individuals from infecting third parties within the constraints of
3 the law. If an HIV-positive individual poses a significant threat of infecting an
4 identifiable third party, the physician should:
- 5 (a) notify the public health authorities, if required by law;
6
7 (b) attempt to persuade the infected patient to cease endangering the third party; and
8
9 (c) if permitted by state law, notify the endangered third party without revealing the
10 identity of the source person. (I, IV, VII)

11
12 (Modify HOD/CEJA Policy)

Fiscal Note: Staff cost estimated at less than \$500 to implement.

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REPORT OF THE COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS*

CEJA Report 4-I-07

Subject: Amendment to Opinion E-2.23, "HIV Testing"

Presented by: Mark A. Levine, MD, Chair

Referred to: Reference Committee on Amendments to Constitution and Bylaws
(Jane C.K. Fitch, MD, Chair)

1 INTRODUCTION

2
3 This report is submitted to update Ethical Opinion E-2.23, "HIV Testing," in response to
4 Resolution 2-A-07, "HIV Testing," and Board of Trustees Report 1-A-07, "Ethical and Legal
5 Issues in Responding to Occupational HIV Exposure." CEJA welcomes this opportunity to revisit
6 its policies on HIV testing, especially in light of new guidelines published by the Centers for
7 Disease Control and Prevention (CDC) that call for the general adoption of routine HIV testing.
8 This Report provides guidelines in support of routine HIV testing while continuing to advocate for
9 protection of patient autonomy and privacy.

11 EMERGENCE OF HIV INTERVENTIONS

12
13 Traditionally, public health interventions for infectious diseases have included screening for
14 infection, reporting infected persons to local public health authorities, and tracing the contacts of
15 those exposed to infected individuals for purposes of notification, testing, and potential treatment.¹
16 However, reliance on these practices has historically been minimized in the treatment of
17 HIV/AIDS due to the once prevailing attitude that HIV/AIDS represented a disease unlike other
18 infectious diseases and therefore warranted exceptions from standard public health interventions.²

19
20 One rationale supporting the differential treatment for HIV/AIDS was the fear that traditional public
21 health interventions would be undermined by prevailing social circumstances. Unlike other
22 infectious diseases that had been effectively treated through public health interventions, such as
23 tuberculosis or smallpox, there was a palpable social stigma attached to persons infected with HIV,
24 particularly among individuals belonging to certain disenfranchised populations.³ Many
25 individuals at high risk for contracting HIV feared that positive HIV test results would subject them
26 to stigmatization and discrimination.⁴ This perception was accentuated by the limited
27 confidentiality protections afforded at that time. Public health officials therefore feared that
28 patients might not seek HIV testing if confidentiality were not guaranteed.⁵

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1 More significantly, the benefits to be derived through the application of traditional public health
2 measures, such as routine screening, were largely outweighed by the potential harms to patients
3 during the early years of the epidemic. Even if public health measures had been applied to HIV,
4 they were not likely to have been effective. It was presumed that the difficulty of traditional
5 contact tracing would render this approach ineffective.¹ Moreover, even if it were possible to
6 identify HIV-infected individuals by way of routine screening or contact tracing, there was no
7 effective treatment then available to afflicted individuals.⁶ As a result, a positive HIV diagnosis
8 was likely to have substantial psychological impact upon patients. From an ethical perspective, in
9 the absence of effective therapies, the negative effects of the psychological consequences of HIV
10 testing were not offset by sufficient positive benefit.⁶

11
12 Policies were established during the early years of the epidemic directing that, with very limited
13 exceptions, patients should only be tested for HIV with their informed, specific consent.^{6, 10} In
14 addition, procedures for HIV testing were instituted that placed a heavy emphasis on pre- and post-
15 test counseling to minimize the psychological harms to patients and to promote patient education as
16 a means of disease prevention.⁷

17 18 EVOLUTION OF HIV TESTING POLICIES

19
20 As HIV has become less threatening in the public eye, the perceived need for additional
21 requirements such as pre- and post-test counseling has decreased.⁶ As a result, there is a
22 willingness to consider traditional public health approaches such as screening, reporting, and
23 partner notification to control the spread of HIV.^{1, 6} Recent recommendations of the Centers for
24 Disease Control and Prevention⁸ stem from the increasing ability of public health measures to
25 reduce rates of HIV infection. Rather than testing only individuals in high-risk demographic
26 groups or pregnant women, the new guidelines call for routine HIV testing of all adults.⁸ Tests for
27 HIV are recommended to be conducted concurrent with other routine screening blood tests,
28 meaning that some patients may ultimately be tested for HIV without their specific knowledge.⁹
29 The CDC's guidelines additionally ease informed consent requirements by stating that patients'
30 general consent for medical care sufficiently implies their consent to undergo routine HIV testing.⁸
31 Accordingly, a separate written consent for HIV testing would no longer be needed.

32
33 A substantial proportion of HIV positive patients are unaware of their carrier status, and expanding
34 HIV screening may be appropriate both from a public health perspective^{10, 11} and to better protect
35 others from acquiring infection from those unknowingly affected. Furthermore, routine testing is
36 likely to identify more affected individuals than targeted testing because many HIV-infected
37 persons do not exhibit symptoms or report risky behaviors.¹² A recent analysis of the new CDC
38 recommendations predicted that routine screening practices would prove clinically and
39 economically effective so long as the rate of undiagnosed HIV infection is above 0.20%.¹²

40 41 INFORMED CONSENT WITHIN ROUTINE HIV TESTING

42
43 Decisions regarding HIV testing and disclosure of source persons must consider issues relating to
44 decisional autonomy, confidentiality, patient welfare, and clinical efficacy. In general, all patients
45 must give their consent prior to undergoing any form of medical treatment (see Opinion E-8.08,

1 “Informed Consent”). For this reason, it is always preferable to seek patients’ voluntary
2 participation in HIV, or any other, testing.

3
4 As great emphasis had historically been placed upon informed consent,⁷ CEJA has previously
5 recommended that physicians ensure that HIV testing is conducted in a manner that respects patient
6 autonomy by seeking the patient’s informed consent specific to HIV testing before testing is
7 performed.¹³ Currently, Opinion E-2.23, “HIV Testing,” emphasizes that the consent should not be
8 derived from a general consent to treatment due to the need for pre-test counseling and the
9 potential consequences of a positive HIV test upon an individual’s job, housing, insurability, and
10 social relationships.

11
12 Making HIV screening more routine would likely identify more infected individuals, especially
13 those with early infection, minimal or no symptoms, and absent risk factors. This would lead to
14 improved protections for uninfected individuals who might be subsequently exposed to these
15 identified individuals. Routine screening might also help reduce the stigma associated with HIV if
16 it were known that all patients were to be tested, as opposed to singling out individuals belonging
17 to populations who have been historically associated with the epidemic.

18
19 While routine testing should be encouraged, such a program should be implemented in a way that
20 continues to respect patient autonomy. Respect for patient autonomy ideally calls for physicians to
21 educate patients and seek their specific consent before performing any medical procedure,
22 including diagnostic ones. However, this consent need not be in writing. In addition to testing all
23 patients over the age of eighteen, the Institute of Medicine, the American College of Obstetricians
24 and Gynecologists and the American Academy of Pediatrics specifically recommend universal HIV
25 testing with patient notification as a routine component of prenatal care in order to decrease vertical
26 transmission of HIV to neonates.^{14,15}

27
28 Beyond demonstrating respect for patient autonomy, effective communication between patients and
29 physicians may help to increase the rate of voluntary HIV testing. By providing appropriate
30 information, physicians can address many of the concerns that might otherwise lead patients to
31 decline testing. Physicians can potentially allay fears of patients concerned about potential
32 discrimination or stigmatization by assuring patients that many states have enacted strict consent
33 and confidentiality requirements,¹⁶ while federal regulations such as HIPAA provide effective
34 privacy protections.⁹ Physicians should also address patients’ fears regarding the test itself by
35 emphasizing the improved accuracy of testing and the availability of effective antiretroviral
36 treatments for patients identified as HIV-positive.

37
38 Proper physician-patient communications and informed consent requirements can also constitute
39 important means of promoting equality within the testing process. Without adequate informed
40 consent requirements, vulnerable populations may be less able to opt out of testing, which could
41 potentially lead to differential treatment. Patients’ perception of such differential treatment could
42 erode their trust in the medical profession.

1 PREVENTION OF OCCUPATIONAL HIV TRANSMISSION

2
3 Exceptions to standard informed consent requirements should only occur when the potential harm
4 to patients' autonomy or privacy is balanced by potential benefit. For example, it can be ethical to
5 test patients without prior consent when doing so is necessary to protect health care professionals
6 who may have been occupationally exposed to HIV. Occupational exposure to infectious diseases
7 can occur when health care personnel come into contact with infectious substances, such as blood,
8 tissues, or specific bodily fluids belonging to an HIV-positive source-person. If a health care
9 professional suspects that he or she has been occupationally exposed to HIV, it is imperative that
10 he or she work with physicians or appropriate colleagues to assess the relative risks presented by
11 disease exposure prior to initiating a prophylaxis regimen.¹⁷ This risk assessment will require
12 physicians to examine the source-person's HIV status. In such instances, it is always preferable to
13 seek patients' voluntary disclosure of this information. However, if a patient is unwilling or unable
14 to provide this information, mandatory HIV testing is ethically justifiable when the potential harms
15 posed to exposed health care personnel outweigh concerns regarding patients' privacy and
16 autonomy (see BOT Report 1-A-07).

17
18 Likewise, it can also be appropriate to test physicians for HIV carrier status when necessary for
19 patients' protection. Physicians performing exposure-prone procedures, such as invasive surgeries,
20 must take appropriate precautions to avoid physician-to-patient transmission of HIV.⁸
21 Accordingly, these physicians are ethically obligated to submit to periodic HIV testing.
22 Seropositive physicians need not abandon their practice, but should make efforts to avoid engaging
23 in exposure-prone procedures and further disclose their HIV status to patients when providing
24 treatments that present a greater-than-average risk of transmission.¹⁸

25
26 POST-TEST PROCEDURES

27
28 Physicians' ethical obligations to promote patients' wellbeing require that they work to ensure that
29 patients receive appropriate follow-up care upon receipt of a positive HIV test. As such, physicians
30 should provide or otherwise assist patients in accessing post-test counseling and health services as
31 necessary. To do so, physicians should make efforts to familiarize themselves with patient
32 resources that may be available through the health system or other community organizations.

33
34 In addition, physicians must comply with applicable disease reporting requirements. When doing
35 so, physicians should protect the confidentiality of patients' medical information to the extent
36 possible (see Opinion E-5.05, "Confidentiality"). This may be accomplished by divulging only the
37 minimum amount of information necessary or by de-identifying information when possible.
38 Physicians should also insist that involved public health workers be held to the same standards of
39 confidentiality as are other health care professionals.

40
41 Finally, physicians' ethical responsibility to protect the public requires that they take necessary
42 precautions to prevent HIV-positive patients from infecting other individuals. If an HIV-positive
43 individual poses an imminent threat of infecting an identifiable third party, the physician should:
44 (1) notify the public health authorities, if required by law; (2) attempt to persuade the infected

1 patient to cease endangering the third party; and (3) if permitted by state law, notify the endangered
2 third party without revealing the identity of the source person.¹³

3

4 CONCLUSION

5

6 The treatment of HIV has historically differed from the treatment of other contagious diseases,
7 which for a long time was due to the limited treatment options and high mortality rate, as well as to
8 the psychosocial concerns related to discrimination of minority patient groups. In recent years the
9 potential harms associated with HIV testing have diminished relative to the potential benefits.

10 Routine HIV testing presents an important means of promoting the public's health. However, it is
11 still appropriate for doctors to seek patients' informed consent before HIV, or any other, tests are
12 performed. By communicating effectively, engaging patients in the decision-making process,
13 supporting the expansion of HIV screening programs, and providing appropriate follow-up care
14 physicians may serve patients' best interests, help to protect the health of third parties, and achieve
15 desired public health goals.

16

17 RECOMMENDATION

18

19 The Council on Ethical and Judicial Affairs recommends that the following be adopted and the
20 remainder of the report be filed.

21

22 E-2.23 HIV Testing

23

24 Physicians' duties to promote patients' welfare and to improve the public's health are
25 fostered by routinely testing their adult patients for HIV. Physicians must balance these
26 obligations with their concurrent duties to their individual patients' best interest by
27 following the guidelines below:

28

29 (1) Physicians should support routine HIV testing procedures in order to protect patients,
30 avoid injury to third parties, and promote public health.

31

32 (2) While medical and social advances may have minimized the need for specific written
33 consent prior to HIV testing, physicians should continue to seek patients' informed
34 consent to undergo any form of medical treatment, including HIV testing. However,
35 patients' consent does not need to be documented in writing. It is justifiable to test
36 patients without prior consent only in limited cases where the harms to individual
37 autonomy are offset by significant benefits to known third parties. Such exceptions
38 include testing for the protection of occupationally-exposed health care professionals
39 or patients.

40

41 (3) Physicians must work to ensure that patients identified as being HIV positive receive
42 appropriate follow-up care and counseling.

43

- 1 (4) Physicians must comply with all applicable disease reporting laws while taking
2 appropriate measures to safeguard the confidentiality of patients' medical information
3 to the extent possible.
4
- 5 (5) Physicians must honor their obligation to promote the public's health by working to
6 prevent HIV-positive individuals from infecting third parties within the constraints of
7 the law. If an HIV-positive individual poses a significant threat of infecting an
8 identifiable third party, the physician should: (1) notify the public health authorities, if
9 required by law; (2) attempt to persuade the infected patient to cease endangering the
10 third party; and (3) if permitted by state law, notify the endangered third party without
11 revealing the identity of the source person.
12
- 13 (New HOD/CEJA Policy)
14
- 15 Issued March 1992 based on the report "Ethical Issues Involved in the Growing AIDS Crisis,"
16 adopted December 1987 (JAMA. 1988; 259: 1360-61); Updated June 1994 and November 2008
17 based on the report "HIV Testing."

Fiscal Note: Staff cost estimated at less than \$500 to implement.

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B. CONSULTATION

HOUSE ACTION: FILED

OPINION 8.04: Consultation

Physicians should obtain consultation whenever they believe that it would be helpful in the care of the patient or when requested by the patient or the patient's representative. When a patient is referred to a consultant, the referring physician should provide a history of the case and such other information as the consultant may need, and the consultant should advise the referring physician of the results of the consultant's examination and recommendations.

(Opinion 8.04 is derived from Principle V of the Principles of Medical Ethics.)

C. CONFIDENTIALITY OF HIV STATUS ON AUTOPSY REPORTS (RESOLUTION 53, A-91)

**HOUSE ACTION: RECOMMENDATIONS ADOPTED IN LIEU OF RESOLUTION 53 (A-91)
AND REMAINDER OF REPORT FILED**

INTRODUCTION

Resolution 53 (A-91), which was referred to the Board of Trustees, asks the American Medical Association to study the issue of confidentiality of HIV status on autopsy reports. The Council on Ethical and Judicial Affairs responds to the resolution with the following report. During its deliberations the Council consulted with several committees within the College of American Pathologists.

BACKGROUND

Autopsies serve a variety of useful and important purposes. Autopsies are routinely performed in the case of sudden, suspicious or unexplained deaths, in order to assist police, prosecutors and other authorities in investigation and law enforcement. Autopsies play a critical role in quality control in medical-care settings. For instance, autopsies are used to evaluate the accuracy of premortem diagnoses, evaluate the efficacy of new drugs, new diagnostic technologies, new surgical techniques and developing technologies such as gene therapy.

Autopsies may assist in epidemiological and medical research, such as identifying and helping to control previously unrecognized diseases, surveilling the incidence of current diseases, and monitoring environment- and occupation-related disorders. Autopsies are also frequently used to evaluate the accuracy of cause-of-death information on death certificates. Several studies have shown that there is a significant amount of disagreement between cause-of-death information on death certificates and the cause-of-death information revealed at autopsies. Checking death certificate information against autopsy findings can help identify which types of diseases or disorders are most likely to be misdiagnosed or missed when determining a patient's cause-of-death.

Significantly, autopsies played a critical role in the identification of AIDS. Analysis and identification of factors which were not previously identified clinically led to greater accuracy in incidence and prevalence information and provided clinicians with a more complete descriptions of AIDS-related disorders, potentially leading to more effective therapy for AIDS.

CONFIDENTIALITY OF HIV STATUS AFTER DEATH

Medicine has long considered the confidentiality of patients' medical information to be of paramount concern. The traditional protection of a patient's medical condition was extended to HIV status, AIDS and AIDS related-diseases soon after medicine was able to diagnose AIDS and determine individuals' HIV serostatus. The Council on Ethical and Judicial Affairs has previously stated that a patient's HIV status should remain confidential, except under certain narrowly-defined circumstances for the purpose of safeguarding public health. Physicians should comply with state statutes which mandate reporting of HIV to public health authorities. Also, in cases where a person is HIV positive and the physician knows that the patient is endangering a third party, the physician may inform the endangered third party if attempts to persuade the patient to inform the third party himself or herself have failed, and if the authorities, after having been notified of the behavior, have also failed to notify the third party.

The physician's duty to maintain the confidentiality of a patient's medical status to the greatest degree possible continues after the death of the patient. A physician's duty is based on respecting the privacy of the patient, fidelity to the best interests of the patient, and maintaining public trust in medicine generally. A patient's interest in the protection of private information continues even after death. Unauthorized disclosure of HIV status or other medical information after death may affect the perceptions of others about the deceased patient or cause speculation, suspicion or judgments regarding the character of the decedent. The effect of unauthorized disclosure by the physician would violate the patient's privacy and best interests.

The privacy of the decedent's family or friends is also violated by unauthorized disclosure. Just as knowledge of an individual's HIV status may have significant consequences for all aspects of an individual's life, the unauthorized disclosure of the HIV status of a deceased family member or friend may also precipitate adverse effects. Such knowledge may affect employment status, insurability, and disrupt social and family relationships. Although the physician's obligations to the family are secondary to the obligations to the patient, medicine has traditionally included consideration of the welfare of the family in its ethical precepts.

INCLUSION OF HIV STATUS ON AUTOPSY REPORTS

It is important to note that the specific laws governing the confidentiality of HIV status and the performance of autopsies varies greatly from state to state. Medical professionals who perform post-mortem examinations should be familiar with the specific legal requirements of their state. All states protect the confidentiality of medical records to some degree, and many protect HIV status in particular. Most states which protect confidentiality of medical information have exceptions to the nondisclosure rule for reasons such as reporting to public health authorities, notifying endangered third parties, i. e., sexual or needle-sharing partners, and informing health personnel involved with the care of the patient. For the purposes of autopsies performed in hospitals, autopsy reports are generally considered part of the patient's medical record. The confidentiality of a patient's HIV status as part of the medical record would be protected under the laws safeguarding the confidentiality of medical records generally. Some states recognize additional exceptions to confidentiality in the case of death. For instance, physicians are often allowed or required to report a decedent's HIV status to funeral directors. However, no state authorizes or requires disclosure of an individual's HIV status to the general public upon death, or in any instance in which an individual's death is not referred to the coroner or medical examiner for investigation.

Currently, only New York requires that every autopsy done under the auspices of the Chief Medical Examiner include an HIV test. However, the autopsy testing program in New York provides for confidentiality of results, with the exception of notification of third parties who may be at identifiable risk of having contracted HIV from the decedent.

In a number of states, autopsy reports done by a medical examiner become a part of official public records. In states where autopsies become part of the public record, some physicians may be reluctant to include a person's HIV

status on the autopsy report. In the case of a patient who died of AIDS or AIDS-related causes, a physician may take care to avoid stating that AIDS was the cause of death, preferring to give the exact medical diagnosis, such as viral encephalopathy or pneumocystis carinii pneumonia. Several studies which examined the stated causes-of-death on death certificates have indicated that physicians often avoid listing causes-of-death which carry a stigmatized connotation. Researchers have speculated that physicians, out of compassion for the decedent's family, choose to state the cause-of-death in a way which will minimize potential social disapproval of the family. For instance, there is evidence that suicides or deaths in which the patient's alcoholism was a factor are underreported or misreported on death certificates. There is also anecdotal evidence that physicians are reluctant to put "AIDS," "AIDS-related causes" or "HIV" down on death certificates as causes-of-death or contributing factors. Although the purposes and requirements of death certificates and autopsy reports are different, the potential underreporting of HIV or AIDS on death certificates may indicate a similar reluctance to include HIV information on autopsy reports in places where the reports are part of public record.

However, it is important that HIV or AIDS information not be excluded from autopsy reports where it is pertinent to the cause of death. Autopsies have played a critical role in improving the diagnosis and treatment of AIDS. Much of the pathophysiology of AIDS is derived from autopsy data. With a disease such as AIDS, where there are significant gaps in knowledge about the diagnosis, treatment, and cure, it is important to maximize the use of any information which could contribute to increased knowledge.

Autopsy data are in general often used to evaluate the accuracy of cause-of-death information included on death certificates. Several studies have shown that medical information listed on death certificates may be in error on 12-29 percent of death certificates. Accurate death certificate information is critical, since national vital statistics, health care resource allocation, and health policy decisions are often highly dependent on data derived from death certificates. In order to ensure that vital statistics and health resources properly reflect actual disease incidence, prevalence, morbidity and mortality, autopsies must include HIV/AIDS where it is relevant to the patient's cause of death.

ETHICAL GUIDELINES FOR CONFIDENTIALITY OF HIV STATUS ON AUTOPSY REPORTS

Legally, a patient's privacy rights may terminate upon death. However, physicians have an ethical obligation to maintain the patient's confidentiality even after the death of a patient. Physicians are sometimes justified in breaching confidentiality when the disclosure is made for public health reasons or to prevent a danger to an identifiable individual. General or public disclosure of a patient's medical record is never ethically justified without authorization from the patient.

Generally, decisions as to whether HIV or other AIDS-related tests should be performed as part of an autopsy, and whether the results of such tests should be included in the autopsy report, are medical decisions that should be made by the pathologist performing the autopsy in accordance with his or her best medical judgment. In deciding whether to perform an HIV test, the pathologist should apply the same principles used to determine whether other types of medical tests may be useful in determining the cause of death or otherwise adding to the clinical findings. There may be exceptions to this general rule. The first is where state law requires informed consent before an HIV test may be performed. In such situations, the pathologists may have to obtain the consent of one of the decedent's relatives before performing the test. The second exception is where state law requires that an HIV test be included in certain autopsies. Under these circumstances, the pathologist must perform the test even when there does not appear to be a medical justification for doing so.

Once an HIV or other AIDS-related test is performed, the results of the test should be entered in the autopsy report. Similarly, if a diagnosis of HIV infection or AIDS is apparent without performing a specific test, (e. g. the diagnosis has been made prior to death, and is in the decedent's medical record) then that information should be included in the autopsy report. The decision to include AIDS-related information in the autopsy report as well as the decision to perform an AIDS-related test should be based on medical, rather than confidentiality, concerns.

In general, hospital autopsy reports should be treated in the same manner as other medical records. However, when AIDS-related information is involved it would appear that there should be a heightened concern for privacy and confidentiality. Furthermore, there may be variation from state to state as to how AIDS-related medical information is to be handled with respect to the level of confidentiality. For example, some states give HIV test results and other AIDS-related information the same degree of protection as other medical information; other states, however, require special precautions, such as separate records and more stringent rules governing disclosure.

Previous court decisions have held that a hospital has a duty of confidentiality by requiring it to take "reasonable precautions" to prevent the disclosure of AIDS-related information in a patient's medical chart. It appears to us that the same level of confidentiality should be accorded AIDS-related medical information contained in autopsy reports. Therefore, something more than the hospital's general precaution for confidentiality of autopsy reports may be required where AIDS-related information is involved. This might include, for example, adopting procedures to limit access to the reports to those individuals demonstrating a justifiable medical need or right to see them.

EXCEPTIONS TO CONFIDENTIALITY

Exceptions to maintaining the confidentiality of a decedent's HIV status include fulfilling statutory obligations to notify public health authorities and fulfilling statutory and ethical obligations to warn endangered third parties. Even in those cases, confidentiality should be maintained to the greatest degree possible. One additional exception would be allowing individuals who are conducting bona fide scientific or medical research, such as disease surveillance, to have access to hospital autopsy records. However, in this case, researchers should be obligated to maintain the same confidentiality of the HIV status of specific individuals as are physicians. From an ethical standpoint, the preferred course would be for the researchers to have access to the pertinent medical information but not to the identities or any individually identifying factors of the decedents. Similarly, in cases where autopsies are performed in conjunction with the coroner's or medical examiner's office, and the autopsy report is not part of the public record, then the physician must also maintain confidentiality of the decedent's HIV status.

State statutes which allow public access to a person's HIV status through autopsy records create a conflict with the obligations of the physician to safeguard the confidentiality of medical information. In cases where autopsies are done under the auspices of the medical examiner's office and state law mandates that the autopsy information be accessible to the public, then physicians should comply with state law. However, in these instances, HIV status should only be recorded when the HIV status of the decedent would be relevant to determining the patient's cause-of-death.

In order to minimize the ethical conflict for physicians who work in states where autopsy records may be made public, the laws should be changed so that all autopsy reports are confidential.

RECOMMENDATIONS

The Council on Ethical and Judicial Affairs recommends that the following recommendations be adopted in lieu of Resolution 53 (A-91):

1. Physicians should maintain the confidentiality of HIV status on autopsy reports to the greatest extent possible.
2. Physicians who perform autopsies or who have access to autopsy information regarding a patient's HIV status should be familiar with state law governing (1) the reporting of HIV and AIDS to public health authorities, (2) obligations to inform third parties who may be at-risk for HIV infection through contact with an HIV-infected decedent, (3) other parties to whom reporting may be required (i.e., funeral directors, health care personnel involved in the care of the patient), and (4) the extent of confidentiality of autopsy records.

3. HIV status which appears on autopsy records performed under the authority of a hospital are part of the decedent's medical record and should be held confidential. The physician should comply with state laws regarding disclosure to public health authorities and at-risk third parties, and, where such laws are absent, fulfill ethical obligations to notify endangered third parties (e. g., identified sexual or needle-sharing partners). This includes reporting to organ or tissue procurement agencies if any parts of the decedent's body were taken for use in transplantation.
4. HIV status which appears on autopsy records performed by a medical examiner in the case of suspicious, accidental, or unexplained death should be kept confidential where autopsy records are not accessible to the public. The physician should comply with state laws regarding disclosure to public health authorities and at-risk third parties, and, where such laws are absent, fulfill ethical obligations to notify endangered third parties (e. g., sexual and needle-sharing partners). This includes reporting to organ or tissue procurement agencies if any parts of the decedent's body were taken for use in transplantation.
5. In cases where autopsies are done under the auspices of the medical examiner's office and state law mandates that the autopsy information be accessible to the public, then physicians should comply with state law. However, in these instances, HIV status should only be recorded when the HIV status of the decedent would be relevant to determining the patient's cause-of-death. In addition, although a patient's HIV status may be learned from public records in some jurisdictions, it is still unethical for a physician to make a public disclosure of an individual patient's HIV status independent of the legal requirements governing the filing or processing of autopsy records. The physician should comply with state laws regarding disclosure to public health authorities and at-risk third parties, and, where such laws are absent, fulfill ethical obligations to notify endangered third parties (e. g., sexual and needle-sharing partners). This includes reporting to organ or tissue procurement agencies if any parts of the decedent's body were taken for use in transplantation.

(References pertaining to Report C of the Council on Ethical and Judicial Affairs are available from the Office of General Counsel.)

D. CARING FOR THE POOR

HOUSE ACTION: REFERRED TO COUNCIL ON ETHICAL AND JUDICIAL AFFAIRS

INTRODUCTION

Despite the fact that the United States is the most affluent country in the world, a significant portion of its citizens have little or no access to medical care. While the barriers to obtaining health care are numerous, perhaps the most difficult hurdle to overcome is the lack of financial resources to pay for it. Although there appears to be a growing consensus that all people should receive basic health care, there is little agreement on how to achieve or finance this goal or even how to define it.

Against that background, this report reviews and examines the individual medical practitioner's ethical obligation to treat the poor. Because much of the recent attention has focused upon broader societal obligations and systematic reform, the role of the individual has been overshadowed. The Council believes that medical professionals should assume significant individual responsibility for making health care available for the needy. To that end, each medical

corporation for securing, soliciting, or drumming patients or patronage. A physician or surgeon may not accept or agree to accept any payment, fee, reward, or anything of value for securing, soliciting, or drumming for patients or patronage for any physician or surgeon . . . The preceding shall not be construed to prohibit advertising except that which is false, misleading, or deceptive or that which advertises professional superiority or the performance of professional service in a superior manner and that is not readily subject to verification. Tex. Stat. Ann. art 4495b Sec. 3.07(c) (Vernon 1986).

B. STATEMENT ON AIDS

(Reference Committee on Amendments to Constitution and Bylaws, page 424)

HOUSE ACTION: FILED

The Council on Ethical and Judicial Affairs of the American Medical Association provides physicians with the following guidelines that should help in responding to questions regarding acquired immunodeficiency syndrome (AIDS).

The medical profession has a social responsibility to provide accurate, current information about AIDS. Only in this way can irrational fears based upon inaccurate information about AIDS be quelled. Currently, containment of AIDS depends primarily upon educating the public about how AIDS is spread so that appropriate precautions can be taken. Physicians are urged to refrain from publicly expressing unfounded opinions as to the risk of contagion, the prognosis for persons exposed to or afflicted with the disease, or the effectiveness of experimental therapies. The physician should avoid unduly optimistic or discouraging comments about when an effective treatment may become available.

Unless there are contravening circumstances, physicians have an obligation to assist in notifying individuals who have been exposed to the infection through a known method of transmission so that appropriate diagnostic tests can be performed; an individual thus notified should also be informed that the percentage of persons with positive HTLV-III/HIV (human immunodeficiency virus) tests who will develop AIDS is unknown. However, a potentially or known infected individual has a duty to refrain from sexual practices or other activities that might result in further dissemination of the disease. Where testing for the HTLV-III/HIV antibody is indicated, informed consent should be obtained. The patient should know that the results may become part of the medical record. Confidentiality within the framework of applicable reporting laws and regulations must be safeguarded. When a diagnosis of AIDS is confirmed, management alternatives should be fully discussed with the patient. Health care professionals must be sensitive to the psychological needs of individuals with a positive HTLV-III/HIV antibody test and of symptomatic patients and may recommend appropriate support groups.

Physicians and other health professionals have a long tradition of tending to patients afflicted with infectious disease with compassion and courage. However, not everyone is emotionally able to care for patients with AIDS. If the health professional is unable to care for a patient with AIDS, that individual should ask to be removed from the case. Alternative arrangements for the care of the patient must be made. All health professionals involved in the care of patients with AIDS must comply with recommended hygienic techniques at all times.

At times the physician may wish to assist patients in deterring third parties, such as school officials or employers, from instituting restrictive actions that are medically unjustified. The physician has a societal responsibility to participate in the development of public policy concerning AIDS.

The Council on Ethical and Judicial Affairs recommends that this report be filed.