

RUTGERS

François-Xavier  
Bagnoud Center

SCHOOL OF NURSING

# WHAT WOMEN NEED TO KNOW



*The HIV  
Treatment  
Guidelines  
for Pregnant  
Women*



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

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*Special thanks to the women living with HIV who helped us  
write and update this booklet for other women.*

This booklet is available on the National AIDS Education & Training  
Centers National Resource Center Website at [www.AIDSetc.org](http://www.AIDSetc.org)

Design: Karen Forgash

The Guidelines referred to in this booklet are: US Public Health Service Task Force.  
2012. *Recommendations for Use of Antiretroviral Drugs in Pregnant HIV-1-Infected  
Women for Maternal Health and Interventions to Reduce Perinatal HIV Transmission in  
the United States*. Retrieved September 4, 2013 from [www.aidsinfo.nih.gov/guidelines/](http://www.aidsinfo.nih.gov/guidelines/)



## Introduction

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. The healthier you are, the less likely you are to pass the HIV virus to your baby. We know that women who know their HIV status, are engaged in care, and are taking their HIV medications have a less than 2% risk of transmitting the virus. You and your providers can work together so you can have a long, healthy life and your baby can be born without HIV.

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 can a woman with HIV do to prepare for pregnancy?

If you are not pregnant but are thinking about it, take good care of yourself and get as healthy as you can.

- Take vitamins with folic acid that prevent certain birth defects in babies. 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.
- 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.
- Your healthcare provider also needs to make sure all your medicines are safe in pregnancy.

### 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. Transmission can also happen early in pregnancy or from breastfeeding.
- Studies have shown, 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 talk with you about your HIV medicines. Ask how they lower the chance of passing the virus to your baby.
- HIV-positive mothers should not breastfeed. Breastfeeding increases the risk that the baby will get HIV through drinking breast milk.
- In the United States, infant formula is available for babies.
- If you are thinking about breastfeeding your baby, talk about it with your healthcare provider.



## 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.
- During pregnancy, you, your OB/GYN, your HIV specialist and your pediatrician should work together.
- Your HIV infection should be carefully evaluated. You need to know how well your immune system is working. This means knowing your CD4 cell number (immune system cells) and your viral load. Viral load is the amount of HIV in your blood.
- What medicine you take now or in the past is important information.
- How far you are in your pregnancy is important, too. This is called your baby's "gestational age."
- Based on this information, your healthcare provider can tell you what medicines are recommended to treat your HIV infection.



## What are HIV medicines?

### How do they work?

- We now have many powerful HIV medicines. They are called "antiretroviral" medicines and they help fight the virus.
- They work by lowering the amount of virus in the body.
- Today, there are many HIV medication options and nearly all patients find a regimen that works for them with few or no side effects.
- When we use several medicines together they work the best. This is called "combination therapy."
- Combination therapy works to keep the amount of virus in your blood (your viral load) as low as possible.
- Sometimes 2 or more HIV medicines are together in one pill. This makes "combination therapy" much easier.



### **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.
- Many women have sex while they are pregnant. Talk with your health care provider about the best safer sex options for you and your partner/s. Condoms can protect you, your partner and your baby from getting new HIV and STIs (sexually transmitted infections).
- Take your HIV medicines every day as prescribed.
- Many pregnant women in the United States are choosing to take HIV medicines; fewer babies are born with HIV.

### **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, giving ARVs to your newborn, and formula feeding your baby.

### **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 doses of your HIV medicines as prescribed.



## How will I know what my viral load is?

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

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

- HIV medicines are recommended for all people with HIV infection to keep you healthy and prevent HIV from passing to people who are not infected.
- HIV medicines are 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?**

HIV medicines are needed in pregnancy for two reasons:

- They help improve the mother's health by fighting the virus and lowering the level of virus in her body.
- They help reduce the risk of the virus passing from the mother to her baby.
- 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. This is an additional protection to your baby against the HIV.

### **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.
- 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.
- 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 have not taken any of these medicines before?

- Your doctor will recommend a combination of HIV medicines that will work best to lower your viral load and protect the baby from getting HIV.
- In the first 3 months of pregnancy, your baby's organs (heart, kidneys, and others) are being formed.
- Starting HIV medicines in the first three months of pregnancy may decrease the chances of passing HIV to your baby.
- You should talk with your doctor about the risks and benefits of starting HIV medicines in the first trimester or waiting until after 3 months.

## What if I am already taking combination therapy and I just found out I am pregnant?

- The guidelines recommend that you continue taking your medicines if they are working to make your viral load undetectable and you feel well.
- During delivery, you will be given ZDV by IV (into your vein) unless your viral load is controlled.
- If your medicines are not working to keep your viral load low, your health care provider will do tests and talk with you about HIV medicines that will work better for your health and protect the baby from getting HIV.
- Certain medicines should be avoided during pregnancy. Your doctor will talk with you about whether you need to change any of your medicines.





### **What might happen to me if I stop taking the medicines for the first 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 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 who learn they have HIV in labor and have not taken any HIV medicines?**

- Scientists believe that most mother-to-baby HIV transmission happens near or at the time of birth.
- It is possible to reduce the chance that a baby will get the virus during the birth process.
- The doctor will decide which medicine is best for the mother and her baby based on the most recent guidelines.
- ZDV will be given into the mother's vein during labor and delivery.



- The baby also needs to take ZDV for 6 weeks after birth plus 3 doses of another medication called nevirapine. The medicine should start right away after the baby is born. The pediatrician will talk with you about any additional medicines for the baby.
- The new mother should have her health and HIV infection evaluated. This should include checking her viral load and her immune system.
- Continuing to see an HIV healthcare provider after pregnancy is important for all women with HIV infection and their HIV-exposed infants.

### **What medicines will I need after my baby is born?**

- Continuing your HIV care and medicines after pregnancy is VERY important for your health.
- You and your healthcare provider will discuss your health and your HIV medicines
- It is also important for you to see your OB/GYN after you deliver your baby.
- It is important to keep the appointments made for your care after the baby is born.

### **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 4 months of life.
- Your baby should take ZDV until he or she is 6 weeks old.
- If your baby was given other HIV medicines in the hospital, it is important to also give those medicines as directed by your healthcare provider.
- 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 or not.



## WHAT WOMEN NEED TO KNOW

- 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.
- At 6 weeks, your baby may start on an antibiotic (Bactrim™ or Septra®). This medicine prevents a serious pneumonia, which babies with HIV infection can get. The medicine may be given to your baby while HIV tests are done to show if the baby has an HIV infection.

### **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 to lower the viral levels in your body with few side effects for you and your baby.
- 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: you are an important part of the healthcare team.
- 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.



### What Women Need to Ask: Questions for Pregnant Women Living with HIV to Discuss with their Providers

- Every pregnant woman needs to know the best ways to take care of herself and her baby during pregnancy. As a pregnant woman living with HIV infection, you will need some special care. By asking questions, you can help ensure that you are getting the care you need and that you know what to do. See the following page for questions to ask your healthcare provider.





## WHAT WOMEN NEED TO KNOW

### Here are some questions you may ask your healthcare provider *(physician, nurse practitioner or midwife, or nurse.)*

*Answers to these questions will give you important information that will help you manage your HIV and stay healthy.*

- What can I do to prepare for a healthy pregnancy?
- How can I become pregnant safely?
- What can I do to stay healthy during my pregnancy?
- What can I do to lower the risk of passing HIV to my baby?
- What HIV medications will I need to take? How do they work?
- How safe are the medications I may need?
- How often will I need to see the healthcare provider?
- Are special laboratory tests needed to monitor my HIV treatment? How often will I need to have them?
- What else can I do to stay healthy?
- Will I need special care or medication during labor and delivery?
- Will I need to have a cesarean delivery?
- What medicine will I need after my baby is born?
- Will my baby need medicine?
- What should I feed my baby?
- What other follow-up visits, tests, and medicines will my baby need?
- When will we know my baby's HIV status?
- I've heard about the "baby blues." How can I get help for that?
- Where can I go for follow-up care for myself after pregnancy? For my baby?
- My family and partner don't know about my HIV diagnosis. How can I tell them?
- Since I'm pregnant, do I need to be concerned about "safer sex"? What about family planning after the baby is born?
- How can I find out about other services I might need like help with insurance, housing, or mental health?



## NOTES AND QUESTIONS

### Important Telephone Numbers

Doctor

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Nurse

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Case Manager

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Pharmacy

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Pediatric HIV Doctor

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### You Can Find Out More Resource Information

- **HIV/AIDS**  
*[www.aidsinfo.nih.gov/guidelines](http://www.aidsinfo.nih.gov/guidelines)*
- *[www.cdc.gov/hiv](http://www.cdc.gov/hiv)*

### Consumer Internet Web Pages

- **[www.thebody.com](http://www.thebody.com)**  
Complete information and lessons  
on treating  
HIV and AIDS
- **[www.thewellproject.org](http://www.thewellproject.org)**  
A web page and resource for women





### Glossary of words used in this booklet

- **antiretroviral drugs** (also called “antiretroviral therapy”) – anti-HIV medicines that prevent the virus from reproducing or replicating (*making more copies of itself*).
- **ZDV** (also called AZT, zidovudine, or Retrovir) – an anti-HIV medicine that was taken by pregnant women in the ACTG 076 research study.
- **CD4 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 cells.
- **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 HIV from reproducing or replicating (*making more copies of it*). These medicines each work against a different part of the virus when it is making copies of itself.



- **healthcare provider** – any doctor including obstetrician (*OB*), nurse, nurse midwife, or 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

The François-Xavier Bagnoud (FXB) Center, School of Nursing, at Rutgers, The State University of New Jersey is dedicated to improving the lives of vulnerable families including those families infected and affected by HIV infection. The FXB Center reaches across traditional boundaries to expand expertise in research and global health while continuing to link research and practice through education. For more information about the FXB Center, visit [www.fxbcenter.org](http://www.fxbcenter.org) or contact 1-973-972-9228 from 9:00 am to 5:00 pm ET.





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