What Women Need to Know: The HIV Treatment Guidelines for Pregnant Women
Introduction

Every pregnant woman needs to know the best ways to take care of herself—and her baby—during pregnancy. And that includes facts about HIV. We wrote this booklet for pregnant women—to share this important information.

HIV is a very complicated disease. We still do not know everything about it, but we are learning more every day. We know that medicines can help reduce the risk of a mother passing HIV to her baby. Doctors and scientists are working hard to make sure that no new babies are born with HIV infection.

Information in this book was taken primarily from the “Perinatal Guidelines.” These guidelines are for doctors and other healthcare providers in the United States. They have the latest information about the safe use of HIV medicines for mother and baby in pregnancy.

Your healthcare provider will help you decide the best treatment for you during your pregnancy. But you need to be informed so that you can understand what is going on with your body. This way, you and your healthcare provider can make the best decisions together about your care.
What Women Need to Know

What have we learned about HIV and pregnancy and in infants?

- A mother with HIV can pass the infection to her baby. This is called “perinatal transmission.” Most transmission of HIV from mother to baby happens near or during delivery.
- In a large research study called “ACTG 076,” women who took a medicine called AZT (also called zidovudine or ZDV) reduced the risk of passing HIV to their babies. 
  
  1 of 4 babies whose mothers did not take AZT were HIV-infected

  However, only 1 in 12 babies whose mothers did take AZT were HIV-infected

- Today, with HIV medicines and special care, the risk of a mother passing HIV to her baby can be as low as 1–2% (1 or 2 babies out of 100).
- Ask your healthcare provider to tell you about AZT. Ask how it lowers the chance of passing the virus to your baby.
- Also, HIV-positive mothers should not breastfeed. Breastfeeding increases the risk that the baby will get HIV through drinking breastmilk.

  In the United States, infant formula is available for babies.

How do I get the best possible care for me and my baby?

- Start prenatal care as soon as you know you are pregnant. Women who get prenatal care early have healthier babies.
What Women Need to Know

Why are HIV medicines needed in pregnancy?

HIV medicines are needed for two reasons:

- They help improve your health by fighting the virus.
- They help reduce the risk of the virus passing from the mother to her baby.

What can a woman with HIV do to protect her baby?

- If you are not pregnant but are thinking about it, take good care of yourself and get as healthy as you can.
- This means taking vitamins with folic acid that prevent certain birth defects in babies. You need to eat healthy foods.
- Work with your healthcare provider to get your viral load level down. This means as low as possible and “undetectable” is best. Undetectable means so low that it cannot be measured by the test.
- Your healthcare provider also needs to make sure none of your HIV medicines cause birth defects.
- See your healthcare provider to take care of any other infections or health conditions.
- Talk to your healthcare provider about safe ways to get pregnant and protect your partner and yourself.

The HIV Treatment Guidelines for Pregnant Women

How can I reduce the risk of passing HIV to my baby?

- There’s a lot that you can do.
- The best way to reduce the risk to your baby is to get your viral load to “undetectable” for the whole pregnancy by taking anti-HIV medicines. One of these medicines should be AZT.

What do we know about viral load in pregnancy?

- HIV infection gets worse when a person’s viral load is high.

We know:

A baby is less likely to get the virus if the mother has an undetectable viral load.

A baby is more likely to get the virus if the mother has a high viral load.

That’s why you need to work with your healthcare provider to get your viral load down.

The best way to do this is to take all the doses of your HIV medicines.

How will I know what my viral load is?

- It is important for doctors to measure viral load at least every 3–4 months during pregnancy.
- After starting new HIV medicines, viral load should also be measured every 2–4 weeks. This is to see how they are working.
What Women Need to Know

Will a cesarean birth protect my baby from HIV?

- Your viral load near the time your baby is due to be born is very important. If your viral load is undetectable, a vaginal delivery is safe. Talk to your OB provider about this.
- If your viral load is higher than 1000, it may be better to have a cesarean section (c-section). This may reduce the risk of passing HIV to your baby through the birth process.
- If you are going to have a c-section, your doctor will schedule it before you start labor and before your water breaks. This is important. Having a c-section after you start labor and your water breaks may not protect your baby.
- Talk to your OB provider about the risks of a c-section to you and the benefits for your baby.

What else can I do if I am pregnant and have HIV infection?

- Eat healthy foods, stop smoking, and stop using drugs and alcohol.
- Tell your healthcare provider about any medicines and/or herbs you are already taking.
- Use condoms while you are pregnant. This protects you and your baby from getting new HIV and STD (sexually transmitted disease) infections.
- Researchers found that pregnant women who take AZT have a lower risk of passing the virus to their babies.
- Many pregnant women in the United States are choosing to take HIV medicines including AZT; fewer babies are born with HIV.

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What are the recommendations for HIV medicines for adults and older adolescents?

- It depends on whether or not someone has symptoms from HIV infection. It also depends on what his or her CD4 T cells (immune system cells) and viral load levels are.
- HIV medicines are recommended if a person has symptoms from HIV or if CD4 count is less than 350. These symptoms can be a condition of AIDS, or thrush, other infections. The symptoms also can be recurrent vaginal infections. If you have symptoms, the medicines are recommended no matter what your CD4 T cell number and viral load are.
- HIV medicines are also recommended for pregnant women with HIV infection regardless of CD4 count.
- Deciding to take HIV medicines is a big commitment. It is important that you are willing to take the medicines every day.
- It is very important to take every dose of these medicines. Missing doses may cause the medicines to stop working.
What about HIV medicines for women who are pregnant? Does pregnancy need special considerations?

- Pregnancy is different.
- HIV experts believe that all HIV positive pregnant women should take these medicines to lower the chance the baby will have HIV infection.
- Some medicines taken by pregnant women go from the mother's blood system to the baby. This means two people are taking medicine—you and your baby.
- Medicines may affect how your baby grows or develops. If they are taken early in pregnancy when the baby's organs are being formed, problems may happen. All of this may depend on the medicine, your dose, and how far you are in your pregnancy.

What do the Guidelines say about the safety of HIV medicines in pregnancy for mother and baby?

- Many pregnant women are taking HIV medicines for their own health and to lower the risk to their babies.
- So far, most medicines seem to be safe.
- However, there are certain HIV medicines you should avoid in pregnancy. They may have serious side effects for a pregnant woman or a developing baby.
- Some women have developed rashes, liver problems or high sugar in the blood (hyperglycemia) while taking certain anti-HIV medicines.
- Talk to your healthcare provider about your HIV medicines. Your healthcare provider will watch you closely and may do special blood tests during pregnancy.

What if I am in the first 3 months of pregnancy?

- In the first 3 months of pregnancy, your baby’s organs (heart, kidneys, and others) are being formed. Doctors do not know what HIV medicines may do at this time.
- You may want to wait to start these medicines until after your first 3 months.
- Talk to your doctor about the benefits and risks of waiting to start HIV medicines.

What if I have not taken any of these medicines before?

- Your doctor will evaluate your health and how HIV is affecting you. He or she will tell you if you need antiretroviral medicines for your health.
- You will need medicine if your CD4 T cell number is low and your viral load is high.
- Your healthcare provider will also recommend the AZT regimen. This reduces the chance of passing the virus to your baby.
- AZT will be one of the HIV medicines that you take during your pregnancy.
- You will also be given AZT by IV (into your vein) during your labor and delivery.
- Your baby will take AZT syrup to drink for 6 weeks after birth.
What if I am already taking combination therapy (the “cocktail” or “HAART”), and I just found out I am pregnant?

- What to do depends on how far along your pregnancy is.
- The guidelines recommend that if you are past the first 3 months you should continue your medicines.
- If AZT is not one of your medicines or in your “cocktail,” it may be added or switched with one that is the same type or belongs to the same family. These are medicines that work against the virus the same way.
- Your healthcare provider may take a blood test to be sure AZT will work for you.
- During delivery, you should be given AZT by IV (into your vein).
- Your baby should take AZT syrup for 6 weeks after birth.
- If you are not past the first 3 months, talk to your healthcare provider about your medicines and the benefits and potential risks of continuing your medicines. Your baby will be watched carefully.
- If you and your doctor decide to stop the medicines, they need to be stopped all at the same time. *They can be started again all at the same time, after the third month.*

Why do the medicines need to be stopped at the same time or started all at the same time?

- We have learned that the best way to fight the virus is to give more than one antiretroviral medicine. Each one works against the virus in a different way. *They work together to decrease the amount of virus to the lowest possible level. This is important.*
- Taking one or two drugs sometimes give the virus a chance to become resistant (the medicines no longer work against the virus).
- If medicines are stopped one by one, the same thing may happen.

What might happen to me if I stop taking the medicines for 3 months to protect my baby?

- Your viral load will go up. How risky this is depends on how high your level is. This may mean that your HIV might get worse. Your immune system might get more damaged by the virus. This would not be good for you or your baby.
- This is why you need to talk it over with your healthcare provider.
Decisions about taking HIV medicines in pregnancy are hard.

- For your doctor, this means knowing what medicines are best for you and your baby and when to use them.
- It also means giving you information and advice, and accepting your decision.
- For you, this means deciding which medicines you will take, if any, during your pregnancy.
- Taking HIV medicines is a big commitment at any time, especially during pregnancy. Talk it over with your healthcare provider. Together you can decide what’s best for you.

What is recommended for women with HIV in labor who have not taken any HIV medicines?

- Scientists believe that most mother-to-baby HIV transmission happens near or at the time of birth.
- It may be possible to reduce the chance that a baby will get the virus during the birth process.
- Experts recommend several medicines to reduce the chance a baby will get HIV infection.
- The doctor will decide which medicine is best for the mother and her baby based on the most recent guidelines.
  - AZT will be given into the vein during labor and delivery. (The baby also needs to take AZT for 6 weeks after birth).

What is recommended for infants whose mothers have not taken any medicines in pregnancy or during labor?

- These babies should be given AZT syrup to drink for 6 weeks after birth. The medicine should start right after the baby is born—no later than 6–12 hours after birth.

The new mother should have her health and HIV infection evaluated, if this was not done during pregnancy. This should include checking her viral load and her immune system. These tests will show if she needs to start antiretroviral therapy for her own health.
After the Baby is Born

What medicines will I need after my baby is born?

- Discuss this with your healthcare provider.
- You may need to go back to taking the HIV medicines you took before you became pregnant.
- You may need to begin combination therapy.
- You may need to stop AZT if it was started only to prevent perinatal (mother-to-baby) transmission.

What follow-up care should my baby get?

In addition to routine well-baby care, your baby needs some special care:

- Your baby needs to get care from a pediatric HIV specialist for at least the first 6 months of life.
- Your baby should take AZT until he or she is 6 weeks old.
- Your baby will be tested for HIV infection in a few days or weeks after he or she is born. By a few months of age, tests can usually show if a baby has HIV infection.
- Even though your baby may look well, keep all the appointments with the pediatric HIV specialist. It is important to have all the testing to find out if your baby has HIV infection.

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- At 6 weeks, your baby should start on an antibiotic (Bactrim™ or Septra®). This medicine prevents a serious pneumonia, which babies with HIV infection can get.

Since the treatment for HIV is always changing, what is the most important thing to remember?

- See your healthcare provider regularly.
- At every visit, go over your medicines with your healthcare provider to make sure they are the right ones for you.

Why are the Perinatal Guidelines important?

They give healthcare providers information about the safe use of HIV medicines (for mother and baby) in pregnancy. The Guidelines include facts about mother-to-baby HIV transmission and ways to reduce it. Each day brings advances in treating HIV. Doctors and other healthcare providers who care for pregnant women with HIV infection need this information. Women need to be informed too.

What do the Guidelines mean for me?

- If you are pregnant and have HIV, your doctor will probably use the Guidelines to determine the best medicines for you and your baby.
- The best HIV medicines work against the virus and cause no side effects or very few side effects for you and your baby.
What Women Need to Know

■ Your healthcare provider should tell you everything we know about these medicines. He or she should tell you about the medicine’s benefits and risks for you and your baby.

■ Remember: the choice to take antiretroviral medicines during pregnancy is yours.

■ Talk to your healthcare provider. Get the facts and advice on what’s best for you and your baby.

What Women Need to Know

As a woman with HIV infection, you have an important role in your health. You need to stay healthy. You can take part in decisions about your HIV medicines. You can help to reduce your baby’s risk of HIV other ways. You can take HIV medicines during pregnancy. You can follow advice about how your baby will be delivered and you can use formula to feed your baby.

This booklet answers many questions women have asked. We hope it answers some of yours. Be sure to ask your healthcare provider any other questions you have about your health or your baby’s.

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Important Telephone Numbers

Doctor

Nurse

Case Manager

Pharmacy

Pediatric HIV Doctor

You Can Find Out More Resource Information

HIV/AIDS Treatment Information Service:
Monday–Friday 12 noon–5 pm EST
1-800-448-0440
(English and Spanish)
1-888-480-3739 (TTY/TDD)
Internet:
www.aidsinfo.nih.gov/guidelines

AIDS Clinical Trials Information Service:
1-800-448-0440
(English and Spanish)
1-888-480-3739 (TTY/TDD)
Internet:
www.aidsinfo.nih.gov/guidelines

CDC Information HOTLINE: 1-800-232-4636
1-888-232-6348 (TTY/TDD)
**Glossary of words used in this booklet**

**ACTG 076** *(also called AIDS Clinical Trials Group #076)* – a research study of perinatal HIV transmission. The study found that mother-to-baby HIV transmission was reduced from 25% to 8% when mothers took AZT during pregnancy and their infants took AZT for 6 weeks after birth.

**antiretroviral drugs** *(also called “antiretroviral therapy”)* – anti-HIV medicines that prevent the virus from reproducing or replicating (making more copies of itself).

**AZT** *(also called ZDV, zidovudine, or Retrovir)* – an anti-HIV medicine that was taken by pregnant women in the ACTG 076 research study.

**CD4 T cells** *(also called T cells or helper cells)* – the cells of the immune system that are attacked by HIV. People who have HIV infection often have too few CD4 T cells. CD4 T cells play an important role in the working of the immune system.

**cesarean section** *(also called c-section and cesarean delivery)* – a baby is delivered by an operation through the mother’s abdomen (belly) and into her uterus (womb).

**combination therapy** *(also called the “cocktail” or “HAART”)* – several different kinds of anti-HIV medicines taken at the same time to keep the HIV virus from reproducing or replicating (making more copies of itself). These medicines each work against a different part of the virus when it is replicating.

**HAART** – Highly Active AntiRetroviral Therapy – a combination of anti-HIV medicines that work well against HIV infection.

**healthcare provider** – any doctor including obstetrician (OB), nurse, nurse midwife, social worker who may be counseling or treating pregnant women.

**perinatal transmission** – HIV transmission from an infected woman to her baby during pregnancy or at the time of birth.

**resistance** *(also called viral resistance)* – a virus’s ability to change its structure, or mutate, so that the same medicine no longer works against it.

**side effect** – a secondary and usually unwanted effect of a medicine or therapy.

**viral load test** *(also called HIV-RNA test or just “RNA”)* – a blood test to measure the amount of HIV in a person’s blood plasma (a part of blood).
What Women Need to Know

NOTES AND QUESTIONS

The François-Xavier Bagnoud Center (FXBC) of the School of Nursing at the University of Medicine & Dentistry of New Jersey (UMDNJ) is dedicated to improving the lives of vulnerable families including those families infected and affected by HIV infection. FXBC reaches across traditional boundaries to expand expertise in research and global health while continuing to link research and practice through education. FXB Center is an initiative of the UMDNJ School of Nursing, in collaboration with New Jersey Medical School, and works closely with other UMDNJ Schools and Centers. For more information about the FXB Center, visit www.fxbcenter.org or contact 1-973-972-9228 from 9:00 am to 5:00 pm EST.

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