We’ve Come a Long Way, Baby

More HIV+ women are realizing their dreams of becoming moms. With proper treatment and care, there’s little reason baby shouldn’t make three (or four...).

By Stacie Stukin and Lark Lands

PLUS Women’s Words: A mother

WHEN KRISTINA GENOVY turned 18 months old, her parents gathered family and friends together for a joyous dinner to celebrate, laugh and have a good cry. Because her mother, Anne, is HIV+, Kristina had to take three HIV tests after she was born to make sure she didn’t get the virus from her mom. The first two came back negative, but the third, administered at 18 months, was the defining result. Like the other tests, this one came back negative, proving the good news: Kristina was positively, no question, HIV negative.

It was a grueling 18 months for Anne. “I felt so guilty until the [third] test came back. I couldn’t live with the thought of Kristina having what I have, because her life is so innocent.” Anne’s pregnancy was also a stressful journey. She found out she had HIV during a routine prenatal checkup and her doctor immediately booked an abortion. But Anne and her husband had other ideas. They wanted their baby and found an HIV specialist who gave them hope, along with a prescription for the antiretroviral that would prevent transmission of the virus.

Kristina was born in 1996, just before the advent of HAART and the status of HIV as a potentially manageable chronic disease where good quality of life is not only possible but a right, at least in a country like Canada. Back then, the medical community, society and even HIV+ women themselves felt that they should not have babies. “There was a stigma,” says Susan King, MD, co-director of the HIV/AIDS program at Toronto’s Hospital for Sick Children.

We sure have come a long way, baby. According to Health Canada, the number of babies born to HIV+ moms increased from 56 in 1991 to 138 in 2001, and since 1996, the number of babies born with HIV has decreased. King says she now has HIV+ patients who are having second, even third babies. That’s because today, with proper treatment, mother-to-child transmission can almost always be prevented. A great example: At Montreal’s Sainte-Justine Hospital, the centre for mothers and children with AIDS boasts a transmission rate of zero.

In spite of these strides, deciding to have a baby is still a decision fraught with emotional, physical and social concerns. That’s why King helped implement a counselling program at Toronto’s Motherisk Clinic for HIV Treatment in Pregnancy as part of every positive mom-to-be’s treatment strategy: “It’s such a specialized area and we were finding that women weren’t getting the most up-to-date information. We decided to create a place where they could come see what choices were available, have help looking at their options and eventually make the decision that’s right for them.”

Yvonne [not her real name], who didn’t learn she was HIV+ until after the birth of her first baby, feels truly blessed that the child is negative. But before she and her husband (who also has HIV) decided to have their second child, she needed to know she had family support. She explained to her mother and siblings what could happen if she or the children got sick. “I needed my family’s approval,” Yvonne says. “If anything happened to me or my husband, I wanted to know they were up for the challenge and knew what they were in for.” Yvonne just gave birth to her
fourth HIV negative child. “I spend a lot of time with the kids,” she says. “I’m lucky.”

Both Anne and Yvonne will tell you that the day-to-day joys of motherhood help them cope with the anxieties of living with a chronic disease. “I love being a mom,” Anne says. “It gives me a reason to live. Kristina makes my day. We call her Angel Bug and we feel like she’s a gift from God.”

So you want to have a baby

Here are some things you should know:

**MTC TRANSMISSION** Mother-to-child transmission of HIV, also called perinatal or vertical transmission, can happen in 3 ways:

- HIV can pass to the fetus while in the womb through mom’s blood supply. This is uncommon and usually only happens when mom’s viral load is high.
- During labour and delivery, the baby can be infected by coming in close contact with mom’s blood and bodily fluids in the birth canal. If mom’s viral load is undetectable, her chances of transmitting the virus this way are greatly reduced.
- Breast milk carries HIV, so breast-feeding is a high-risk way to transmit the virus.

Strategies to protect mom and baby

There are two very important components of treatment when a woman is pregnant. First and foremost, the health of the mother must be protected. Second, consideration should be given to preventing HIV transmission from the mother to the baby, and otherwise supporting the health of the baby. Alas, in focusing on the latter, the former is sometimes under-stressed. Deborah Money, MD, FRCSC, assistant professor and head of the Division of Maternal Fetal Medicine at the University of British Columbia, says, “We absolutely must focus primarily on the mother’s health. The worst thing for a fetus is a critically ill mum.”

In terms of HIV, the first thing to consider is whether the woman needs HAART for her own health. If she’s already on an effective combination, she should stick with it. If she isn’t on meds but the standard treatment guidelines indicate that she should be, then “they should be started immediately, even if it’s early in the pregnancy,” Dr. Money says. “The only caveat is that you pick the least toxic drugs. And, of course, avoid any drugs that might cause birth defects, including delavirdine (Rescriptor) and efavirenz (Sustiva).” She most commonly recommends a regimen containing the nukes AZT (it’s tried and true and has been used for years in pregnant women with few problems) and 3TC (another long-used, non-problematic drug), combined with either the non-nuke nevirapine (Viramune) or the protease inhibitor nelfinavir (Viracept).

Standard treatment guidelines recommend doing genotyping (a blood test to look for drug resistance) with all pregnant women. However, in the treatment-naive (those who’ve never been on HAART), Dr. Money and her colleagues tend to begin HAART without the test as a cost-saving measure, while storing the woman’s blood to preserve the possibility of later testing if a failure to achieve a low viral load indicates the likelihood of drug resistance. In women who have previously taken HAART, genotyping is done before re-starting meds to increase the chances for picking an effective combination.

The mother should also be given any other therapies that are important to her health. For those with a CD4 count below 200, this would include prophylactic drugs to prevent opportunistic infections. “Don’t avoid drugs because of fears,” Dr. Money says. “You must protect mom first.”

For expectant mothers whose viral loads and CD4 counts would not otherwise indicate a need for antiretrovirals (according to standard treatment guidelines), reducing the risk of MTC transmission is the key concern. Experts recommend that all pregnant HIV+ women begin HAART between 14 and 18 weeks into the pregnancy. “At that point, we start the woman on HAART and suppress her viral load to undetectable throughout the rest of the pregnancy, if possible,” Dr. Money says.

There are two main reasons for this. First, although relatively rare overall, the possibility of HIV transmission in the womb goes up in synch with the mother’s viral load. Second, there is always the possibility of a premature delivery. “In many HIV+ women, there are factors that increase the risk for pre-term delivery, including injection-drug or cocaine use, lack of access to care, and increased rates of sexually transmitted diseases,” Dr. Money says. “So it’s
important to keep the viral load as low as possible through the last months of pregnancy to help prevent transmission during delivery.” Even in women with undetectable viral loads, HAART has been shown to further reduce the risk of MTC transmission.

Blood tests to look for problems should be performed two weeks after starting antiretrovirals and then every month throughout the pregnancy. Also, it’s very important that fetal growth and well-being be evaluated every four to six weeks until delivery.

When active labour begins (there is cervical dilation and/or contractions) or any time there is a ruptured membrane, doctors recommend that the mother continue taking her meds on schedule to the greatest extent possible (although nausea may prevent this). In addition, an AZT drip (intravenous) should be done throughout labour and delivery (with oral AZT discontinued). This helps prevent transmission by pre-loading the baby with AZT. For reasons that are unclear, this seems to work even when genotypic testing has shown that the mom is resistant to AZT, so the drip is recommended for all. After delivery, the AZT drip is stopped, and if the mom was only taking meds for the baby’s sake, her HAART is stopped immediately. If she needs the meds for her own health, they’re continued. The baby is given AZT syrup for the first six weeks of life.

In women who haven’t taken HAART prior to going into labour, it’s recommended that they be given a single dose of nevirapine (200 mg) as soon as possible after going into labour, that an AZT drip be given throughout labour, and that the baby be given a single dose of nevirapine immediately after birth, followed by six weeks of AZT syrup.

Clinicians used to believe that Cesarean section was the best way to reduce a newborn’s exposure to mom’s blood and bodily fluids. But a C-section is major surgery with multiple inherent risks, and experts now believe that if the mother’s viral load is fully suppressed, there is no benefit to be gained from it. In a woman who has not been on HAART or whose viral load is not fully suppressed, a C-section can be considered at 38 weeks.

Last, but not least, just say no to breast-feeding. “It’s quite clear the virus is in breast milk and even if mom has a low viral load, we suggest formula feeding,” Dr. King explains. “It’s safe and has nutritional benefits.”

Will HIV drugs hurt your baby?

Most HIV doctors, like Anita Rachlis, MD, medical director of the Ambulatory HIV Clinic at Sunnybrook and Women’s College Health Sciences Centre in Toronto, agree that combination therapy is a must for HIV+ pregnant women but say that there are definite caveats. “Women considering pregnancy must discuss this with their treating physicians because certain drugs have the potential to cause malformations in the developing embryo.”

For moms-to-be, the prospect of their children experiencing adverse reactions from HIV meds is a common fear. Because HAART has only been around since 1996, we don’t really know its long-term effects. A French study of more than 4,000 women reported increased seizure disorders in infants exposed to HIV meds, but the seizures weren’t life-threatening and affected only 30 babies. Additionally, researchers have speculated that HAART might negatively affect cellular energy, possibly harming organs like the brain and liver, but to date, research has not shown this. Research coordinator Johanne Samson, from Ste-Justine Hospital, says, “We’re still concerned about the long-term effects and more research needs to be done.”

Luckily, in December of 2001, the United States’ Antiretroviral Pregnancy Registry released a study of 2,800 pregnancies that found that taking HIV meds during the first trimester did not increase the incidence of birth defects. For many women and clinicians, these results helped alleviate fears.

Dr. Money sums up the bottom line by saying: “Despite any remaining concerns, it should never be forgotten that the one thing we absolutely do know is that taking antiretrovirals very greatly reduces the risk of having an HIV+ baby, with all the lifetime risks and problems that creates. Any concerns about possible drug side effects must be put in that perspective.”

Caring for the whole woman

In addition to anything related to HIV, it should never be forgotten that mom-to-be needs all the things that any pregnant woman needs: good nutrition, supplementation with a prenatal vitamin/mineral formula, good prenatal care that includes being checked for diabetes and other possible complications, and so on. “There are a million and one
standard pregnancy issues that need to be taken care of,” Dr. Money says. “Physicians should not get so focused on the HIV that they forget this is a pregnant woman with all the usual needs that are related to pregnancy in any woman.”

For women not yet pregnant but planning to be, folic acid should be taken to prevent neural tube defects. During pregnancy, excellent nutrition is crucial for both mom and growing baby. In the 2nd and 3rd trimesters, it’s important to add 300 calories and 15 extra grams of protein each day. Asking for a referral to a dietitian who can make recommendations on these and other dietary changes is an excellent idea for all moms-to-be. It is well known that the health of a newborn is influenced by the nutritional health of the mother throughout pregnancy.

Even without pregnancy, HIV infection is known to cause many nutrient deficiencies while increasing the need for calories, so it’s even more important to optimize nutrient intake through both diet and prenatal supplements. The latter are higher in folic acid and iron and lower in vitamin A (which can cause birth defects in too-high doses). If you’re considering taking other vitamins or complementary medicines, make sure they’re safe during pregnancy. Check with your doctor, pharmacist and/or naturopathic physician.

Stacie Stukin is a Los Angeles-based magazine writer and a regular contributor to POZ magazine and Yoga Journal.

Diana Johansen, RD, is a clinical dietitian at the Oak Tree Clinic, a part of the Children’s and Women’s Health Centre of British Columbia. The clinic’s Women and Family HIV Centre has clinical guidelines for the treatment of HIV+ women during labour and delivery and for the treatment of infants born to HIV+ women.

A mother

*Diagnosed with HIV: 2000; CD4 count: 450; Viral load: 3,000. Montreal (Quebec)*

It’s very important to have good health care, regular follow-ups and a good doctor you can talk to. A good, well-informed doctor is essential so you don’t end up with misconceptions. Your doctor has to put you at ease and you must have good information.

I was pregnant with my second child when I was diagnosed with HIV. It was a shock, but I never thought my child would be infected because I took my meds and was told that if I followed the instructions carefully, my child would be OK. I never had any doubts about my child. My pregnancy wasn’t any different from the first one. I had a C-section. I wanted to be sure that my doctor would be delivering the baby. I didn’t want to have to deal with another doctor and have to tell my story. There was no problem.

I want to tell women with HIV not to give up when it comes to getting pregnant. The only problem is the treatment for the newborn. It was the most difficult time, six weeks of treatment with very frequent doctors’ appointments. But besides that, everything is normal. We have to tell women to go forward, there’s no reason not to.
Disclaimer

Decisions about particular medical treatments should always be made in consultation with a qualified medical practitioner knowledgeable about HIV- and hepatitis C-related illness and the treatments in question.

CATIE provides information resources to help people living with HIV and/or hepatitis C who wish to manage their own health care in partnership with their care providers. Information accessed through or published or provided by CATIE, however, is not to be considered medical advice. We do not recommend or advocate particular treatments and we urge users to consult as broad a range of sources as possible. We strongly urge users to consult with a qualified medical practitioner prior to undertaking any decision, use or action of a medical nature.

CATIE endeavours to provide the most up-to-date and accurate information at the time of publication. However, information changes and users are encouraged to ensure they have the most current information. Users relying solely on this information do so entirely at their own risk. Neither CATIE nor any of its partners or funders, nor any of their employees, directors, officers or volunteers may be held liable for damages of any kind that may result from the use or misuse of any such information. Any opinions expressed herein or in any article or publication accessed or published or provided by CATIE may not reflect the policies or opinions of CATIE or any partners or funders.

Information on safer drug use is presented as a public health service to help people make healthier choices to reduce the spread of HIV, viral hepatitis and other infections. It is not intended to encourage or promote the use or possession of illegal drugs.

Permission to Reproduce

This document is copyrighted. It may be reprinted and distributed in its entirety for non-commercial purposes without prior permission, but permission must be obtained to edit its content. The following credit must appear on any reprint: This information was provided by CATIE (the Canadian AIDS Treatment Information Exchange). For more information, contact CATIE at 1.800.263.1638.

© CATIE

Production of this content has been made possible through a financial contribution from the Public Health Agency of Canada.

Available online at: