Expecting the Worst

One thing gets policymakers interested in in the lives of women with HIV -- pregnancy

August 1, 1995 By Amy Feehan

Didn't we win this battle a long time ago? A coalition of well-meaning children's groups and law-makers want to test every baby born for HIV -- which amounts to mandatory testing of their mothers as well. And that's not the end of it: Some even want to force all pregnant HIV positive women to take AZT, which one study has shown reduces the chance that the baby will be born infected. Protecting babies from HIV may sound like a good thing, but what are the long-term consequences for the child? Once again, women's bodies have become the battlefield of choice.

Maybe I've seen too many science-fiction movies, but for me the words mandatory testing conjure images of screaming victims being strapped to hospital gurneys and poked with sharp needles, their cries going unheeded because they have no choice. That's extreme, but the term mandatory indicates a power struggle, where someone superior is in command of someone inferior. I can almost hear the patriarchal cliche, "Here, take this -- it's good for you."

A decade after AIDS activists successfully beat back calls for mandatory testing and quarantine in response to the epidemic, politicians and policy makers at both the state and national level in the United States are currently debating mandatory testing for HIV. There are several approaches being tossed around: Mandatory testing of all newborns for HIV -- which is, in essence, mandatory testing of their mothers -- and the unblinding of anonymous seropositivity tests on newborns being performed in 45 states to help track the epidemic.

Women and newborns are being targeted in particular because they constitute the fastest growing segment of the HIV population. The number of AIDS cases among women increased by about 17 percent last year, and about 6,000 HIV positive mothers in the U.S. give birth each year.

Infant seropositivity tests reveal if a newborn carries HIV antibodies, which means for certain the mother is HIV positive. Approximately 25 percent of all babies who have the HIV antibodies also picked up the virus from their mother, and hence will eventually test positive for the virus itself. As the surveys stand now, neither the mothers nor physicians ever learn the results. The anonymity is an attempt to balance the need for data on the number of women with HIV -- which is crucial information for AIDS funding purposes -- with the right of the mother to privacy, since people with HIV and AIDS do face discrimination.

Until just recently, the Centers for Disease Control and Prevention (CDC) funded the anonymous

HIV screening of newborns, but in May the Clinton administration stunned even the CDC by suspending the seven-year program in response to threats to unblind the study. Some states, such as New York, are continuing the surveys.

However, many legislators say it's time to unblind them. They say not informing mothers if their babies test positive is ludicrous, especially when there is so much that can be done today to treat and care for babies with HIV. Others propose HIV testing be included in routine prenatal blood screening, right along with tests for syphilis and hepatitis, especially since there is a greater likelihood of encountering HIV today than older diseases.

The debate over mandatory testing -- in whatever form -- is back in the limelight, along with a new crop of legislation, for two main reasons. First, because of new research findings. AZT has been found -- in one important study, ACTG 076 -- to significantly reduce the risk of transmission of HIV from mother to child. In that 1993 clinical trial, pregnant women taking AZT transmitted the virus to their babies at a rate approximately two-thirds lower than those not taking the drug. The transmission rate for women given a placebo was 25.5 percent, while those given AZT transmitted the virus at a rate of 8.3 percent. The only immediate side effect observed was mild anemia in some infants.Given that advance, it seems reasonable that pregnant women should test for HIV not only so they can avoid breast feeding if they test positive, but also so they can take advantage of treatments to reduce the risk of perinatal transmission.

Second, HIV positive babies are living longer with the help of medical advances. In 1991, a group of doctors reported that *Pneumocystis carinii* pneumonia (PCP), the most common opportunistic infection among children with HIV, could be successfully treated with antibiotics. Blood tests have become increasingly more sophisticated, to the point where babies with HIV can now be diagnosed weeks, not months, after birth. Knowing that, proponents ask: Why not test all newborns for HIV so that not one child slips through the cracks? Further, early detection would likely save health care costs in the long run, since prophylactic treatments generally cost less than caring for a very sick child in a hospital.

Taken alone, these arguments are convincing and seem reasonable, particularly from a public health standpoint. However, if you value individual rights -- specifically the right of a woman to control her own body -- or are concerned about giving AZT to fetuses, mandatory testing seems wrong and, frankly, scary. Irene, a mother who's been positive since 1989, agrees. "What is scary about the notion of mandatory testing, is, personally, it makes me feel I've lost all control, and part of me worries what else doctors will get control of."

Opponents of mandatory testing say it should be up to each pregnant woman to decide if she wants to get tested, if she wants to take AZT if she is HIV positive and if she wants to have her newborn tested. She needs to be informed of all of her options and the risks and benefits involved with each -- which should include studies on transmission risk in addition to AZT data and information about different delivery methods. Opponents of mandatory testing also firmly believe that women want to be good mothers, and when properly informed will do what is best for them and their baby -- without having to be forced.

Everyone wants HIV positive pregnant women to know their status. But opponents say that information and counseling, not mandatory testing, is the answer. Don't scare them away from the health care system or shock them with the news they're HIV positive when it may be too late to do anything to reduce the risk to their child, they say. Many women fear losing their children or being unable to afford care if they test positive.

Interestingly, there is a division in thinking among advocates of even voluntary HIV testing -- which is a major sub-theme to this whole issue. While some advocate the use of AZT by pregnant women, others say too little is known yet about perinatal transmission and the long-term effects of AZT on children to say that AZT should be the standard treatment. Some argue that ACTG 076 was not scientifically sound and was too small of a study from which to generalize. They want to focus on why AZT decreased transmission -- possibly by lowering the mother's viral load -- and study alternatives such as vitamin A.

Adding further confusion to the larger debate is the issue of mandatory counseling combined with voluntary testing, where health care providers by law would have to counsel every pregnant woman about her right to an HIV test and her options should she test positive. That approach is favored by some AIDS activists and health care providers, namely the American Academy of Pediatrics, the American College of Obstetrics and Gynecology, and the American Association of Nurses . These groups know that many women who may not appear to be at risk for HIV are not informed of their option to be tested. Indeed, many physicians still believe that only prostitutes or drug users are actually at risk.

The majority of HIV/AIDS agencies and providers favor a more common sense approach: Routine counseling and voluntary testing. That's the way things pretty much work now, where health care providers, as a matter of routine, inform pregnant women of the option of testing, but that decision is left entirely up to the individual. Whatever the approach, the mandatory testing debate boils down to the allocation of health care dollars. States only have so much to spend on HIV testing, how should they spend it to get the maximum benefits? Do they put the money into HIV prevention so that fewer women become positive? Or do they put the money into testing newborns in the hopes of saving lives? So then it boils down to whose rights should take precedence: The mother's or her baby's. Is there a hierarchy of "innocence" when it comes to HIV and AIDS?

Many say yes, the public likes the idea of saving "innocent" babies and that AIDS research on women to date -- particularly in regards to clinical trials -- has focused mainly on pregnant women, reaffirming many women's groups' cry that women count only as reproductive vessels. Who counts in all of this depends on whom you ask: Many legislators and children's groups say if we have the science to effectively treat babies with HIV, let's employ it.

Women's groups, on the other hand, argue that if we can inform pregnant women of their choices and keep them from becoming infected in the first place, then the argument is moot. But, these groups say, above anything else women should remain in control of their bodies and reproductive choices.

America claims it's all about freedom. But if proposed legislation is any indication, it looks as if the government thinks informed women cannot be trusted to get tested and so it needs to force them to do so.

Two major pieces of mandatory testing legislation are currently being debated. Rep. Tom Coburn (R-OK) is proposing two amendments to the Ryan White CARE Act. The first amendment says that any state receiving funding under the Act must require each newborn to be tested for HIV and the results disclosed to the mother, unless the mother has been previously tested. The second amendment states that a woman's insurance cannot be terminated if she and/or her baby is found to be HIV positive.

According to legislative assistant Roland Foster, Coburn, who is a family physician, feels strongly that "it is important to slow the spread of the disease amongst women and children," the fastest growing population of HIV infection. Coburn is working with Rep. Gary Ackerman (D-NY), who is currently revising a draft of his bill called the Newborn Infant HIV Notification Act, or, as it is known on the streets, the "baby AIDS bill." The Congressman wanted to unblind seropositivity tests on newborns.

Ackerman was gaining wide support for his bill from some 220 co-sponsors (Democrats and Republicans alike). After the Clinton administration pulled funding for the surveys, Ackerman began revising his bill to require the testing of all newborns in every state for HIV and to have the test results disclosed to the mother. Ackerman's press secretary, Jordan Goldes, explained that mandatory testing of newborns for HIV is necessary because, 1) we do not live in an ideal world where every women would choose to have an HIV test if she were given the choice, and 2) not every woman seeks prenatal care, so there are babies whose HIV status goes undiagnosed until they end up in a hospital deathly ill. When pressed on the issue of why the focus on newborns versus prenatal testing or HIV prevention efforts for women, Goldes stumbled: "We've been dealing with babies, with the issue of testing newborns. Mothers are a different subject area."

Supporters of the Ackerman bill believe not disclosing test results is "immoral and unconscionable," Goldes says. Nettie Mayersohn, a New York State assemblymember (D-Queens), agrees. She and State Senator Guy Vellela (R-Bronx) are pushing not only for the unblinding of seropositivity tests in New York state but to make an AIDS test part of the prenatal "standard of care" for pregnant women unless a woman refuses in writing. Mayersohn has been fighting for such legislation for three years, but this session the bill is closer to being passed. It was approved by the New York Senate Health Committee in mid-March, and is awaiting a vote before the full assembly.

Mayersohn's legislation has some notable backers, including New York Health Commissioner Barbara DeBuono and Governor George Pataki. Perhaps its biggest backer is a Manhattan-based advocacy group and primary care organization for HIV positive children and their families, the Association to Benefit Children (ABC), which has filed a lawsuit to force the state to unblind test results, disclose the results to mothers and physicians and require women to take AZT if they are found to be positive. New York has the largest number of HIV positive women and children in the country.

Gretchen Buchenholz, head of ABC, says the lawsuit is about more than unblinding test results. “We are asking in a gentle way for all newborns to be tested, and their mothers and families counseled, tested and treated for HIV,” she says. “We also are asking [the same] for children in foster care who show risk factors for HIV.” She vehemently denies unblinding test results is in any way a witch-hunt to single out women with HIV. “We will invade a mother’s privacy, but that’s a heavy choice to make against offering [a baby] a whole childhood.”

Attorneys from the HIV Law Project in New York and Housing Works believe a mother’s privacy is worth protecting. The two agencies filed papers, on behalf of many women and AIDS agencies, to intervene against ABC’s lawsuit. They argue that the proposed changes are unconstitutional and establish a class -- women who have just given birth -- and then “denies them equal protection, a right to privacy and a right to due process.”

Theresa McGovern, executive director of the HIV Law Project, wants to know exactly how the results will be disclosed and to whom. The logistics of mandatory testing have not been adequately addressed yet in this debate. “It makes me nervous. If a woman signs a statement refusing testing, what happens to those forms, that information?” McGovern asks.

McGovern and those she represents believe mandatory testing will drive women away from health care and that the only proper response is mandatory counseling and increased access to health care services for all women and infants, particularly if they are HIV positive. “If you care about getting babies into care, you have to get women to buy into the process. And you don’t do that by forcing them. It’s really about trust,” says McGovern, who knows that it’s mothers who bring babies in for check-ups and follow-up studies. McGovern has been working for women’s rights in the AIDS battle for seven years and says she is disheartened by the whole debate, which she calls “ridiculously short-sighted.”

The director of AIDS policy for the national group Children, Youth and Families, David Harvey, echoes McGovern’s sentiments. “The current legislation attempts are misguided,” he says. “The appropriate way to prevent pediatric AIDS is to prevent HIV infection in the first place. We must do better with prevention and treatment options for women,” he stresses, but admits his side may be losing the battle with Mayersohn’s bill so close to becoming law.

Harvey, whose group works with health care providers who receive funding under the Ryan White CARE Act, notes the whole issue is indicative of a new Congress. “We obviously are seeing a conservative bend toward public health policies relating to the prevention and treatment of HIV and AIDS,” Harvey says. He worries about how AIDS spending will be allocated in the future.

The whole debate of mandatory testing and what programs will receive funding has many blurry ethical dimensions that do not fall cleanly into conservative or liberal orthodoxy. Buried in all of this is the issue of abortion. If a woman learns she is HIV positive before giving birth, she might choose to have an abortion, which may not sit well with pro-life legislators who would prefer to fund treatment for infants and children with HIV.

Claire Towle, a social worker in the family HIV clinic at Memorial Miller Children’s Hospital in Long

Beach, California and a board member of the Children Affected by AIDS Foundation, sees all the ethical dimensions in her job on the front-lines. She knows a few HIV positive women choose to have abortions and may be hated for that. Others plan to get pregnant knowing they are positive and will be called monsters by some just the same. Towle knows very well that confidentiality is important to her clients, but sees how much money is spent on caring for babies who go undiagnosed until it's too late. "There are so many issues," she says, sounding like a person trapped in the middle. "The reality is you just have to measure what the benefits are going to be, and if the benefits are greater than the risks, then you have to go with that."

Diane Bartels, acting director of the Center for Biomedical Ethics at the University of Minnesota explains that such risk/benefit analyses can be done by individuals, and that U.S. courts have long supported personal autonomy. "In this country, we don't like to mandate things in the interest of public health. The absolute right of the individual to refuse testing has been nearly unanimously upheld in the Courts, [such as] in end-of-life decisions," Bartels says.

If that's the case, maybe mandatory HIV testing will never fit within the autonomy framework of our Constitution and will never be upheld as law. Or maybe it's just that AIDS is going to remain a political disease rather than a medical disease, so issues around it will always be debated. "There is unanimity in the public health arena, but the debate persists in the political arena," notes Arthur Ammann, MD, director of research for the Pediatric AIDS Foundation and the physician who documented the first case of perinatal HIV transmission.

The consistency in thinking Ammann refers to is the support of universal, prenatal, voluntary HIV testing and routine counseling by the majority of groups involved in this debate. Government agencies (the office of National AIDS Policy headed by Patsy Fleming, the National Institutes of Health, the CDC and Human Resource Service Administration), medical groups (the American Medical Association and the American Academy of Pediatrics), AIDS activists (American Foundation for AIDS Research, Gay Men's Health Crisis, the Pediatric AIDS Foundation, Being Alive) and women's groups (WORLD and the National Organization for Women) all say no to mandatory testing. The Pediatric AIDS Foundation is so convinced voluntary testing is imperative that they have launched -- with the support of First Lady Hillary Rodham Clinton -- a three-year advertising campaign promoting voluntary, prenatal testing.

The American Academy of Pediatrics advocates the same, emphasizing a common sense approach to HIV testing, specific to each woman's situation. "Simply put, we think folks should have some idea of their HIV status when entering into parenthood," says Louis Z. Cooper, MD, an Academy board member and practicing pediatrician. He stresses that some women may need more information and counseling than others, depending on their situation, but if physicians behave sensibly and mothers have the best interest of the child in mind -- which they do -- then the two can work together as a team to raise a healthy, hopefully HIV-free child. "We oppose any activities that would be coercive, intrusive or disrespectful of the woman's rights," Cooper says.

ACTG 076 showed that a child is more likely to escape contracting HIV if the mother takes AZT during her pregnancy and delivery and if the newborn takes it immediately after birth. That

protocol, however, is not supported unanimously by all the players in the debate.

The CDC supports it, issuing new counseling and testing guidelines for pregnant women with HIV on July 7. The recommendations call for health care providers to counsel pregnant women on the benefits of HIV testing and AZT therapy and the testing remains voluntary.

AIDS czar Patsy Fleming strongly supports the CDC recommendations to use AZT. Her spokesman, Richard Sorian, noted: “Our underlying goal is to save the lives of babies who might become infected during perinatal transmission. AZT can greatly reduce the risk of perinatal transmission. We believe it is necessary and urgent to put that science to work.”

Lynne Mofenson, MD, of the Pediatric, Adolescent, and Maternal AIDS branch of the National Institutes of Health -- and co-author of the NIH’s recommendations on the use of AZT for pregnant women -- is a firm believer in 076. “In the United States, it would be unethical to ever do another placebo-controlled study with what we know now,” Mofenson commanded. “However,” she adds, “I do not believe that translates into mandatory testing.”

She is quick to point out that the issue of mandatory testing would have resurfaced even without 076, given the startling findings in pediatric AIDS prophylaxis. “Many activists denigrate 076, but this debate is not the trial’s fault. We unequivocally proved that taking AZT can reduce perinatal transmission.”

Mofenson agreed that neither the exact mechanisms of how AZT reduces transmission or the long-term effects of AZT are known, so every woman should choose for herself if she wants to take the drug.

The one ongoing long-term study of the effects of AZT in children -- ACTG 152 -- has so far found AZT to be less effective than ddI or a combination of ddI and AZT in preventing disease progression. The AZT arm of the blinded study was halted in April after two years of the trial was completed. AZT had “unexpectedly high rates of adverse side effects in children, like bleeding and biochemical abnormalities,” according to federal health officials quoted in the February 14 issue of *The New York Times*.

HIV positive mom Gina Grenata worries about the long-term effects of her taking AZT during pregnancy on her three-year-old HIV negative son Juan David, who is in a follow-up study. They found out that although Juan David is perfectly healthy, his main arteries are double normal size. Soon after learning that, while carpooling with some women on the way to an AIDS meeting, one of them she’d never met started talking about how she knew of babies born during 076 that had died from enlarged arteries. Grenata burst into tears immediately. "I told them *I* have such a child! What do the doctors know that I don’t? The doctors say, no, no, no, Juan David’s heart may have nothing to do with my AZT use. I love my doctor and want to believe that, but perhaps a lot of things are not being said."

It seems difficult to find documentation of the side effects of AZT, however. Arlene Buck, a study nurse on ACTG 076 and the natural history study of women with HIV, WITS (Women and Infant

Transfer Study), reports that of the many babies studied at Brigham and Women's Hospital in Boston, none have showed any signs of any long-term adverse effects.

The 839 enrollees of the ongoing ACTG 152 are between the ages of three and 18, and only eight percent had received antiretroviral therapy prior to enrollment; none had received more than six months' therapy. The study is scheduled to end in August. The design was overseen by Carol J. Baker, MD, and Janet Englund, MD, both of Texas' Baylor College of Medicine.

Englund says eagerly that AZT is not necessarily toxic, just less effective. "The kids on AZT did worse. I haven't seen all the data to say why, because the study is still blinded, but they were sicker." She still recommends AZT for pregnant women.

Michelle Murrain, Ph.D., a neurobiologist and AIDS researcher, has her own theories why children on AZT might be sicker. She is opposed to the use of AZT as the standard of care for pregnant women for two reasons. One, she believes AZT is risky to give to asymptomatic people. In her opinion, approximately 75 percent of the children born to mothers with HIV will be getting an unnecessary toxic drug. Two, AZT may be especially dangerous to give to a fetus.

"AZT has the effect of slowing down cell replication, particularly in cells that are rapidly reproducing -- such as in a developing fetus. If the rate of cell replication is interrupted, it's possible that complex processes -- such as cognitive abilities -- could be adversely affected." Murrain noted that many HIV positive women take AZT during their second trimester, a critical growth period for fetuses.

Murrain has had a difficult time finding others who are willing to step forward and question AZT as first-line therapy. Linda Meredith, a long-time AIDS activist, knows what's it's like trying to get someone to listen. She and colleague Maxine Wolfe have worked since 1989 to bring their fears about AZT to the forefront, writing articles that never see print in newspapers such as *The New York Times*, or magazines, such as the *New England Journal of Medicine*. "We want to bring attention to the poor science [of the study]. No one is talking about that. The public has accepted the results de facto and have moved quickly to the discussion of mandatory testing," she says.

Meredith, who holds a masters in immunology, and Wolfe, a major player in ACT UP/New York, have analyzed the study at great lengths. Specifically they question the test's shotgun design, which "ensured that we would never know from its findings when, if ever, AZT should be given to interrupt perinatal transmission," they wrote in a manuscript sent to *POZ*. "[The researcher's] hypothesis that AZT would decrease transmission because it would decrease maternal viral load was never tested." A recent study showed that the odds were 75 percent that children of women with high viral load would be infected; women with low viral loads had only a three percent chance of transmitting the virus perinatally.

Further, Meredith and Wolfe argue, 076 is scientifically unsound because the researchers went outside the standard care guidelines in designing the trial by including women with CD4 counts above 500. The CDC's current guidelines on testing and counseling are for women with counts between 200 and 500 to take AZT. It is possible then that women could develop a resistance to

AZT before they actually need it, they counter. One of their final arguments is that AIDS investigators were biased in their research, and that their careers “rest on the advancement of AZT.”

Perhaps after reading all this about AZT and hearing all the sides you no longer know who to believe. You likely don’t envy pregnant women with HIV who actually have to decide what they are going to do. But -- as you know if you *are* one of those women -- they say they would rather have the choice.

Mindy Benson, a pediatric nurse for five years at BAYPAC, Bay Area Perinatal AIDS Center, in San Francisco finds that ACTG 076 has been good news for her patients. “Before the results of 076 were published, a lot of women with HIV expressed feelings of shame and guilt about their pregnancies. Now that we know we can reduce the rate of perinatal transmission, HIV positive women aren’t hanging their heads anymore or feeling bad. A select number of positive women are even coming to us for pre-conception counseling and fertility counseling.”

Wait a minute. Women with HIV are actually planning to have children, and not just dealing with all the issues after learning of an unexpected pregnancy? Yes, they want to have a family, they want to leave a bit of themselves behind and they want to lead normal lives.

Gina Grenata thought a normal life was in short order when in late 1991 she finally got a job with health insurance and saw the “clear blue easy” line on a home pregnancy test. Two days later later, however, the insurance company notified her that her application had been declined because she tested positive for HIV. “All I could think was, my baby is going to die, I’m not going to deliver a dead baby, I can’t handle this, I’m going to abort the baby.” After consulting her boyfriend and a woman physician, she decided to have the baby and eagerly became the first Chicagoan to enroll in ACTG 076. “I wrote up a list of questions and had them all answered before I enrolled,” she says. Despite her concerns for Juan David’s heart condition, she withholds judgment. “I’m very proud to have been enrolled in something like 076. We have to have answers. We have to educate women about their options. God forbid I had aborted my child. He is my life. He passes out condoms to people when I speak to groups.”

Grenata’s obvious delight in motherhood shows why positive women are going to keep having babies. Arlene Buck, the 076 nurse, knows that. “I have yet to meet a woman, no matter how drug addicted, how much she prostituted, who didn’t want to be a good mother,” she says matter-of-factly. In the face of all the questions around mandatory testing and AZT in mothers and children, perhaps that is the only solid fact in this whole debate.

© 2026 Smart + Strong All Rights Reserved.

http://beta.docker.poz.com/article/Expecting-the-Worst-1845-3361