HIV and Pregnancy

A Guide to Medical and Legal Considerations for Women and Their Advocates

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Women's Advocacy Resource Connection

THE CENTER FOR HIV LAW & POLICY

Pregnancy and HIV:
Medical and Legal Considerations for Women and Their Advocates

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MISSION STATEMENT

The Center for HIV Law and Policy is a national legal and policy resource and strategy center for people with HIV and their advocates. CHLP works to reduce the impact of HIV on vulnerable and marginalized communities and to secure the human rights of people affected by HIV.

We support and increase the advocacy power and HIV expertise of attorneys, community members and service providers, and advance policy initiatives that are grounded in and uphold social justice, science, and the public health.

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Preface

In the 1980s and early 1990s, approximately 25% of the infants born to women with HIV were also infected, and of these about a quarter died before they were five years old.[1] The development and availability of antiretroviral therapies (ARVs) has sharply reduced transmission of HIV from mother to infant. Research has shown that mother-to-child transmission rates can be reduced to less than 2% with the use of ARVs during pregnancy and labor and, when appropriate, a cesarean surgery.[2] ARVs also can sustain the health and extend the lives of HIV-infected women and children for whom they are appropriate. As a result, AIDS diagnoses in children following perinatal HIV transmission declined by more than 90% between 1994 and 2005.[3]

However, many women fear that the same drugs that can significantly decrease the risk of HIV transmission from mother to infant may have troubling long-term health consequences for both themselves and their children. The research about the relative benefits and harms of different ARVs, types of delivery, infant feeding methods, and other factors is far from complete. Some women who harbor mistrust of health care providers or drug companies may also be persuaded by the misinformation about HIV or the drugs used to treat it that they find online or in the community. Decision making is further complicated by the ongoing development of new drugs that have yet unproven benefit—and risk—to both HIV-positive women and their children. However, the data clearly show that properly prescribed ARV therapy can be an effective component of a comprehensive strategy to prevent mother-to-child transmission.

Women who are pregnant and HIV-positive should understand the various risks and advantages of the different strategies for avoiding perinatal transmission, and discuss these with doctors and other knowledgeable health care providers, as they decide what is best for both their children and their own health. The Center for HIV Law and Policy recognizes and supports women's abilities to make informed decisions when they have medically sound, understandable, accurate information and access to treatment. We also understand that the best decisions for each woman will depend on her own health, medical care, and life circumstances.

Health care providers and advocates have a crucial role in assisting pregnant women and new mothers who are anxious about HIV testing, and those who are already HIV-positive and managing their own HIV care while trying to prevent transmission to their children. In order to benefit from the medical advances that can reduce perinatal transmission and extend health and life, women need accurate, complete, and understandable information that trustworthy professionals provide honestly and respectfully. Women at greatest risk—including poor women, substance users, sex workers, and survivors of domestic violence—often have, at best, very fragile connections to health care. Many have experienced disrespectful treatment from doctors, service providers, and bureaucrats and rely on their peers for information about HIV, other health issues, and medicine. In addition, HIV-positive pregnant women may fear that medication will be forced on them and that the state will

[1] *Protection of Foster Children Enrolled in Clinical Trials: Hearing Before the Subcomm. on Income Security and Family Support of the H. Comm. on Ways and Means*, 109th Cong. (2005) (statement of Alan Fleischman, MD, Senior Advisor, New York Academy of Medicine).

[2] CDC, *Achievements in Public Health: Reduction in Perinatal Transmission of HIV Infection—United States, 1985–2005*, 55 MMWR 592 (2006), *available at* http://cdc.gov/mmwr/preview/mmwrhtml/mm5521a3.htm.

[3] CDC, *Cases of HIV Infection and AIDS in the United States and Dependent Areas, 2005*, 17 HIV/AIDS SURVEILLANCE REPORT, June 2007, at 46.

seize their children. Health and legal advocates can help women make informed health decisions and protect their rights, but only if they take the time to address the women's deeply felt concerns about testing, the risks of antiretroviral treatments, HIV itself, and the role of the state in women's lives.

This guide is intended to be a resource for HIV-positive women and their advocates. It has three primary purposes: (1) to direct users to current, medically accurate, and accessible information about pregnancy and HIV; (2) to help users frame the risks and opportunities before them and make decisions that will be most beneficial for individual women and their children; and (3) to enable legal advocates to argue compellingly that women have the right to determine the best course of medical treatment during their pregnancies and should not be forced to undergo treatment against their will, and that women who have made good faith efforts to protect their children's health after birth should not be prosecuted or lose custody of their children due to their medical treatment choices while pregnant.

This review of the current state of perinatal HIV care for pregnant women and newborns is based on the following core principles:

- Women have the right to the highest quality reproductive and HIV health care available;
- Women have the right to initiate, prevent, maintain, or terminate pregnancies, irrespective of their HIV status;
- Women need and are entitled to comprehensive, accurate, accessible, and linguistically and culturally appropriate information about HIV treatment, prevention of mother-to-child transmission, and their own health, so that they can make the best possible decisions in their particular circumstances;
- Misinformation about HIV and AIDS is a threat to the health of women and children;
- A healthy mother is one of a child's greatest health assets, which means that she must consider her own health and treatment carefully when making decisions about PMTCT health care;
- Imposing mandates for unconsented testing and coercive prophylaxis and care is counterproductive. The best outcomes will follow when women are supported in making informed, autonomous decisions in respectful partnership with knowledgeable doctors and other healthcare providers; and
- There is no one right course of action or treatment regimen for all HIV-positive pregnant women. Each woman must balance a complicated set of risks and advantages to her child and herself in making her decisions.

This paper draws on guidelines developed by the U.S. Public Health Service Task Force for pregnant women and newborns, as well as other major sources. In addition, we are including important findings from recent studies, and we encourage HIV-positive pregnant and nursing women to discuss these findings with their doctors and other qualified providers.

CHLP cannot and does not recommend any particular course of action or treatment regimen. In the end, women must make their own decisions based on what they know about available treatments, what is already approved, the possibilities of participation in clinical trials for promising new drugs, and what advantages, side-effects, and risks to mother and child are associated with different strategies.

The information about PMTCT that follows is organized in five sections: (1) general information, (2) pre-pregnancy, (3) pregnancy, (4) labor and delivery, and (5) post-delivery and infancy. We

highlight the decisions women must make at each stage, and important issues that their advocates should understand.

The Center for HIV Law and Policy has also prepared a Legal Advocacy Supplement to accompany this guide. The Legal Advocacy Supplement addresses in more detail the legal issues and strategies covered in this guide. It is available on request to attorneys representing individuals on reproductive and parental choice issues. For more information, contact info@hivlawandpolicy.org.

Abbreviations and Terms

ACTG	AIDS Clinical Trials Group
AIDS	Acquired Immune Deficiency Syndrome
ARVs	Antiretroviral medications
AZT	Azidothymidine, an antiretroviral medication (specifically a nucleoside reverse transcriptase inhibitor) also known as zidovudine (ZDV) or Retrovir (brand name)
CD4 count	The number of CD4 cells (white blood cells, also called T-cells, that fight infection) in a 1 mm^3 sample of blood. A low CD4 count indicates a lack of defenses to other infections.
CDC	Centers for Disease Control and Prevention (the U.S. federal public health agency, housed within the Department of Health and Human Services)
EIA	Enzyme immunoassay (a type of HIV antibody test)
ELISA	Enzyme-linked immunosorbent assay (a type of EIA). The ELISA is usually the first test used to detect HIV antibodies. A reactive ELISA is generally confirmed by a second test of the same blood sample; if that is also positive, the result will be confirmed by a second, different test, usually a Western blot.
Fusion inhibitor	A class of ARV that prevents HIV from entering a cell
HAART	Highly Active Antiretroviral Therapy
HIV	Human Immunodeficiency Virus (the virus that cause AIDS)
IUI	Intrauterine insemination. A type of artificial insemination involving injecting cleaned sperm directly into the uterus (in contrast to into the vagina, below the cervix) in order to conceive a pregnancy. Sperm used in IUI is always "washed" and free of HIV, HCV, and other infectious agents.
IV	Intravenous drip (the delivery of medications directly into the veins)
MTCT	Mother-to-child transmission
NNRTI	Non-nucleoside reverse transcriptase inhibitor (a class of ARV).
NRTI	Nucleoside reverse transcriptase inhibitor (a class of ARV)

OB/GYN	Obstetrician/gynecologist (a physician specializing in perinatal care and women's sexual and reproductive health)
PACTG	Pediatric AIDS Clinical Trials Group
PCP	Pneumocyctis carinii pneumonia (a common opportunistic infection, caused by a fungus)
PMTCT	Prevention of mother-to-child transmission
Prophylaxis	A measure taken to prevent infection
TMP-SMX	Trimethoprim-sulfamethoxazole. A combination of two medicines known by the brand names Bactrim, Septra, and Cotrim, used to prevent PCP. TMP-SMX is available as a liquid for infants and young children.
Perinatal	The childbearing period before, during, and after birth
PI	Protease inhibitor (a class of ARV)
Seroconversion	The process of developing antibodies to HIV, the presence of which are identified by HIV antibody tests
Teratogenic	Capable of causing birth defects
Viral load test	A test to detect the actual number of HIV virus particles or viral load, in contrast to the HIV antibody. These tests are extremely sensitive, but they are expensive and labor intensive and so not used for routine screening. Viral load HIV tests are used to guide treatment for HIV-positive people, and to test pregnant women who may be in the "window period" after infection but before antibodies are produced, and infants born to mothers with HIV.
Western blot	A more specific and accurate test for HIV used to confirm a positive ELISA test. In this test, any HIV antibodies in the diluted serum being tested will bind to bands of viral proteins on the test strip.
ZDV	Zidovudine, an antiretroviral medication (specifically a nucleoside reverse transcriptase inhibitor) also known as Azidothymidine (AZT) or Retrovir (brand name).

I. Introduction

All women have the fundamental right to make informed, uncoerced choices about their sexual and reproductive health, contraception, pregnancy, and medical care. In making these choices, women living with HIV may be presented with more complicated health decisions than many HIV-negative women face. It is true that HIV infection does not by itself preclude a safe and happy pregnancy, and that being pregnant does not speed up HIV disease progression. It is also true that, with advances in antiretroviral medicines (ARVs) and other improvements in HIV care, HIV-positive women can look forward to bearing children, being healthy enough to care for them, and living to see them grow to adulthood. However, because HIV can be transmitted from mother to child during pregnancy, at birth, and through breast milk, HIV-positive women who are pregnant or new mothers have a challenging set of goals to consider: preventing HIV transmission to their children, while minimizing possible health risks to those children from the prophylactic ARVs and other interventions, and simultaneously protecting their own health and avoiding developing resistance to ARVs.

This paper explores the issues relevant to pregnant women with HIV and examines the available testing, treatment, conception, and birth options that these women may have to consider. The discussion begins with pre-conception considerations, and moves on to considerations during pregnancy, at labor and delivery, and after birth.

II. General Information

A. HIV Transmission

HIV is transmitted in three ways: (1) sexual contact, (2) exposure to blood through contaminated needles (recreational or occupational), and (3) from mother to child during pregnancy, childbirth, or breastfeeding.[4] However, just because HIV can be transmitted in these ways does not mean that people living with HIV should not engage in these activities. There are several ways to significantly reduce the risk of transmission, including condom use during sexual activity and careful cleaning and disposal of needles. For HIV-positive pregnant women, however, the means of decreasing the risk of HIV transmission is somewhat more complicated. Although the risk of an HIV-positive mother transmitting the virus to her fetus or newborn is only 25% without any intervention, the risk may be reduced to as low as 2% if the mother follows certain protocols, including the use of anti-HIV medications during pregnancy and childbirth.[5] Whether following these protocols is appropriate, however, will depend on the woman's individual medical circumstances. Such protocols must also be respectful of the woman's right to make informed, uncoerced choices about her own health care and the health care of her newborn.

B. Informed Consent

Informed consent is the cornerstone of medical treatment in the United States. Without it, health care providers may not treat patients, which includes testing patients, except in certain emergency circumstances. In *Schloendorff v. Society of New York Hospital*, Justice Cardozo explained that "[e]very

[4] CDC, HIV/AIDS Basic Information, http://www.cdc.gov/hiv/topics/basic/index.htm#transmission (last visited July 10, 2009).

[5] *See* CDC, *supra* note 2. There is evidence suggesting that a woman's viral load plays a role in whether or not, and at what point, HIV is transmitted to her fetus. *See* Patricia M. Garcia et al., *Maternal Levels of Plasma Human Immunodeficiency Virus Type 1 RNA and the Risk of Perinatal Transmission,* 341 NEW ENG. J. MED. 394 (1999).

human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault, for which he is liable in damages." [6] Much later, the U.S. Supreme Court, citing *Schloendorff*, concluded that the "notion of bodily integrity has been embodied in the requirement that informed consent is generally required for medical treatment."[7]

Informed consent involves more than a simple agreement to be treated or tested. In order for consent to be informed, the patient must possess the requisite information about treatment options to make a rational choice. In *Matthies v. Mastromonaco*,[8] a case in which a patient received a course of noninvasive treatment without her informed consent, the New Jersey Supreme Court found that the treating physician was liable for negligence.[9] Discussing the need for informed consent, the court explained that the informed consent requirement is derived not from a patient's right to reject a nonconsensual touching, but from the patient's right of self-determination.[10] The court went on to state that, "[t]he patient's right of self-decision can be effectively exercised only if the patient possesses enough information to enable an intelligent choice."[11]

All states require informed consent for medical treatment, including treatment for HIV and related conditions. In addition, most states require specific informed consent from individuals who are tested for HIV,[12] and a majority of those states require that the informed consent be provided in writing.[13] The same requirements apply to pregnant minors who, at least in most states, may consent to their own health care.[14] This means that the person being tested must understand what the test is and why it is being administered, and must then sign a form to that effect. Obtaining written informed consent from the test subject is critical to ensuring that people are not being tested without their knowledge or against their will. Although the CDC has issued guidelines suggesting that written informed consent is a barrier to HIV testing and should be eliminated,[15] evidence

[6] 105 N.E. 92, 93 (N.Y. 1914).
[7] Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261, 269 (1990).
[8] 733 A.2d 456 (N.J. 1999).
[9] Although historically most courts considered treatment without informed consent as a battery, most courts now view such action on the part of the physician as an act of negligence or malpractice. *See id.* at 460-61.
[10] *Id.* at 460.
[11] *Id.* at 463.
[12] Two caveats should be noted. First, whether or not consent is actually informed in some instances is open to debate. For example, if a patient does not receive pre-test counseling, the patient is less likely to be making an informed choice, which is why many advocates oppose opt-out testing for HIV. Second, a small minority of states allow providers to test patients for HIV without consent, informed or otherwise, in certain circumstances. *See, e.g.,* ARK. CODE ANN. § 20-15-905 (allowing providers to test patients for HIV without consent if the provider is exposed to the patient's blood or if the provider determines that the test is medically indicated for diagnosis or treatment); ALA. ADMIN. CODE r. 420-4-1.14 (requiring providers to test pregnant women for HIV and not requiring providers to obtain consent or notify pregnant women of their right to refuse the test); 10A N.C. ADMIN. CODE 41A.0202(4),(15) (requiring providers to test patients for HIV without consent if the provider is exposed to the patient's blood or if the patient is pregnant and presents at labor and delivery with an unknown HIV status). As discussed in more depth below and in the Legal Advocacy Supplement, there are strong legal and policy arguments against mandatory testing.
[13] *See, e.g.,* ARIZ. REV. STAT. ANN. § 36-663; HAW. REV. STAT. § 325-16; MD. CODE ANN., HEALTH-GEN. § 18-336; MASS. GEN. LAWS ch. 111, § 70F; MICH. COMP. LAWS § 333.5133; NEB. REV. STAT. § 71-531; N.Y. PUB. HEALTH LAW § 2781; 35 PA. CONS. STAT. § 7605.
[14] *See, e.g.*, ALA. CODE § 22-8-4; 410 ILL. COMP. STAT. 210/1; MASS. GEN. LAWS ch. 112, § 12F; MINN. STAT. §§ 144.342, 343; N.Y. PUB. HEALTH LAW § 2504.
[15] CDC, *Revised Recommendations for HIV Testing of Adults, Adolescents, and Pregnant Women in Health-Care Settings*, MMWR Sept. 22, 2006, at 7–8, *available at* http://cdc.gov/mmwr/PDF/rr/rr5514.pdf. The 2006 guidelines, however, failed to identify evidence to support this contention.

indicates that having test subjects sign a consent form is not a barrier to testing, and actually leads to increased positive outcomes, including greater access to care.[16]

C. HIV Testing

1. Overview

Many women are confident that they are not at risk for HIV and regard an HIV test as unnecessary. Other women worry that they have been exposed to HIV and may not want to take the test because they are afraid to find out that they are HIV-positive. This reluctance is understandable, but, if a woman is infected, knowing her status is essential to monitoring her health, starting medication when it becomes necessary (sometimes many years after infection), and preventing transmission of the virus to her child in the event that she becomes pregnant. Although there is no cure yet for HIV/AIDS, antiretroviral drugs and prevention and treatment of opportunistic infections can keep HIV-positive individuals alive and healthy for multiple decades.

Before testing, women should insist on the counseling and information they need to understand what a positive or negative result means. Women who are unhappy with the way their providers discuss HIV testing with them might consider finding another doctor or clinic. Connecting with organizations and networks of HIV-positive women is a good way to identify skilled providers who understand the importance of mutual respect and communication with their patients.

Getting tested is also a good idea for minors who are sexually active. In all 50 states and the District of Columbia, minors may seek and receive testing for sexually transmitted infections (STI) without parental consent.[17] In the majority of states, minors may also consent to HIV testing.[18] Minors should be aware, however, that in some states they may not be able to receive treatment for HIV without parental consent. Most states that specifically categorize HIV as an STI allow minors to consent to HIV treatment.[19] In other states, the rules will vary.[20]

2. How It Works

There are several different types of HIV tests. The ELISA, which has been the most common preliminary HIV test, detects the presence of HIV antibodies in the blood. Although the ELISA is an accurate test (99.5% sensitivity), a positive ELISA must still be confirmed by a secondary test.[21] The confirmatory test is known as the Western blot. When a positive ELISA result is confirmed by a positive Western blot, the likelihood of an inaccurate diagnosis is less than 1 in 1,000.[22] Confirmatory tests are conducted because, although it is unlikely, false positive results can occur.

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[16] *See* ACLU AIDS Project & Lambda Legal, *Increasing Access to Voluntary HIV Testing: The Importance of Informed Consent and Counseling in HIV Testing* (2007), http://www.aclu.org/images/asset_upload_file15_30248.pdf.

[17] GUTTMACHER INSTITUTE, STATE POLICIES IN BRIEF: MINORS' ACCESS TO STD SERVICES (updated monthly), *available at* http://www.guttmacher.org/statecenter/spibs/spib_MASS.pdf.

[18] *Id.*

[19] Wing Wah Ho et al., *Complexities in HIV Consent in Adolescents,* 44 CLINICAL PEDIATRICS 473, 476 (2005). *See, e.g.,* CAL. FAM. CODE § 6926(a).

[20] In Connecticut, for example, the law requires parental consent for HIV treatment unless the physician determines that notification of the parents would result in treatment being denied or the physician determines that the minor would not access treatment if the parents were notified and the minor requests that the parents not be notified. *See* CONN. GEN. STAT. § 19a-592. For a state-by-state reference sheet regarding a minor's authority to consent to STD services, HIV testing and treatment, and confidentiality protections afforded to a minor, *see* GUTTMACHER, *supra* note 17.

[21] San Francisco AIDS Foundation, *HIV Testing*, http://www.sfaf.org/aids101/hiv_testing.html#accuracy (last visited July 9, 2009).

[22] *Id.*

Increasingly, however, newer rapid testing technologies are being used instead of the ELISA. Unlike the ELISA, which can take weeks to process, these rapid tests can be done with a sample of saliva and are able to return preliminary results in as little as 20 minutes. The rapid tests are highly accurate in detecting the presence of antibodies, but, as with the ELISA, a western blot is still required to confirm the preliminary positive result.[23]

Because it can take up to three months after infection for the body to develop antibodies to HIV that show up on standard tests,[24] HIV antibody testing will miss recently acquired, acute infections. It is also possible that a woman can contract HIV during pregnancy but after HIV testing. This is especially problematic for pregnant women, who have only a short window of time within which to make treatment decisions. Thus, pregnant women may consider having a second HIV test three months after the first to rule out new infections.[25] Some states that require opt-out testing also require health care providers to offer a follow-up test in the third trimester.[26]

3. Opt-In, Opt-Out, and Mandatory Testing

When a health care provider offers an HIV test and the patient has the option of accepting or declining the test, and the patient will not be tested unless she affirmatively accepts the test, the process is called opt-in because the patient actively chooses to have the test. This method also includes pre-test counseling, which, although different from state to state, generally requires the provider offering the test to explain what the test is, how it works, and what different results mean. This is the method that most people with HIV and their advocates support because it ensures that people are engaged in their diagnosis and care from the outset and will not be tested for HIV without their informed consent.

A number of states have enacted laws that either require or encourage physicians to test (or offer to test) pregnant women for HIV, unless the women opt out.[27] This means that the woman will be tested, unless she specifically refuses.[28] After many years of support for informed consent as a

[23] *Id.* A recent report by the CDC highlighted the importance of confirmatory testing in light of an unusually high number of false positive oral fluid (saliva) rapid tests in New York City between 2005 and 2008. *See* CDC, *False-Positive Oral Fluid Rapid HIV Tests—New York City, 2005-2008*, 57 MMWR 660 (2008), *available at* http://cdc.gov/mmwr/preview/mmwrhtml/mm5724a4.htm,

[24] *Id.*

[25] A 2007 North Carolina study found that five of fifteen women who tested negative for antibodies but positive by RNA assay were pregnant. All received ARVs and delivered HIV-negative infants. The study also looked at the maternal testing records of six HIV-infected infants, and found that three had tested positive and three negative. The researchers concluded that blood samples of HIV antibody-negative women should be pooled and tested by RNA assay to identify new infections and prevent these cases of perinatal transmission. *See* Kristine B. Patterson et al., *Frequent Detection of Acute HIV Infection in Pregnant Women*, 21 AIDS 2303 (2007).

[26] *See, e.g.*, R.I. GEN. LAWS § 23-13-19(a); TENN. CODE ANN. § 68-5-703(a).

[27] *See e.g.,* CAL. HEALTH & SAFETY CODE § 125090; CONN. GEN. STAT. § 19a-593(a); DEL. CODE ANN. tit. 16, § 1204; FLA. STAT. § 384.31; IND. CODE § 16-41-6-5, 7. *See also* Jeremy W. Peters, *New Jersey Requires H.I.V. Test in Pregnancy*, N.Y. TIMES, Dec. 27, 2007. For examples of general opt-out HIV testing laws not related to pregnancy, see LA. REV. STAT. ANN. § 40:1300.13(A); ME. REV. STAT. ANN. tit. 5, § 19203-A. For information about testing in all 50 states, refer to the State HIV Testing Laws Compendium at http://www.ucsf.edu/hivcntr/StateLaws/Index.html (updated Jan. 2009).

[28] In a few states, and under certain circumstances, women are not even offered the right to refuse if the provider determines that an HIV test is necessary for diagnosis or treatment. In these cases, testing is neither opt-in nor opt-out; it is mandatory. However, the onus is on the provider to conduct the test, not on the woman to obtain the test. See *supra* note 12 for a list of such laws.

precedent to HIV testing, opt-out testing is now recommended by the CDC for all pregnant women who present for care[29] and is also supported by the American College of Obstetricians and Gynecologists (ACOG).[30] Depending on the particular opt-out testing protocol, the physician may simply inform the woman that she is going to be tested unless she specifically indicates that she does not want to be tested, or the physician may first explain a little about the test. Ideally, providers will choose to provide their pregnant patients with the information necessary to ensure an informed choice. However, physicians may be unwilling to expend staff time to explain the test to all of their patients and may simply expect their patients to trust their judgment. When this happens, consent is not "informed" because patients lack sufficient information on which to base a decision. Instead, agreement is assumed wherever opposition is not recorded.

Proponents of opt-out testing argue that these measures will lead to increased testing rates, and thus identify more HIV-positive pregnant women earlier. However, the main reason why some women deliver without knowing their HIV status is not that informed consent was a barrier, but rather that they were not engaged with prenatal care.[31] This is especially true for very poor women and women who use drugs. In addition, almost all women will consent to an HIV test during pregnancy if they are properly informed, counseled, respected, and protected, yet many physicians fail to offer them a test.[32]

A small minority of states have further eroded the principle of informed consent by allowing—and even mandating—HIV testing without *any* consent from the patient under certain circumstances. In Arkansas, for example, providers may test patients without the patient's consent if the provider determines that the test is medically indicated for diagnosis or treatment.[33] Alabama state law *requires* providers to test pregnant women for HIV but does not require providers to obtain consent or even notify women of their right to refuse the test.[34] Similarly, North Carolina law requires providers to test pregnant women who present for labor and delivery if the woman's status is unknown.[35] By eliminating informed consent—and, in some instances, physician judgment—these laws are inherently problematic from both a legal and policy perspective. As discussed in greater detail in the Legal Advocacy Supplement, testing without consent violates a patient's right to refuse treatment as guaranteed under the U.S. Constitution, international law, and many state patient bills of rights.[36]

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[29] *See* CDC, *supra* note 15.

[30] *See* AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, COMM. OPINION NO. 411: ROUTINE HUMAN IMMUNODEFICIENCY VIRUS SCREENING (2008). *But see* AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, COMM. OPINION NO. 389: HUMAN IMMUNODEFICIENCY VIRUS (2007), *available at* http://www.acog.org/from_home/publications/ethics/co389.pdf.

[31] *See* Denise J. Jamieson, et al., *Rapid Human Immunodeficiency Virus-1 Testing on Labor and Delivery in 17 U.S. Hospitals: The MIRIAD Experience*, 197 AM. J. OBSTETRICS & GYNECOLOGY (SUPPLEMENT) S72, S72 (2007).

[32] *Id. See also* CDC, *HIV Testing Among Pregnant Women—United States and Canada, 1998-2001*, 51 MMWR 1013 (2002), *available at* http://cdc.gov/mmwr/preview/mmwrhtml/mm5145a1.htm (indicating that "increases in pre-natal HIV testing rates…were probably associated with a greater likelihood that [women] were offered HIV testing during prenatal care").

[33] *See* ARK. CODE ANN. § 20-15-905. This statute also allows providers to test patients without consent if the provider is exposed to the patient's blood. *See id.*

[34] *See* ALA. ADMIN. CODE r. 420-4-1.14.

[35] *See* 10A N.C. ADMIN. CODE 41A.0202(14). This regulation also requires a provider to test a patient for HIV if the provider is exposed to a patient's blood. *See id.* 41A.0202(4).

[36] *See* Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261 (1990) (recognizing a right to refuse medical treatment under the U.S. Constitution). Under international law, consent to HIV testing is protected under the right to privacy guaranteed by Article 12 of the Universal Declaration of Human Rights and Article 17 of the International Covenant on Civil and Political Rights. Universal Declaration of Human Rights, G.A. Res. 217A, U.N. GAOR, 3d Sess., 1st plen.

Moreover, it fails to provide necessary counseling, may deter patients from seeking medical help, and compromises the physician-patient relationship.[37]

D. Treatment

1. Overview of HIV Treatment[38]

Treatment for HIV infection usually takes the form of antiretroviral therapy (ART), which involves the use of antiretroviral (ARV) drugs that have been developed to interfere with or prevent various processes within the HIV life cycle. ARVs fall into four classes, each of which combats HIV in a different way.[39] Treatment typically consists of the use of two or more classes of ARVs in combination. These drugs cannot cure HIV, but can help HIV-positive individuals live longer, healthier lives by suppressing the virus, frequently to undetectable levels.

Despite their effectiveness in combating HIV, however, these drugs do not come without their drawbacks. Many of these drugs cause unpleasant and sometimes debilitating side effects that may compel some people to stop taking them. Missing doses may lead to drug resistance, which results in a decrease in treatment options. This particular problem can be complicated by drug regimens that require people to take multiple pills, several times a day. Fortunately, this problem has been alleviated in part by the development of therapies that require fewer doses, and pills that contain two or three medications in one. For those who, for whatever reason, still have trouble consistently taking the drugs, medication adherence counseling and side effect management can help some people taking these drugs adhere to their regimens to prevent resistance and cope with side effects. However, those experiencing burdensome side effects should first explore medication alternatives with their physicians; it is the responsibility of all physicians to listen to their patients and take them seriously.[40]

2. General Right to Medical Treatment without Discrimination

Mtg., U.N. Doc. A/810 (Dec. 12, 1948); International Covenant on Civil and Political Rights, art. 17, Mar. 23, 1976, 99 U.N.T.S. 171; *see also* Office of the High Commissioner for Human Rights & Joint United Nations Programme on HIV/AIDS, International Guidelines on HIV/AIDS and Human Rights, ¶ 119, U.N. Doc. HR/Pub/06/9 (2006) (stating that the right to privacy includes the obligation to seek informed consent to HIV testing); *see also, e.g.*, FLA. STAT. § 381.026; N.Y. COMP. CODES R. & REGS. tit. 10, § 405.7.

[37] For a full discussion of the dangers of mandatory testing, see *HIV Testing*, ALQ (AIDS Legal Network, Cape Town, South Africa), Sept. 2006, available at http://www.aln.org.za/sep2006.asp.

[38] Information in this section is from the National Institute of Allergy and Infectious Diseases (NIAID), *Treatment of HIV Infection* (Nov. 2007), http://www.niaid.nih.gov/factsheets/treat-hiv.htm, and Avert, *Continuing Antiretroviral (ARV) Treatment*, http://www.avert.org/conttrt.htm (last visited July 10, 2009). For more in-depth information on HIV treatment, see Panel on Antiretroviral Guidelines for Adults and Adolescents, *Guidelines for Use of Antiretroviral Agents in HIV-1-Infected Adults and Adolescents* (Nov. 3, 2008), *available at* www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf.

[39] The four classes are reverse transcriptase inhibitors (both nucleoside and non-nucleoside), protease inhibitors, entry and fusion inhibitors, and integrase inhibitors.

[40] Although long-term effects of ARV therapy for both the mother and fetus are not entirely understood, some medications may come with risks. This is why the U.S. Department of Health and Human Services recommends that patients discuss potential drug-related toxicity with their care providers before engaging in long-term treatment. *See* Panel on Antiretroviral Guidelines for Adults and Adolescents, *supra* note 38, at 22, 33, 60–61.

Although the U.S. Constitution does not provide or protect a fundamental right to health care,[41] the right to access medical treatment without discrimination is protected by several laws. The most commonly invoked of these is the Americans with Disabilities Act (ADA),[42] which prohibits places of public accommodation, including medical facilities, from discriminating against individuals on the basis of their disability. When considering the impact of the ADA on people living with HIV, the U.S. Supreme Court has held that HIV infection, although not a *per se* disability, is an impairment that can be considered a disability if all of the statutory requirements are met.[43] As a result, physicians are prohibited under the ADA from denying medical treatment to patients solely on the basis of their HIV infection. Physicians are similarly barred by the Rehabilitation Act of 1973,[44] the precursor to the ADA, which prohibits such discrimination by the federal government and federally funded entities. In addition to these federal protections, there are state laws that provide protection to individuals seeking medical care.[45]

III. Considerations Before Pregnancy

A. Getting Tested

Testing for HIV is usually recommended for anyone who is contemplating pregnancy. Because interventions are available that minimize the risk of transferring HIV to her child or a partner, a woman should know her own and her partner's HIV status before getting pregnant. Like anyone else considering an HIV test, a woman contemplating pregnancy may ask her physician about a test, or may go to an HIV counseling and testing site, information about which is usually available through the state HIV/AIDS office. However and wherever she chooses to be tested, the laws of the state in which she is tested will determine the extent to which she is counseled about the test and its meaning, and whether or not her true informed consent is obtained prior to the test. Keep in mind that state laws establish minimum requirements; no state actually prohibits a health care provider from discussing the meaning and purpose of HIV testing, and a good physician will ensure that women are adequately counseled before and after testing.

B. Considerations after a Positive Test

Being HIV-positive does *not* mean that a woman should avoid pregnancy. In fact, a recent study found that, in general, HIV-positive women who become pregnant stay healthier and are less likely to have an AIDS-defining event or die from AIDS than HIV-positive women who do not become pregnant.[46] Researchers think that this may be because HIV-positive women who become pregnant

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[41] *See* Estelle v. Gamble, 429 U.S. 97 (1976); DeShaney v. Winnebago County Dep't of Social Servs., 489 U.S. 189, 198-200 (1989); Wideman v. Shallowford Cmty. Hosp., 826 F.2d 1030, 1032-33 (11th Cir. 1987); *see also* Mark Earnest & Dayna Bowen Matthew, *A Property Right to Medical Care*, 29 J. LEGAL MED. 65, 67-68 (2008); Puneet K. Sandhu, *A Legal Right to Health Care: What Can the United States Learn from Foreign Models of Health Rights Jurisprudence?,* 95 CAL. L. REV. 1151, 1162 (2007).

[42] Pub. L. No. 101-336, 104 Stat. 327 (1990) (codified as amended at 42 U.S.C. § 12101, *et seq.*).

[43] *See* Bragdon v. Abbott, 524 U.S. 624 (1998).

[44] Pub. L. No. 93-112, 87 Stat. 355 (1973) (codified as amended at 29 U.S.C. § 701, *et seq.*).

[45] *See, e.g.*, MASS. GEN. LAWS ch. 272, § 98; CAL. CIV. CODE § 54.1; COLO. REV. STAT. § 24-34-601; 775 ILL. COMP. STAT. § 5/5-102; LA. REV. STAT. ANN. § 51:2247. Florida law specifically prohibits discrimination by places of public accommodation against people living with HIV and AIDS. *See* FLA. STAT. § 760.50. There have also been a few attempts on both the national and state levels to make health care a constitutional right, although these attempts have thus far not been successful. *See* H.R.J. Res. 30, 110th Cong. (2007); H.R.J. Res. 18, 74th Leg. Assem., Reg. Sess. (Or. 2007).

[46] Jennifer H. Tai et al., *Pregnancy and HIV Disease Progression During the Era of Highly Active Antiretroviral Therapy*, 196 J. INFECTIOUS DISEASES 1044, 1046–47 (2007). *See also* Kathryn Anastos, *Good News for Women Living with HIV*, 196 J. INFECTIOUS DISEASES 971 (2007).

are "highly motivated" to take medications to prevent transmission, and generally to manage their own health with regular clinic visits and dietary supplements.[47]

For an HIV-positive woman, having the lowest possible viral load before conception and through the pregnancy provides the best chance of avoiding transmission to her child.[48] Health care providers working with HIV-positive women who are taking ARVs should work to "attain a stable, maximally suppressed maternal viral load prior to conception," and at the same time "evaluate and control for therapy-associated side-effects which may adversely impact maternal-fetal health outcomes (e.g., hyperglycemia, anemia, hepatic toxicity)."[49] Knowing that she is HIV-positive before conceiving will give the woman time to find expert HIV medical care, to make sure that her health is stable, and to find an obstetrician who is experienced and sensitive with HIV-positive patients. The HIV doctor and OB/GYN should collaborate to ensure the best possible outcome for the patient. Referrals to experienced providers can be obtained from local HIV service organizations.[50] In addition, several resources are available for HIV-positive women who are considering pregnancy.[51]

C. Serodiscordant Couples: Conception without Transmission

If an HIV-negative woman would like to get pregnant, and the man who would be the father is HIV-positive, traditional methods of conception typically are not recommended because of the risk of HIV transmission from the man to the woman, unless both partners are free of sexually transmitted infections and the male partner has no detectable HIV.[52] Although in the United States it is far more difficult for a man to contract HIV from a woman, if the woman is HIV-positive, a couple may want to explore ways to further reduce transmission risk during conception.[53] To address this situation, alternative methods of conception that reduce but do not eliminate the risk of transmission have been identified. One such method is pre-exposure prophylaxis (PrEP) along with timed intercourse, which involves the woman taking antiretroviral medications and then limiting sexual intercourse with her HIV-positive male partner to the point in her cycle when she is most likely to conceive.[54] The risk of HIV transmission with this method is further decreased if the

[47] Joe De Capua, *Pregnancy May Offer Some Protection Against Full-Blown AIDS*, VOANEWS.COM, Sept. 19, 2007, *available at* http://www.voanews.com/english/archive/2007-09/2007-09-19-voa7.cfm?CFID=275295770&CFTOKEN=66167017 (last visited July 10, 2009).

[48] 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 7.

[49] *Id.* at 14.

[50] The HIV/AIDS Resource Center for Women at The Body can assist with referrals. *See* http://www.thebody.com/women/resource/resources.html.

[51] *See, e.g.*, Kay Johnson, et al., *Recommendations to Improve Preconception Health and Health Care—United States*, 55 MMWR RR-06 (2006), *available at* http://cdc.gov/mmwr/preview/mmwrhtml/rr5506a1.htm; Erika Z. Aaron et al., *Preconception Health Care for HIV-Infected Women*, 15 TOPICS IN HIV MED. 137 (2007); HIV i-Base, *HIV, Pregnancy and Women's Health* (Jan. 2009), http://www.i-base.info/guides/pregnancy/index.html (last visited on July 10, 2009). These sources address two concerns that are different sides of the same coin: treating a woman's HIV appropriately without putting a future child at risk of birth defects, which some drugs (such as efavirenz) can cause, and preventing transmission of the virus to the baby without the mother developing resistance to ARVs.

[52] There have been some recent studies suggesting that a low viral load may reduce the risk of HIV transmission among heterosexual couples. *See* David P. Wilson et al., *Relation Between HIV Viral Load and Infectiousness: A Model Based Analysis*, 372 LANCET 314 (2008).

[53] Nancy S. Padian, et al., *Female-to-Male Transmission of Human Immunodeficiency Virus*, 266 JAMA 1664 (1991).

[54] *See* Pietro Vernazza, *Pre-Exposure Prophylaxis and Timed Intercourse for HIV-Discordant Couples Willing to Conceive a Child* (2007), http://www.aegis.com/conferences/iashivpt/2007/MOPDC01.pdf.

woman's partner is on ARV therapy.[55] Another method involves "sperm washing" and intrauterine insemination (IUI) technologies, which have been developed for conception of a child with the man's sperm without putting the woman or the fetus at risk of infection.[56] The IUI procedure is expensive and often not covered by insurance,[57] but the sperm washing technique is virtually 100% effective for elimination of both HIV and hepatitis C.[58]

IV. Considerations During Pregnancy

A. Getting Tested

In most states, women receiving prenatal care will be offered an HIV test. More commonly now, in response to CDC recommendations,[59] many states are either encouraging or compelling physicians to test pregnant women for HIV unless they opt-out.[60] Although it is important for pregnant women to know their HIV status, opt-out or mandatory testing raises serious legal and policy issues, discussed above[61] and in the Legal Advocacy Supplement. As one commentator notes:

> For a pregnant woman unaware of her HIV infection, the decision to be tested is the first decision in a potential series of decisions. These are by no means easy decisions, and cannot be undertaken without counseling and support from healthcare professionals who have patients' implicit trust and confidence. After all, the decision whether to commence antiretroviral treatment must be made without knowing the long-term effects of *in utero* drug exposure on the infant. But an effective provider-patient relationship is not established by imposing HIV testing in a manner that displays little, if any, respect for a patient's decision making.…Nor is such a relationship established when…an HIV testing protocol turns prenatal care providers into enforcers of a legislative policy that is, for many women, a *de facto* mandatory testing requirement.[62]

Several studies have demonstrated that when a woman is satisfied with her care provider, she is more likely to remain in care.[63] Lack of communication and trust are often cited as reasons for dissatisfaction with care, and the subsequent decrease in positive health outcomes. This is particularly true for women who identify as African-American and Hispanic, for whom cultural differences may lead to communication challenges. It stands to reason then that women whose

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[55] Thérèse Delvaux & Christiana Nöstlinger, *Reproductive Choice for Women and Men Living with HIV: Contraception, Abortion and Fertility*, 15 REPRODUCTIVE HEALTH MATTERS (29 Supp.) 46, 55 (2007).

[56] *See* Louis Bujan et al., *Safety and Efficacy of Sperm Washing in HIV-1-Serodiscordant Couples Where the Male Is Infected: Results from the European CREAThE Network*, 21 AIDS 1909 (2007); ANN A. KIESSLING ET AL., ASSISTED REPRODUCTION WITH SPERM FROM HIV-INFECTED MEN, http://www.bedfordresearch.org/articles/ASRM07PrizePaper.pdf. For additional resources, see http://www.thebody.com/content/art911.html#resources.

[57] *See* Greg Lucas, *Ban of Use of Sperm from HIV-Positive Men Under Review*, S. F. CHRON., Mar. 27, 2007, at B2.

[58] *See* Nicolas Garrido et al., *Semen Characteristics in Human Immunodeficiency Virus (HIV)- and Hepatitis C (HCV)-seropositive Males: Predictors of the Success of Viral Removal after Sperm Washing*, 20 HUM. REPROD. 1028 (2005).

[59] *See* CDC, *supra* note 15.

[60] *See supra* note 27.

[61] *See supra* notes 33-37 and accompanying text.

[62] David W. Webber, *HIV Testing During Pregnancy: The Value of Optimizing Consent*, 18 AIDS & PUB. POL'Y J. 77 (2003).

[63] *See* Health Resources and Services Administration, Women's Health USA 2009, Satisfaction with Health Care, http://mchb.hrsa.gov/whusa09/hsu/pages/312shc.html (last visited Oct. 29, 2009); J.K. Burke et al., *Dissatisfaction with Mecical Care Among Women with HIV: Dimensions and Associated Factors*, 15 AIDS CARE 451 (2003); Lisa M. Sullivan et al., *The Doctor-Patient Relationship and HIV-Infected Patients' Satisfaction with Primary Care Physicians*, 15 J. GEN. INTERNAL MED. 462 (2000); Jules Levin, Perceptions of Care by HIV-Infected Women of Color in the United States, 48th Annual ICAAC / IDSA 46th Annual Meeting (2008), http://www.natap.org/2008/ICAAC/ICAAC_93.htm.

providers talk to them about HIV testing and encourage them to be tested without coercion are more likely to remain in care, regardless of their test results.[64]

B. Considerations after a Positive Test

1. The Woman Is Already Being Treated with ARVs

All women, regardless of pregnancy, have the right to treatment of their own HIV infection, and to make treatment decisions without coercion. The U.S. Public Health Service Task Force Recommendations affirm that

> [t]reatment recommendations for pregnant women infected with HIV have been based on the concept that therapies of known benefit to women should not be withheld during pregnancy unless there are known adverse effects on the mother, fetus, or infant and unless these adverse effects outweigh the benefit to the woman. Pregnancy should not preclude the use of optimal therapeutic regimens. The decision to use any antiretroviral drug during pregnancy should be made by the woman after discussing with her health care provider the known and potential benefits and risks to her and her fetus.[65]

The Public Health Service recommends continuation of ARV therapy when a woman becomes pregnant.[66] However, some ARVs that are safe and effective for non-pregnant adults can cause problems for pregnant women or their fetuses and women should discuss these issues with their HIV doctor and obstetrician. For example, efavirenz (EFV, brand names Sustiva and Atripla) has been shown to cause birth defects and is not recommended for pregnant women.[67] In addition, there have been documented cases of mitochondrial toxicity in uninfected children associated with prenatal use of AZT, but these cases are rare, and the risk of harm to the fetus or newborn from perinatally prescribed AZT is much less than the risk of HIV transmission.[68] According to one review, "current evidence from large clinical trials does not show that in utero exposure to ARVs poses a significant risk of severe congenital abnormalities, increased malignancy, or impaired growth and development."[69] However, research of this issue is limited and, ultimately, a woman will need to consider all of her options and, in consultation with her doctor, make her own decision about treatment.

2. The Woman Is Not Being Treated with ARVs

One of the most important interventions to date for preventing perinatal infection is antiretroviral prophylaxis. A landmark 1994 clinical trial known as PACTG 076 found that AZT, started at some point during the second trimester of pregnancy and taken until labor, and administered

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[64] A number of successful HIV testing models around the country demonstrate that it is readily possible to increase HIV testing without abandoning safeguards ensuring that testing is informed and voluntary. In New York, for example, where pre-test counseling, post-test counseling, and written proof of consent are required, testing rates increased dramatically when the process was streamlined, but protections were maintained. *See* Bernard M. Branson, Overview of Routine/Expanded HIV Testing in the U.S., Slide Presentation, 2008 National Summit on HIV Diagnosis, Prevention, and Access to Care (Nov. 2008), *available at* http://www.hivforum.org/storage/hivforum/documents/HIV%20Summit/Presentations/1120_pl_06_branson.pdf.

[65] U.S. Public Health Service Task Force, *supra* note 48, at 42-43.

[66] *Id.* at 16, 18.

[67] *Id.* at 42-43.

[68] Arthur Ammann, *In Utero Exposure to Antiretroviral Drugs and Birth Defects: A Brief Review of the Evidence* (2007), http://www.womenchildrenhiv.org/wchiv?page=tp-02-08.

[69] *Id.*

intravenously during labor, reduced the risk of transmission to newborns by approximately 67%.[70] AZT, administered in combination with other interventions, including cesarean surgery and avoiding breastfeeding, reduces the perinatal transmission rate still further, to less than 2%.[71]

Although AZT monotherapy has proved effective for reducing perinatal transmission, it is well established, as reflected in current treatment guidelines, that monotherapy is suboptimal and that a three-drug combination regimen is preferred for treatment of the woman's own infection as well as prevention of transmission to her fetus.[72] The timing of the pharmacologic intervention will depend on whether the mother needs ARV therapy for her own health, or whether the purpose of the ARV therapy is solely to lower the risk of transmission to her fetus. According to the Public Health Service, healthy HIV-positive women who do not need immediate treatment for their own infection (i.e., those with high CD4 counts and low viral loads) may wait to initiate ARV treatment, at least until the second trimester of pregnancy to minimize potential toxicity to the infant.[73] In general, immediate ARV treatment during the first trimester of pregnancy should be offered only to pregnant women who need treatment for their own infection.[74] As with pregnant women who are already taking ARVs for their own HIV infection, the treatment decision ultimately should rest with the woman.

C. Can HIV-Positive Pregnant Women Refuse Treatment?

1. Right to Refuse Medical Treatment Generally

Every adult has the right to refuse medical treatment under state common law and the United States Constitution. The Supreme Court has held that the right to refuse medical treatment is a liberty interest under the Fourteenth Amendment.[75] In some cases, this right has been upheld for minors who are deemed to be mature enough to make rational, informed decisions about their own health care.[76] The right to refuse medical treatment is not absolute, however, and courts have recognized four countervailing state interests that might override that right: (1) the prevention of suicide, (2) the preservation of the ethical integrity of the medical profession, (3) the preservation of life, and (4) the protection of third parties. An analysis of these interests in the context of the right to refuse ARV treatment is included in the Legal Advocacy Supplement.

2. Right to Refuse ARV Treatment During Pregnancy

For a number of reasons, an HIV-positive pregnant woman may choose to forego ARVs, even against the advice of her doctor. In such a situation, the doctor, hospital, or a state agency may attempt to coerce the woman into taking ARVs by threatening legal action, or may seek a court order that forces the woman to undergo treatment. Although courts generally do not involve themselves in the medical treatment of individuals, hospitals and state agencies have asked courts to

[70] Denise J. Jamieson et al., *Recommendations for Human Immunodeficiency Virus Screening, Prophylaxis, and Treatment for Pregnant Women in the United States*, 197 AM. J. OBSTETRICS & GYNECOLOGY (Supp.) S27 (2007).
[71] *See* CDC, *supra* note 2.
[72] U.S. Public Health Service Task Force, *supra* note 48, at 1.
[73] *Id.* at 20. According to the guidelines, EVF has been shown to have potentially detrimental effects on both maternal health and fetal development and, as a result, should be avoided during the first trimester. *Id.* at 18.
[74] *Id.* at 19.
[75] *See* Cruzan v. Dir., Mo. Dep't of Health, 497 U.S. 261 (1990).
[76] In *Planned Parenthood of Central Missouri v. Danforth*, the court concluded that, "[c]onstitutional rights do not mature and come into being magically only when one attains the state-defined age of majority. Minors, as well as adults, are protected by the Constitution and possess constitutional rights." 428 U.S. 52, 74 (1976). *See, e.g., In re* E.G., 549 N.E.2d 322 (Ill. 1989). *See also*, *Assembly Gives 14-Year-Olds a Say on Key Medical Care*, WASH. POST, Feb. 24, 2007, at B5; VA. CODE ANN. § 63.2-100(2).

compel the medical treatment of pregnant women based on two sources of jurisdiction. The first is the common law power of *parens patriae*, which gives the state the power to override a parent's wishes in certain circumstances in order to protect the health of a child.[77] The second is the state statute protecting children from abuse or neglect. Hospitals or state agencies attempting to compel medical treatment have sought legal custody of the fetus—and by extension the mother—by extending to fetuses a statute that prohibits child abuse or neglect and arguing that a mother's refusal to take medication is an act of abuse or neglect.[78]

Although numerous well-recognized constitutional and common law rights protect a pregnant woman's right to refuse medical treatment that might be beneficial to her fetus, there are no specific Supreme Court decisions addressing this issue. A New Jersey state court, however, has upheld a pregnant woman's right to refuse ARV treatment. In *New Jersey Division of Youth and Family Services v. L.V.*, the state Division of Youth and Family Services (DYFS) filed a complaint against an HIV-positive mother alleging that her failure to take ARVs while pregnant constituted neglect of her child, to whom she had since given birth.[79] The court rejected the state's argument on several grounds. First, the court held that a pregnant woman's right to choose what medications she will take is protected under her right to privacy, which includes "the ability to refuse medical treatment, even at the risk of her death or the termination of her pregnancy."[80] Her decision to refuse ARVs was protected from state interference even though it meant that the fetus would therefore be exposed to HIV.[81] Second, the New Jersey child abuse statute requires proof that the child was harmed as a result of the parent's actions. Because the statute protected only born children, the state had to demonstrate that the mother's actions while pregnant resulted in harm to the child after it was born.[82] The state, however, failed to demonstrate that the child was HIV-positive, and thus could demonstrate no harm.[83] Moreover, even if the child were HIV-positive, there would have been no guarantee that the child would not have been born HIV-positive even if the mother had taken ARVs, since the medication only reduced, rather than eliminated, the risk.[84] The *L.V.* case

[77] *See* Prince v. Massachusetts, 321 U.S. 158, 166-70 (1944). Cases that have cited this source of jurisdiction in the context of pregnancy include *Fosmire v. Nicoleau*, 536 N.Y.S.2d 492, 496 (N.Y. App. Div. 1989) (where "a pregnant woman refuses medical treatment and, as a result of that refusal, places the life of her unborn baby in jeopardy," then "the state's interest, as *parens patriae*, in protecting the health and welfare of the child is deemed to be paramount") and In re *Jamaica Hospital*, 491 N.Y.S.2d 898, 900 (N.Y. Sup. Ct. 1985) (ordering a pregnant woman to undergo a blood transfusion against her will because, for the purposes of the proceeding, the fetus could "be regarded as a human being, to whom the court stands in parens patriae"). However, even though these cases may state that *parens patriae* power can be cited as a source of jurisdiction in the context of pregnancy, these cases do not provide strong support for the proposition that a court may compel medical treatment of pregnant women, as discussed more fully below and in the Legal Advocacy Supplement.

[78] *See, e.g.*, Jefferson v. Griffin Spalding County Hosp. Auth., 274 S.E.2d 457, 459 (Ga. 1981) (per curiam); *see also* N.J. Div. of Youth and Family Servs. v. L.V., 889 A.2d 1153 (N.J. Super. Ct. Ch. Div. 2005) (holding that child abuse and neglect statute did not protect harm to a fetus, but that actions of a mother that took place while she was pregnant could be used to demonstrate neglect of a *born* child if the state could show that the actions resulted in harm to the child *after the child was born*). However, *Jefferson*'s reasoning and precedential value can be called into question on several levels, as discussed in more depth in the Legal Advocacy Supplement. For example, *Jefferson* was decided on an emergency basis, with little briefing, and does not properly consider the common law and constitutional right to refuse medical treatment. Furthermore, *L.V.*'s holding upheld the mother's right to refuse ARV treatment during pregnancy.

[79] *L.V.*, 889 A.2d at 1154-55.

[80] *See id.* at 1158.

[81] *See id.*

[82] *See id.*

[83] *See id.*

[84] *See id.*

demonstrates the substantial rights pregnant women have to determine the course of their medical treatment and the complexities involved in mandating ARV treatment. However, because the *L.V.* case relies on state law, and is a lower court decision, it is not dispositive in other jurisdictions. Advocates should therefore look to their own state precedent, as well as cases in other states, that consider the question of whether the state may order a pregnant woman to receive medical treatment for the benefit of the fetus.

While there are many cases in which courts have compelled medical treatment, these cases can be called into question based on several factors. For example, most of these cases were decided on an emergency basis with little briefing or preparation, do not adequately discuss the common law or constitutional right to refuse medical treatment, and have subsequently been called into question by other decisions.[85] In contrast, courts that have been given adequate briefing have written well-reasoned opinions that consider the pregnant woman's rights and have explicitly upheld a pregnant woman's right to refuse medical treatment, even where doing so might harm the fetus or risk fetal death.[86] A more in-depth discussion of these cases and a pregnant woman's right to refuse treatment is provided in the Legal Advocacy Supplement.

Cases compelling treatment also conflict with the most recent recommendations of major medical associations and the U.S. Public Health Service Task Force. Major medical associations discourage doctors from seeking judicial intervention when pregnant women refuse ARVs. The American Medical Association (AMA) has taken the position that a doctor's duty is to "ensure that the pregnant woman makes an informed and thoughtful decision, not to dictate the woman's decision,"[87] and has stated that "judicial intervention is inappropriate when a woman has made an informed refusal of a medical treatment designed to benefit her fetus." [88] Similarly, the American College of Obstetrics and Gynecologists has concluded that coercive and punitive policies towards treatment of pregnant women are neither ethically nor medically sound.[89] The 2008 U.S. Public Health Service Task Force recommendations specifically defend the right of a woman to refuse or limit prophylaxis: "[A] pregnant woman's informed choice on whether to take antiretroviral drugs either for her treatment or for prevention of mother-to-child transmission or to follow other medical recommendations intended to reduce perinatal HIV transmission should be respected."[90] Forcing treatment also jeopardizes the doctor-patient relationship and may cause women to avoid prenatal care.[91] Rather than forcing or coercing treatment, it is the responsibility of doctors to ensure

[85] *See, e.g.*, *Jefferson*, 274 S.E.2d 457 (decided with little briefing and with no discussion of the right to refuse treatment); *In re* Madyun Fetus, 114 Daily Wash.L.Rptr. 2233 (D.C. 1986), *appended to In re* A.C., 573 A.2d 1235 (DC. 1990) (decided with little briefing and subsequently called into doubt by In re *A.C.*); In re Jamaica Hospital, 491 N.Y.S.2d 898 (Sup. Ct. 1985); Raleigh Fitkin-Paul Memorial Hospital v. Anderson, 201 A.2d 537 (N.J. 1964).

[86] *In re* Fetus Brown, 689 N.E.2d 397 (Ill. App. Ct. 1997); *In re* Baby Boy Doe, 632 N.E.2d 326 (Ill. App. Ct.1994); *In re* A.C., 573 A.2d 1235 (D.C. 1990).

[87] Board of Trustees, American Medical Ass'n, *Legal Interventions During Pregnancy: Court Ordered Medical Treatments and Legal Penalties for Potentially Harmful Behavior by Pregnant Women*, 264 JAMA 2663, 2666 (1990).

[88] *Id.* at 2670; *see also In re* Brown, 689 N.E.2d 397, 403 (Ill. App. Ct. 1997).

[89] *See* American College of Obstetricians & Gynecologists, *Committee Opinion No. 321*, 106 OBSTETRICS & GYNECOLOGY 1127 (2005).

[90] U.S. Public Health Service Task Force, *supra* note 48, at 1. The October 2006 version of the guidelines included similar language, but the November 2007 version of the guidelines did not. This language was included in the July 2008 and April 2009 versions after the question was raised with guidelines authors who reviewed the section and opted to insert new language related to a woman's right to make her own treatment decisions.

[91] Robin Trindel, Note, *Fetal Interests vs. Maternal Rights: Is the State Going Too Far?*, 24 AKRON. L. REV. 743, 757-58 (1991). *See also id.*

that HIV-positive pregnant women can make informed, uncoerced choices about ARV treatment. Failure to inform a patient about the risks of proposed treatment and the alternatives may result in a doctor being held liable for negligence.[92]

V. Considerations During Labor and Delivery

A. Getting Tested

Although a great majority of the infants born to HIV-positive women in the United States do not develop HIV infection, some do contract HIV from their mothers. Of those infants who are determined to have HIV, a large percentage (40-85%) are born to women whose HIV status is unknown to their doctor before delivery.[93] This is mainly because women who are at the greatest risk of HIV infection are also likely to have less access to prenatal care, which in turn means less access to HIV testing.[94] Therefore, if a woman's HIV status is unknown when she goes into labor and presents for delivery at a hospital, current practice dictates that she should be counseled and offered a rapid test for HIV at that time.[95] As with all other methods of HIV testing, consent from the woman is usually required before a test may be conducted.[96]

The primary benefit of rapid testing technology is that it allows for preliminary results in as little as 20 minutes, which gives women and health care providers an opportunity to make quick, but informed, decisions about next steps. Research shows that a vast majority of women will accept the test if it is offered.[97] If the result is positive, there are interventions that still can reduce the risk of transmission to a newborn. In order to implement a rapid testing protocol, however, hospitals must have policies and qualified staff in place to provide sensitive counseling, and the laboratory capacity to offer rapid testing.[98] Some states require rapid testing during labor or delivery if the mother's HIV status is unknown at the time, and if the mother consents.[99]

B. ARV Treatment

1. Current Recommendations

If a rapid test is conducted and the result is positive, current guidelines recommend immediate initiation of AZT monotherapy without waiting for results of a confirmatory test.[100] This is because transmission usually occurs during labor and delivery, or close to that time, and AZT is well known to help prevent transmission. If the woman already knows she is HIV-positive and is on antepartum

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[92] Eric M. Levine, Comment, *The Constitutionality of Court-Ordered Cesarean Surgery: The Threshold Question*, 4 ALB. L.J. SCI. & TECH. 229, 272 (1994).

[93] AMERICAN COLLEGE OF OBSTETRICIANS AND GYNECOLOGISTS, COMMITTEE ON OBSTETRIC PRACTICE, PRENATAL AND PERINATAL HUMAN IMMUNODEFICIENCY VIRUS TESTING: EXPANDED RECOMMENDATIONS, COMM. OPINION NO. 304 (2004).

[94] *See* Jamieson et al., *supra* note 31, at S72.

[95] *See* U.S. Public Health Service Task Force, *supra* note 48, at 60; s*ee generally* CDC, *Rapid HIV Antibody Testing During Labor and Delivery for Women of Unknown HIV Status: A Practical Guide and Model Protocol*, Jan. 30, 2004, *available at* http://www.cdc.gov/hiv/topics/testing/resources/guidelines/pdf/Labor&DeliveryRapidTesting.pdf.

[96] In some states, consent from the woman is not required for an HIV test at labor and delivery. *See supra* note 12.

[97] Jamieson et al., *supra* note 31, at S80.

[98] *See* CDC*, supra* note 95*,* at 6.

[99] *See, e.g.*, CONN. GEN. STAT. § 19a-593(a); GA. CODE ANN. § 31-17-4.2; IND. CODE § 16-41-6-6.

[100] U.S. Public Health Service Task Force, *supra* note 48, at 60. A 1998 New York State study found that when this protocol was followed, transmission was reduced to about 10%, compared to 18.4% if ZDV began on day 3 or later, and 26.6% if there was no prophylaxis at all. *See* Nancy A. Wade et al., *Abbreviated Regimens of Zidovudine Prophylaxis and Perinatal Transmission of the Human Immunodeficiency Virus*, 339 NEW ENG. J. MED. 1409 (1998).

antiretroviral therapy, current guidelines indicate that she should continue her regular regimen during labor and delivery.[101] In addition, recent research has suggested that a single dose of nevirapine (NVP, brand name Viramune) during labor and delivery can increase the odds of preventing transmission from mother to child.[102] Nevirapine has been shown to be highly effective in reducing transmission, and the need for a single dose makes it cost effective.[103] This is especially useful in underresourced settings where complicated and expensive drug regimens are often not realistic, or when the mother did not receive ARV therapy during pregnancy. However, due to the potential risk of NVP resistance in both mother and infant, as well as a risk of toxicity, NVP is not currently recommended as a means of reducing intrapartum transmission for women who received ARV therapy during pregnancy.[104]

2. The Right to Refuse ARV Treatment During Delivery

Inevitably, some pregnant women will refuse ARV treatment during childbirth, for reasons such as religious beliefs or concerns the ARV treatment will pose risks to their health or the health of their child. The legal issues surrounding a pregnant woman's right to refuse ARV treatment are discussed briefly in the previous section and in greater detail in the Legal Advocacy Supplement. The legal issues regarding a woman's right to refuse ARV treatment during pregnancy are similar to the issues surrounding the right to refuse ARV treatment during childbirth.[105]

C. Vaginal Delivery vs. Cesarean Surgery

1. Background Information

Vaginal delivery may have greater risks of transmission to the child than a scheduled cesarean surgery before the membranes rupture because the infant is exposed to blood and vaginal secretions while in the birth canal.[106] While a cesarean surgery poses a greater risk for infection and other surgery-related problems, and also an increased risk of respiratory distress for the newborn, it is generally a safe and effective procedure for reducing the risk of HIV transmission.[107] Currently, cesarean surgery is recommended at 38 weeks gestation, before rupture of membranes, for women with viral loads >1000 copies/mL.[108] However, scheduled cesarean surgeries may not be appropriate for women who have been receiving HAART during their pregnancies and have low viral loads.[109]

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[101] U.S. Public Health Service Task Force, *supra* note 48, at 59-60. The guidelines also indicate that if the woman's antepartum regimen did not include ZDV, she should receive intrapartum IV ZDV in addition to her other medications.

[102] See Michelle S. McConnell et al., *Use of Single-Dose Nevirapine for the Prevention of Mother-to-Child Transmission of HIV-1: Does Development of Resistance Matter*, 197 AM. J. OBSTETRICS & GYNECOLOGY (Supp.) S56 (2007).

[103] *Id.*

[104] *See* U.S. Public Health Service Task Force, *supra* note 48, at 60-61. However, one study concluded that risk of toxicity was low and, when considered along with cost-effectiveness and high efficacy, should not preclude its use. *See* Jeffrey S. A. Stringer et al., *Effect of Nevirapine Toxicity on Choice of Perinatal HIV Prevention Strategies*, 92 AM. J. PUB. HEALTH 365 (2002).

[105] A few of the arguments in the previous section that supported a pregnant woman's right to refuse ARV treatment discussed the fact that such treatment might be drawn-out across several months; this is obviously not the case for ARV treatment during delivery. However, the remaining arguments apply equally to ARV treatment during delivery. ARV treatment is an invasive drug treatment with the possibility of adverse side effects. Moreover, ARV treatment given solely during delivery is provided solely for the benefit of the fetus rather than the benefit of the mother. For the reasons outlined in the previous section, CHLP argues that such treatment cannot be compelled.

[106] Denise J. Jaimeson et al., *Cesarean Delivery for HIV-Infected Women: Recommendations and Controversies*, 197 AM. J. OBSTETRICS & GYNECOLOGY (Supp.) S96 (2007).

[107] *Id.* at S99.

[108] *Id.* at S97. *See also* U.S. Public Health Service Task Force, *supra* note 48, at 60.

[109] Jamieson et al., *supra* note 106, at S99; U.S. Public Health Service Task Force, *supra* note 48, at 65.

Although some researchers have theorized that vaginal disinfection with chlorhexidine would decrease the likelihood of HIV transmission during delivery, there is little evidence that this intervention in fact reduces mother-to-child transmission.[110] However, two small trials that involved cleansing with chlorhexidine either before rupture of membranes or four hours or more after rupture did indicate that there might be some benefit, and there are no serious risks or side effects involved in this intervention.[111]

2. The Right to Refuse a Cesarean Surgery

Pregnant women retain the right to refuse a cesarean surgery, particularly where, as in the case of mother-to-child-transmission, the surgery is performed solely for the benefit of the fetus. While cesarean surgeries are generally safe, they are far more invasive than vaginal birth and pose greater risks to the mother; the risk to a pregnant woman's life is four to five times greater in cesarean deliveries than vaginal deliveries and the surgery poses several short-term and long-term risks.[112] HIV-positive women in particular may face greater risks from a cesarean surgery.[113] Moreover, a cesarean surgery involves a much greater recovery time than a vaginal birth.[114] As outlined in further detail in the Legal Advocacy Supplement, courts have seldom ordered cesarean surgeries over a pregnant woman's objections, and the precedential value of the few cases that have is limited; such decisions were trial court opinions decided on an emergency basis without the benefit of full briefing and participation by expert amicus that would have brought attention to the woman's common law and constitutional rights, and many of the opinions have been called into question by subsequent opinions.[115] In contrast, several recent and well-reasoned cases that have considered the mother's right to refuse medical treatment have upheld a pregnant woman's right to refuse medical treatment.[116] These cases and their application in the context of a pregnant woman living with HIV, are discussed more fully in the Legal Advocacy Supplement.

VI. Considerations after Delivery

A. Initial HIV Testing & Treatment

Current guidelines recommend that mothers who received ARVs during delivery and have low CD4 counts ($<350/mm^3$) continue the ARV postpartum without interruption.[117] Women with higher CD4 counts may be counseled to discontinue ARV after delivery, depending on whether they received ARVs only during delivery or during pregnancy, and whether the ARV therapy during

[110] Robert J. Biggar et al., *Perinatal Intervention Trial in Africa: Effect of a Birth Canal Cleansing Intervention to Prevent HIV Transmission,* 347 Lancet 1647 (1996).
[111] P. Gaillard et al., *Vaginal Lavage with Chlorhexidine During Labour to Reduce Mother-to-Child HIV Transmission: Clinical Trial in Mombasa, Kenya*, 15 AIDS 389 (2001).
[112] *See* Levine, *supra* note 92, at 238-39.
[113] Vaughn Taylor & Hanna Tessema, *Positive Pregnancy*, 17 ACRIA UPDATE 18, 20 (Winter 2008), *available at* http://img.thebody.com/cria/2008/winter2008.pdf#page=18.
[114] Margaret M. Donohoe, *Our Epidemic of Unnecessary Cesarean Sections: The Role of Law in Creating It, The Role of Law in Stopping It*, 11 Wis. Women's L.J. 197, 201 (1996).
[115] Pemberton v. Tallahassee Mem'l Reg'l Med. Ctr., Inc., 66 F.Supp.2d 1247 (N.D. Fla. 1999); Jefferson v. Griffin Spalding County Hosp., 274 S.E.2d 457, 458 (Ga. 1981) (per curiam); Raleigh Fitkin-Paul Memorial Hosp. v. Anderson, 201 A.2d 537 (N.J. 1964); *In re* Jamaica Hosp., 491 N.Y.S.2d 898, 899 (N.Y. Sup. Ct. 1985); *In re* Madyun Fetus, 114 Daily Wash.L.Rptr. 2233 (1986); *see also In re* A.C., 573 A.2d 1235 (D.C. 1990).
[116] *In re* Fetus Brown, 689 N.E.2d 397 (Ill. App. Ct. 1997); *In re* Baby Boy Doe, 632 N.E.2d 326 (Ill. App. Ct.1994); *In re* A.C., 573 A.2d 1235 (D.C. 1990).
[117] U.S. Public Health Service Task Force, *supra* note 48, at 48-49.

pregnancy was solely to prevent transmission to the infant or was for their own health.[118] Those women who received a preliminary HIV-positive diagnosis with a rapid test during labor should, after a follow-up test confirms the diagnosis, be counseled in the same manner as any other newly diagnosed person, taking into account any postpartum health issues.[119]

If a woman presents for labor and delivery with unknown HIV status, and does not consent to an HIV test, some states require that the infant be tested within a certain amount of time after birth.[120] However, if a standard antibody test comes back positive, it will not be conclusive because all infants born to HIV-positive women will test positive for HIV antibodies.[121] In other words, the test will indicate only that the infant was exposed to HIV, not infected with HIV. Nonetheless, because the test indicates exposure to HIV, current guidelines recommend immediate (6-8 hours after birth) ARV therapy for the infant, usually with a six-week course of AZT alone, to help prevent infection.[122] The same therapy is recommended for all infants born to known HIV-positive mothers, regardless of whether or not the mother was on ARV therapy during her pregnancy, or received short-course ARV therapy during labor and delivery.[123]

If the infant's antibody test is positive, it will have to be confirmed with a virologic (as opposed to immunologic) test, which is designed to detect the virus itself, as opposed to the antibodies the body develops to fight the virus.[124] However, even the virologic tests do not necessarily prove with absolute certainty whether or not the infant is infected. It is recommended that newborns be tested within the first 14 days of life, again at 1-2 months, and again at 3-6 months.[125] A positive HIV diagnosis is not made unless there are two separate positive virologic tests.[126] Conversely, a negative diagnosis is made when there are two separate negative virologic tests, even if the infant previously had one positive test.[127] If it is determined that an infant is infected with HIV, health care workers should discuss appropriate continued ARV therapy for the infant with the mother.

B. Can a Parent Refuse ARV Treatment on Behalf of an Infant?

In general, while parents have the right to choose the proper course of medical treatment, including refusal of treatment for the child, the state may intervene under its common law *parens patriae* obligation and child welfare statutes in order to protect the health and well-being of the child by ordering medical treatment and taking custody of the child.[128] Thus, although a parent may refuse

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[118] *Id.*

[119] *Id.*

[120] *See* CONN. GEN. STAT. § 19a-55 (amended 2009); 410 ILL. COMP. STAT. § 335/10 (2008); N.J. STAT. ANN. § 26:2-111.2 (West 2008); N.Y. PUB. HEALTH LAW § 2500-f (2001), N.Y. COMP. CODES R. & REGS. tit. 10, §§ 69-1.3(l)(2), 405.21 (2009).

[121] Jennifer S. Read, *Diagnosis of HIV-1 Infection in Children Younger Than 18 Months in the United States*, 120 PEDIATRICS e1547, e1555 (2007).

[122] U.S. Public Health Service Task Force, *supra* note 48, at 75-76; *see also* Susan M. King, *Evaluation and Treatment of the Human Immunodeficiency Virus-1 Exposed Infant*, 114 PEDIATRICS 497, 499 (2004).

[123] U.S. Public Health Service Task Force, *supra* note 48, at 77.

[124] Read, *supra* note 121. Although virologic tests are used for diagnosis in very young children, antibody tests may also be informative because the number of antibodies will decrease over time, and ultimately be eliminated by 18 months, in children who are not infected with HIV. *Id.*

[125] *Id.*; *see also* WORKING GROUP ON ANTIRETROVIRAL THERAPY AND MEDICAL MANAGEMENT OF HIV-INFECTED CHILDREN, GUIDELINES FOR USE OF ANTIRETROVIRAL AGENTS IN PEDIATRIC HIV INFECTION 7 (2009), *available at* http://aidsinfo.nih.gov/contentfiles/PediatricGuidelines.pdf.

[126] Read, *supra* note 121.

[127] *Id.*

[128] *See Prince*, 321 U.S. at 166-70; *see also Fosmire*, 536 N.Y.S.2d at 496; *Jamaica Hosp.*, 491 N.Y.S.2d at 900.

ARV treatment for his or her newborn child, in certain circumstances a court may see fit to order ARV treatment in order to decrease the chances of HIV transmission. An Oregon court has already ordered six weeks of ARV treatment to be administered to a newborn with an HIV-positive mother over the parents' objections.[129] It should be noted that this type of coercive intervention is at odds with U.S. Public Health Service guidelines and, in any event, advocates should ensure that any effort at intervention is responsive to the individual medical facts rather than broad assumptions about what is in the newborn's best interests.

The circumstances that courts consider worthy of compelled medical treatment vary by state, and advocates are advised to look to state statutes and previous judicial decisions to determine where a specific situation fits within the jurisdiction's interpretation of its laws. While states often use different standards and reach different conclusions when weighing whether to override a parent's objection to medical treatment of a child, several common issues emerge. Courts weighing judicial intervention generally consider several variables, including: the nature of the child's diagnosis, the risks of the proposed treatment, the proposed treatment's likely success, the parents' understanding of the prognosis, and whether the parents are seeking alternative treatment. The more invasive a treatment is and the less likely it is to result in success, the less likely a court is to order it.[130] The more threatening the medical condition, the more likely a court will override a parent's decision to refuse medical treatment; if the child is likely to die without treatment, a court is very likely to order treatment.[131] Courts are less likely to intervene if the child's diagnosis is not life-threatening or if the threat is not imminent.[132] Courts also are more likely to defer to parents' decisions where parents understand the child's prognosis and have selected an alternative treatment that is recommended by a physician and is not rejected by the medical community.[133]

Thus, while a parent's decision to reject ARVs on behalf of his or her child may face a legal challenge, the court's decision whether to intervene pursuant to its *parens patriae* powers will likely depend on numerous case-specific factors concerning the risk of HIV transmission, the efficacy of ARV treatment, the side-effects of ARV treatment, the parent's understanding of the child's prognosis, whether a doctor agrees with the parent, and whether the parent can provide other

[129] *See* Monique Anikwue, *Breast Still Best: An Argument in Favor of One HIV-Positive Mother's Right to Breastfeed*, 9 WM. & MARY J. WOMEN & L. 479, 483 (2003). A few cases have considered ARV treatment in older HIV-positive children. *See In re* Nikolas E., 720 A.2d 562, 565-67 (Me. 1998) (mother's decision to delay child's treatment for HIV with HAART did not constitute neglect because treatment was considered experimental and mother's decision was well reasoned). *But see* A.D.H. v. State Dep't of Human Resources, 640 So.2d 969, 971 (Ala. Civ. App. 1994) (court ordered mother to submit child for HIV treatment because mother was incapable of making rational decision regarding child's best interests).

[130] *See* Newmark v. Williams, 588 A.2d 1108, 1118 (Del. 1991); *see also* State v. Perricone, 181 A.2d 751, 760 (N.J. 1962) (parents' refusal would be more likely to be respected if "there were substantial evidence that the treatment itself posed a significant danger to the infant's life); Wallace v. Labrenze, 104 N.E.2d 769 (Ill. 1952) (same).

[131] *See, e.g.*, *In re* McCauley, 565 N.E.2d 411, 414 (Mass. 1991); *In re* D.L.E., 645 P.2d 271 (Colo. 1982); *In re* Cicero, 421 N.Y.S.2d 96, 967-68 (1979); *Perricone*, 181 A.2d at 760; *Wallace*, 104 N.E.2d 769; Morrison v. State, 252 S.W.2d 97 (Mo. App. 1952).

[132] *See, e.g.*, *In re Nicholas E.*, 720 A.2d at 565-67; *In re* Cabrera, 552 A.2d 1114, 1119-20 (Pa. Super. 1989) (ordering treatment but recognizing that court ordered treatment is not appropriate when there is no imminent risk of severe injury or death).

[133] In New York, for example, courts must look to "whether the parents, once having sought accredited medical assistance and having been made aware of the seriousness of their child's affliction and the possibility of cure if a certain mode of treatment is undertaken, have provided for their child a treatment which is recommended by their physician and which has not been totally rejected by all responsible medical authority." *See, e.g.*, *In re* Hofbauer, 393 N.E.2d 1009, 1014 (N.Y. 1979).

medical treatment that is not rejected by the medical community. These legal issues are explored in more depth in the Legal Advocacy Supplement. However, because the mother's individual health history will determine the effect ARVs will have in her particular circumstances, her medical history will be as relevant, if not more so, than general statistics on risk and transmission. Defending a parent's refusal to administer ARV in a child neglect proceeding will require a supporting medical expert to discuss both relevant statistics and the specific facts of the case.

C. Minimizing HIV Transmission from Breast Milk

The benefits of breastfeeding are well established: optimal nutrition, fewer childhood infections, and bonding between mother and infant all lead to decreased infant morbidity and mortality.[134] However, because of the risk of HIV transmission, breastfeeding is not recommended for HIV-positive women who live in areas where easy and reliable access to alternative feeding methods is widely available.[135] If an HIV-positive woman chooses to breastfeed, or has no other viable option, there are certain precautions she can take to minimize the risk of transmitting HIV to her infant. These include early weaning to reduce the duration of exposure, decreasing the mother's viral load by means of ARV therapy, avoiding mixed feeding with breast milk and formula, administering antiretroviral prophylaxis to the infant, and treating breast milk before or during feeding.[136] Recent studies have also suggested that transmission of HIV from mother to infant via breastfeeding can be significantly reduced by prolonging ARV therapy beyond the usual course.[137] Whether the treatment regimen involves monotherapy or a multi-drug cocktail will depend on the circumstances of each individual woman.[138] It is also important to note that recent studies have concluded that exclusive breastfeeding poses less risk of HIV transmission compared to alternating formula and

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[134] *See* Jennifer S. Read, *Human Milk, Breastfeeding, and Transmission of Human Immunodeficiency Virus Type 1 in the United States*, 112 PEDIATRICS 1196 (2003, *reaff'd*, 2007).

[135] U.S. Public Health Service Task Force, *supra* note 48, at 5; *see also* Read, *supra* note 134, at 1200. In developing countries, where access to clean water for mixing formula is not reliable, and malnutrition is a common cause of death in children, the benefits of breastfeeding may outweigh the benefits of alternative feeding methods, despite the HIV transmission risk. *See* Marie-Louise Newell, WORLD HEALTH ORGANIZATION, HIV TRANSMISSION THROUGH BREASTFEEDING: A REVIEW OF AVAILABLE EVIDENCE 6 (2004), http://www.unfpa.org/upload/lib_pub_file/276_filename_HIV_PREV_BF_GUIDE_ENG.pdf.

[136] *See* Read, *supra* note 134, at 1199-1200. A September 2008 BBC report indicates that a device to prevent HIV transmission during breastfeeding has been developed by an engineer at Cambridge University. The device, known as a nipple shield, disinfects the milk as it leaves the breast and before it is ingested by the baby. *See Breast Milk Purged of HIV Virus*, BBC News, Sept. 22, 2008, *available at* http://news.bbc.co.uk/2/hi/uk_news/england/cambridgeshire/7629253.stm.

[137] *See* Lawrence K. Altman, *Longer Drug Regimen Found to Help Babies Avoid HIV*, N.Y.TIMES, Feb. 5, 2008; Newton I. Kumwenda, et al., *Extended Antiretroviral Prophylaxis to Reduce Breast-Milk HIV-1 Transmission*, 359 New Eng. J. Med. 119, 122-23 (2008) (available at http://content.nejm.org/cgi/content/full/NEJMoa0801941). Another recent study found that early, abrupt cessation of breast feeding does not increase the likelihood that infants will remain HIV-negative, and may be harmful to HIV-positive infants. *See* Louise Kuhn et al., *Effects of Early, Abrupt Weaning for HIV Survival of Children in Zambia*, 359 New Eng. J. Med. 130, 137, 139 (2008) (available at http://content.nejm.org/cgi/content/full/NEJMoa073788).

[138] Adherence is particularly important during breastfeeding because resistance increases over time and studies have found that there is a "viral burst" when treatment is interrupted. *See* Michael Carter, *Short Course AZT for Breast-Feeding Mothers: Warning of Viral Rebound When AZT Stopped* [correction], AIDSmap, Oct. 3, 2004, http://www.aidsmap.com/en/news/94AF032C-5029-47AD-8686-D239C91F271B.asp; *see also* O. Manigart et al., *Effect of Perinatal Zidovudine Prophylaxis on the Evolution of Cell-Free HIV-1 RNA in Breast Milk and on Postnatal Transmission*, 190 J. INFECTIOUS DISEASE 1422, 1426 (2004).

breastfeeding.[139] Thus, HIV-positive women who choose to breastfeed should do so exclusively, if possible.

It is unclear whether courts will intervene to prevent HIV-positive women from breastfeeding. Breastfeeding a child falls within the ambit of parental decision-making, which is generally protected from state interference absent a need for the state to interfere pursuant to its *parens patriae* authority. At least one court has explicitly held that breastfeeding is an important liberty interest under the federal constitution that the state cannot infringe upon unless the infringement furthers sufficiently important state interests and is closely tailored to effectuate those interests.[140] However, courts have already begun to intervene in cases in which HIV-positive mothers wish to breastfeed their children. In a brief, unpublished opinion, the Circuit Court of Oregon issued an order providing the state with legal custody of an HIV-positive woman's child in order to prevent her from breastfeeding him.[141] The opinion provides little guidance into the court's legal reasoning, and is therefore of little use as precedent, but serves as a warning regarding steps that medical and child welfare officials may take in response to women who reject advice against breastfeeding.

Given that the debate continues to rage over whether the potential harms of breastfeeding are outweighed by the potential harms of not breastfeeding, it is impossible to predict whether a court will decide that a mother's choice to breastfeed should be subject to judicial override. Such a prediction is made more difficult by the numerous variables involved in the health and well-being of a particular mother and child that can affect the decision of whether or not to breastfeed. For example, the mother's viral load and whether she is taking ARVs may affect the risk of transmission through breastfeeding, while a child's sensitivity to formula or refusal to bottle-feed could affect the risks of not breastfeeding. Courts are likely to weigh these factors in making their determination.

VII. Conclusion

The right to make autonomous choices about one's body is fundamental and has been supported by case law in the United States for at least a century. This right becomes especially important for women, and in particular those women who are HIV-positive and are pregnant or thinking of becoming pregnant. Women who are HIV-positive have the right to be pregnant and the right to determine what tests and treatment they undergo during their pregnancy. In the end, it is up to each individual woman, in consultation with health care professionals and social support networks, to decide what is best for her own health, and the health of her child.

[139] H.M Coovadia *et al.*, *Mother to Child Transmission of HIV-1 During Exclusive Breastfeeding in the First Six Months of Life: An Intervention Cohort Study*, 369 LANCET 1107 (2007); Press Release, Johns Hopkins Bloomberg School of Public Health, *Exclusive Breastfeeding Reduces the Risk of Mother-to-Child HIV Transmission*, Apr. 29, 2005, http://www.jhsph.edu/publichealthnews/Press_Releases/2005/Humphrey_breastfeeding.html.

[140] *See* Dike v. School Bd. of Orange County, 650 F.2d 783 (5th Cir. 1981).

[141] *See In re* Tyson, No. 98-558J-01, 1999 WL 997489 (Or. Cir. Apr. 20, 1999); *see also* Anikwue, *supra* note 129, at 483.

Appendix A:
Web-Based Resources

Avert. Straightforward information in a question and answer format from the large London-based international NGO. (http://www.avert.org/pregnancy.htm)

AIDSinfo. Information from the National Institutes of Health related to HIV/AIDS treatment, prevention, and research. (http://aidsinfo.nih.gov/HealthTopics/ go to "Women's Issues" and click on "Mother-to-Child Transmission" or "Pregnancy")

AIDSmeds. Practical information on HIV infection, treatment, and prevention. (http://aidsmeds.com/ click on "Women & Children" then "Special Issues for Women & Children" then "Family Planning, Pregnancy, and HIV")

American College of Obstetricians and Gynecologists. (www.acog.org click on "Women's Issues" then "HIV" then "Routine Screening Welcome" or "Perinatal Welcome")

The Body. Accessible information about HIV treatment, prevention, testing, public policy, and other issues. (http://www.thebody.com/index.html click on "All Topics" then "HIV Treatment" then "Pregnancy and HIV)

The Center for HIV Law and Policy. Resources for people living with HIV and their advocates. (http://www.hivlawandpolicy.org/ click on "Pregnancy and Newborns" in left column)

Center for Reproductive Rights. Resources for pregnant women regarding their legal rights. (http://www.reproductiverights.org/ click on "Resources," then "Publications," then "Our Archive" to browse by issue, then select "HIV/AIDS" from the top drop down menu)

Guttmacher Institute. Research, policy analysis, and public education related to reproductive health. (http://www.guttmacher.org/index.html click on "Pregnancy" or "HIV/AIDS and STIs")

i-base. Treatment information for health care professionals and HIV-positive people from the London-based, HIV-positive led treatment activist group. (http://www.i-base.info/guides/pregnancy/index.html)

National Advocates for Pregnant Women. Resources to secure the human and civil rights, health and welfare of all women, focusing particularly on pregnant and parenting women, and those who are most vulnerable. (http://advocatesforpregnantwomen.org)

National HIV/AIDS Clinician's Consultation Center. A compilation of state HIV testing laws. Note that compilations such as these inevitably contain some errors, and thus information obtained here should be checked for accuracy. (www.ucsf.edu/hivcntr)

Women, Children, and HIV. Resources for HIV prevention and treatment from a collaboration between the François-Xavier Bagnoud (FXB) Center at the University of Medicine and Dentistry of New Jersey (UMDNJ) and the Center for HIV Information (CHI) at the University of California

San Francisco. (www.womenchildrenhiv.org click on "HIV Resource Library" then "Topic Areas" then "General Care During Pregnancy, Labor & Delivery)

Women's Health. The federal government source for women's health information. http://www.womenshealth.gov/ click on "Health Topics" then "HIV/AIDS" then "Living with HIV/AIDS" then "HIV/AIDS and pregnancy")