

Pregnant Women and HIV Counseling and Testing: Recommendations



Pregnant women who know they are HIV positive now can avail themselves of therapies that dramatically reduce the chances that their newborns will be HIV infected. With this compelling reason to know one's HIV status has come an intense public policy debate about HIV counseling and testing in pregnancy. At stake in the debate are the legal and medical rights of pregnant women and the opportunity to almost eliminate perinatal transmission of HIV infection in the United States.

AIDS Alliance for Children, Youth & Families offers the following recommendations for sound public health policy on HIV testing that will save lives, guarantee informed decision making, and minimize medical, social, and legal risks for women and families.

AIDS Alliance recommends:

Universal HIV counseling and voluntary HIV testing should be routine components of prenatal care for all pregnant women.

RECOMMENDATIONS FOR HEALTH CARE PROVIDERS

- 1 Prenatal care providers should counsel every pregnant woman about the benefits of knowing her HIV status so that she can make informed decisions about being tested as part of prenatal care.**

Many HIV-positive women not only do not know their HIV status, but also are unaware that they were ever at risk for contracting HIV infection. This became increasingly true when the primary risk factor for women in the U.S. became the sexual and drug-using behavior of their partners. Therefore, many HIV-positive women who become pregnant may not know that there is any reason to be tested for HIV as part of prenatal care. In order for a pregnant woman to make an informed decision about being tested for HIV, she must be provided with information about the benefits to herself and her baby of knowing her HIV status, including the availability of therapies that can dramatically reduce perinatal HIV transmission.

- 2 Prenatal care providers should offer HIV testing to every pregnant woman as part of prenatal care. A woman who refuses testing should be given multiple and continuing opportunities to be tested for HIV throughout the course of her pregnancy.**

Pregnancy is a window of opportunity for a woman to learn her HIV status and to take steps to care for her own health and that of her unborn child. Therefore, all pregnant women should be offered HIV testing following counseling about the benefits of knowing their HIV status. A pregnant woman who refuses HIV testing should continue to be counseled throughout her pregnancy about the benefits of HIV testing to herself and her baby.

- 3 Prenatal care providers should provide every pregnant woman who is tested and found to be HIV-positive with counseling and support that includes complete and unbiased information about the benefits of ZDV and other therapies in reducing the chances that her baby will be HIV infected and about any risks associated with the therapy.**

HIV counseling and testing alone will not prevent a single case of perinatal HIV transmission. An HIV-positive pregnant woman must know the potential benefits, as well as any risks, of ZDV therapy or other therapies to herself and her unborn child before she is able to make an informed decision about these therapies. Because an HIV diagnosis is often a life-altering event, post-test counseling also must address the psychosocial needs of newly diagnosed women. Health care providers and organizations offering HIV testing to pregnant women should provide or arrange for such support when HIV-positive test results are delivered.

- 4 Prenatal care providers should provide every pregnant HIV-positive woman who chooses ZDV or other therapies with the care and support necessary to help her complete the regimen.**

Optimal care for HIV-positive pregnant women and their infants is complex and specialized. ZDV and other therapies to reduce perinatal transmission require adherence to a treatment regimen that can be difficult. Women choosing these therapies must be offered comprehensive, coordinated care and support for adherence.

- 5 Women who are found to be HIV positive must be referred immediately to health care providers and organizations qualified to provide HIV specialty care to pregnant women, such as Ryan White CARE Act Title IV programs and other community-based providers.**

HIV-positive pregnant women require continuing medical care and support from health care providers with HIV experience. Medical research continues to demonstrate significantly better outcomes for patients treated by physicians and other health care providers with a high level of HIV expertise and experience. Prenatal care providers without such experience should work with more experienced providers and should refer HIV-positive women to Title IV and other community-based programs where they can be offered care and support tailored to their needs and circumstances. Choosing not to participate in ZDV or other therapies to prevent perinatal HIV transmission must not interfere with a woman's access to continuing prenatal care and HIV specialty care.

- 6 Hospitals, clinics, managed care plans, and other prenatal care providers should develop, implement, and evaluate policies and clinical practice guidelines that facilitate universal HIV counseling and voluntary testing for pregnant women.**

Health care professionals and organizations that provide HIV counseling and testing to pregnant women should follow clinical practice guidelines that reflect state-of-the-art opportunities to reduce perinatal HIV transmission, while at the same time guaranteeing that pregnant women are tested for HIV infection only with their fully informed consent and with adequate pre- and post-test counseling. New models and approaches to counseling pregnant women about the benefits of HIV testing, such as expedited counseling, are appropriate if they ensure fully informed consent. Rapidly changing treatment options mean that clinical practice guidelines for HIV counseling and testing must be periodically evaluated and revised as needed.

RECOMMENDATIONS FOR PROVIDERS OF PRESERVICE AND CONTINUING EDUCATION

- 1 Training programs for professionals caring for pregnant women and their newborns should highlight the vital role of universal HIV counseling and testing in preventing perinatal transmission of HIV infection.**

Health care providers who work with pregnant women and their newborns are on the front-line in the fight to reduce perinatal transmission of HIV infection. It is imperative that preservice and continuing education for these professionals include the latest information about advances in preventing perinatal HIV transmission, including the role of HIV counseling and testing in pregnancy. The range of complex ethical and legal issues surrounding informed consent should be addressed at both the preservice and continuing education levels.

- 2 Professional training programs and organizations whose members care for pregnant women and their newborns should offer training to community-based organizations serving women about the vital role of HIV counseling and testing in preventing perinatal HIV transmission.**

Community-based organizations that are traditional providers of care to women living in high-risk circumstances, such as those in communities with a high prevalence of HIV infection, can be key resources for reaching pregnant women and informing them about the benefits of HIV testing in pregnancy. Many of these organizations already participate in local networks of HIV care for women, including Title IV programs and other programs funded through the Ryan White CARE Act.

- 3 Professional training programs and organizations whose members care for pregnant women and newborns should offer training and technical assistance to community-based organizations and providers in their localities who are not part of local HIV care networks and may be unaware of the role they can play in helping pregnant women in high-risk circumstances learn about the importance of an HIV test during pregnancy.**

RECOMMENDATIONS FOR POLICY MAKERS AND ADVOCATES

- 1 Federal and state policy makers should avoid interfering with a pregnant woman's right to make decisions about her own medical care, including her right to provide informed consent for HIV testing and treatment.**

Pregnancy does not invalidate a woman's legal and ethical right to medical autonomy and control of decision making. Testing pregnant women for HIV without their informed consent violates accepted standards of ethical practice, as well as their Constitutionally protected privacy rights. Voluntary, non-coercive measures to encourage and promote HIV counseling and testing during pregnancy are proving successful and must be strengthened and continued.

- 2 The minimum components of informed consent for HIV testing in pregnancy should be identified and promoted as the standard of care for universal HIV counseling and voluntary testing of pregnant women.**

In the urgent push to ensure that all pregnant women know their HIV status, there is a real danger women will not be provided with the necessary counseling to ensure their fully informed consent to be tested. To protect the privacy and autonomy of pregnant women while at the same time facilitating HIV testing during pregnancy, the minimum components of counseling to ensure fully informed consent for HIV testing in pregnancy must be identified.

AIDS Alliance proposes a blue-ribbon panel of clinicians, ethicists, researchers, and women in high-risk circumstances and their advocates be convened to develop a consensus on these minimum necessary components of informed consent. We view this final recommendation as a necessary next step forward to promote universal, voluntary HIV testing of pregnant women, with fully informed consent.

Through education, training, and advocacy, AIDS Alliance for Children, Youth & Families works on behalf of women, children, young people, and families affected by HIV and AIDS. In the complex public policy debate on HIV counseling and testing in pregnancy, AIDS Alliance has created a forum to listen to women's voices and bring diverse stakeholders together to seek common ground.