

Baby Steps: Family Planning and Pregnancy for People With HIV

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In developed countries like the United States, effective antiretroviral (ARV) treatment hasn't just saved lives, it has also rekindled the goals and dreams of thousands of people with HIV. For some, successful treatment has meant reviving stalled careers or embarking on entirely new ones. For others, it has meant giving in to the overwhelming parental instincts that the sight of an infant's impossibly tiny fingers and toes can elicit.

For HIV-positive people with a baby-shaped hole in their lives and hearts, parenthood no longer needs to be a dream deferred. With lifespans approaching normal and the chance of transmitting HIV to their babies near zero, most HIV-positive adults likely need to worry more about how they're going to pay for their kids' college tuition than about passing on HIV to their baby or living long enough to see them through grammar school.

Last month's substantial update to the U.S. Department of Health and Human Services (DHHS) HIV pregnancy guidelines, the Public Health Service Task Force 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, offers HIV-positive women the information they'll need to stay healthy and to greatly reduce the chances of their babies being born without the virus. According to one of the guidelines' principal authors, Lynne Mofenson, MD, the chief of the Pediatric, Adolescent and Maternal AIDS Branch of the National Institute of Child Health and Human Development, if a woman and her provider follow the guidelines carefully, "the risk of transmission [of HIV] is probably under 1 percent. Very, very low."

But HIV-positive women aren't the only ones wanting to start a family these days. Some HIV-positive men, both straight and gay, are quite eager to become fathers. For these men, the concern isn't so much transmitting HIV to their babies as much as it is transmitting the virus to the HIV-negative women with whom they are partnered or who have agreed to be a surrogate and to carry their child. A host of technologies like sperm washing and in vitro fertilization are now available to help HIV-negative women get pregnant without the heightened risk of infection associated with unprotected vaginal intercourse.

And so with good treatment guidelines and assisted reproduction techniques there

should be little to stand in the way of HIV-positive people who want to have children, provided that they first do the same kind of soul searching and critical thinking as any HIV-negative parents.

Dawn Averitt Bridge, a 38-year-old HIV-positive activist and mother of two healthy daughters, engaged in just that kind of critical thinking before she decided to get pregnant. She learned the value of preparation and a good support system during her pregnancies, and when asked what helped most when she decided to have children she says, “Planning, planning, planning!”

Be Prepared!

Averitt Bridge, who’s been living with HIV since 1988 and is the founder and chair of the board of the women’s HIV website The Well Project, distinctly remembers how some people reacted when she decided to have her first child about six years ago. She cautions that all pregnant women become, “the object of everyone’s free advice, comments and even criticisms.”

Averitt Bridge says that when her belly began to broadcast her pregnancy, the reactions were a mixed bag. An AIDS activist, she would tell people, particularly health care professionals she encountered in her work, about her HIV status. The negative reactions, she says, “ranged from raised eyebrows to ‘Isn’t this a very selfish decision? What were you thinking?’”

Even Averitt Bridge’s greatest supporters, like her brother, sometimes had a hard time. She says he later called her first pregnancy “18 months of white knuckles.” His prolonged worrying, in this case, was because babies born to HIV-positive women carry their mom’s antibodies after birth and that standard antibody testing may not be conclusive for up to a year and a half. Fortunately, PCR testing—an assay that looks for the virus itself—is now widely available and can confirm whether or not infection has occurred during the baby’s first month of life.

To Averitt Bridge’s credit, she began discussing her desires and plans with her family, friends and health care provider long before she actually became pregnant. Though she was living in rural North Carolina at the time, she did manage to find a supportive doctor but had to do a lot of educating. She says, “When I selected [my doctor] I actually took her out to breakfast and did this whole interview and said, ‘This is one of the things I’m considering. How do you feel about it?’ I talked with her a lot and shared a lot of information. And she was willing to read, she was willing to seek consultation from others, and those things were really important to me. The most important thing was that she was so supportive of me and of my choice and willing to do whatever it would take to make that successful.”

This kind of intensive preparation and rallying of the troops, Averitt Bridge feels, is key to having a healthy pregnancy and preparing for what it will be like to have a baby. She says, “I think that the big thing is to really give yourself the opportunity to think about why you want to have a child, what that will mean for you during the process of being pregnant, what that will mean for you for the next five years or 10 years. I mean it’s a much bigger decision and a bigger question than just ‘Do I want to have a baby?’”

Guiding Lights

For HIV-positive women who’ve decided to become pregnant, the new DHHS guidelines are a great first place to turn for information and guidance—not only for themselves, but also for their providers. The guidelines were developed by a group of top experts on HIV, pregnancy and

pediatrics as well as community activists that included Averitt Bridge. They spent months reviewing the best available data on the use of antiretroviral drugs in pregnant women, and the most proven methods for preventing transmission from mother to child.

According to Dr. Mofenson, the new guidelines were significantly reorganized to make them more user-friendly and are designed to follow women from preconception considerations to the preventive use of antiretrovirals in newborns. (For detailed coverage of the new guidelines, see AIDSmeds.com's updated lesson: "[Family Planning, Pregnancy & HIV](#).")

Among the revisions are new suggestions regarding when therapy should be used. Whereas the older guidelines were more open to women delaying or going off treatment during the first three months of pregnancy—when toxic effects of drugs are most likely to affect the developing fetus—the new guidelines now strongly encourage all HIV-positive women who need treatment to go on it or stay on it during that first trimester.

DHHS has also changed its lineup of medications to use during pregnancy. Viracept (nelfinavir), a first-choice protease inhibitor in years past, should now be avoided due to the discovery of EMS, a potentially cancer- and birth-defect-causing impurity in the drug. Kaletra is now the preferred PI option during pregnancy. And some things don't change: Retrovir (zidovudine), an extensively studied and trusted drug during pregnancy, should still be used during the last trimester and labor, and given to the newborn for six weeks.

Following the best available data led Averitt Bridge to change her antiretroviral regimen during her first pregnancy. And though she'd previously had problems with Retrovir, she did use it intravenously during labor and gave it to her daughter after birth. Averitt says, "That was actually the hardest part for me. It was very challenging to give it to her."

Making those kinds of tough decisions is one area where the guidelines certainly aren't perfect. Particularly, as Dr. Mofenson says, "in places where there's a gray area," such as whether or not to give the baby more than one antiretroviral drug.

Averitt Bridge, who was on the guidelines committee, says there were some issues that the group really struggled with. "I think the guidelines do a good job of representing the data as it exists," she adds. "What I don't think is that [they are] representative of the experience that every provider or HIV-positive woman comes to face when making decisions about how to best manage a pregnancy. And so those limitations are important and real."

The Paternal Instinct

The guidelines also don't apply to couples where it's the prospective dad who has HIV. That's where experts like Ann Kiessling, PhD, come in. Kiessling has long been a champion of HIV-positive couples who want to have children and has worked for many years developing and refining reproductive options for them. In 1996, she founded the Special Program for Assisted Reproduction (SPAR) at the Bedford Research Foundation. SPAR, which she still directs, offers sperm testing, "washing" and preservation services to HIV-positive men who want to father a child. Though Dr. Kiessling couldn't remember the exact number of couples that SPAR has worked

with since it started, she joyfully offers, “What I know is that we’ve got 73 babies!”

SPAR requires HIV-positive men, usually working with a number of affiliated fertility clinics nationwide, to provide semen samples. The men usually need to be on ARV treatment, in order to ensure that HIV is not detectable in their blood or semen. SPAR tests the semen sample for HIV. If the virus is detected, it is discarded and another sample is produced and tested. If the sample is negative, it then undergoes a process called “sperm washing” to further reduce the risk of HIV endangering the fertilization process.

Sperm washing involves placing collected semen in a test tube and mixing it with a solution that is denser than the seminal fluid—where HIV can be found, amid the white blood cells—but less dense than sperm. The test tube is then placed in a centrifuge and spun at a high speed, causing the seminal fluid to rise to the top and the sperm to sink to the bottom. The seminal fluid is then skimmed off and the remaining sperm sample can then be used to fertilize the egg.

While SPAR will test, wash and preserve the semen samples, it does not offer insemination services. Dr. Kiessling’s group works with 28 clinics across the United States that do offer this expertise, including in vitro fertilization and less invasive procedures. These techniques, combined with the testing and treating services offered by SPAR, have helped dozens of couples have healthy babies while greatly reducing the risk of the woman’s becoming infected with HIV in the process. Dr. Kiessling says the demand for SPAR’s services continues to go up and that although most of the couples she’s worked with live in the United States, she adds, “Actually we have a baby in Hong Kong, and I think one or two in Africa.”

The process isn’t free, or even cheap. The charge for SPAR’s services, according to Dr. Kiessling, is roughly \$1,000 per semen specimen, and they need two specimens to guarantee that they’ll end up with enough sperm. Fertility services may also involve substantial costs, though some states and health insurance plans do cover them.

Although SPAR has been doing this for nine years, it’s really only been since about 2003 that a number of fertility clinics opened up to couples with HIV. Dr. Kiessling says, “In 2003, the American Society of Reproductive Medicine came out with a white paper saying that reproductive needs could not be denied people because they were HIV infected.... When the professional society changed its view, each of the clinics had to rethink their stance. Many clinics had just refused to help because that was the easiest thing to do.”

And as fertility services are opening up for people with HIV, they’re also opening up for people who aren’t in traditional heterosexual couples. Dr. Kiessling says, “We actually have a number of gay couples that are contacting us. Now they’re feeling positive about their lives and they’re also interested in going through egg donor and surrogacy and want to have their families.”

Conceiving a child naturally may also be an option. While there are few, if any, official recommendations in place to help mixed-status couples become pregnant via unprotected vaginal intercourse without endangering the HIV-negative partner’s health, there are some possible strategies to discuss with a doctor. For example, if the positive partner is on antiretroviral

treatment and his or her viral load is undetectable, the risk of transmission decreases. Other ways to potentially reduce the chance of transmission include pre-exposure prophylaxis (PrEP), a short course of HIV drugs given to the negative partner before intercourse to help prevent infection. There's also timed intercourse—engaging in unprotected vaginal sex only during times of peak ovulation.

Reasonable Choices

Now that there are services and techniques to help mixed-status couples have babies, and effective guidelines to help HIV-positive women stay healthy and drastically reduce the chance of transmission, it's no wonder that plenty of people with HIV want to join the ranks of Americans who proudly push their strollers through the local supermarket.

As Averitt Bridge experienced during her pregnancies, some people may call you selfish for putting your desire for a baby ahead of the relatively minor risk of the child becoming infected. But how selfish is it really? Society rarely condemns the thousands of HIV-negative couples each year who have babies despite the much higher risk of passing on genetic diseases.

Obviously, deciding to bring a child into the world is no small decision, but it's a choice for which a person with HIV shouldn't have to provide special justification. Averitt, who once told POZ, "There has been a child inside of me waiting to come into this world for as long as I can remember," understands how difficult it can sometimes be to explain why she decided to have children. About her second pregnancy she says, "You know [my first pregnancy] went very easy until the end and then I had this kind of crazy, horrifying delivery story that makes people wonder why anyone ever has children. And then I promptly got pregnant a year later, and people said, 'What the hell?'"

Finding friends, family and a healthcare provider who support your desire to have a child will help tremendously as you navigate the risks and realities of family planning, pregnancy and childbirth. When asked if she has any words of wisdom for HIV-positive people who are contemplating bringing a baby into the world, Averitt Bridge says, "Know that we're not alone...and that it's not an unreasonable choice...in this day and age."