

CHAPTER 1  
**HIV:**  
**The Basics**



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HIV is a virus that hurts the body's immune system.

It is not who you are. It is what you do that puts you at risk for getting HIV.

## What is HIV?

**HIV** (Human Immunodeficiency Virus) is a **virus** that attacks the **immune system**. (The immune system fights infections and diseases in a person's body.) Over time, HIV weakens a person's immune system so it has a very hard time fighting diseases. HIV causes **AIDS** (Acquired Immune Deficiency Syndrome). People with HIV can have it for many years before it develops into AIDS.

## How is HIV spread?

**HIV** is passed from person to person. This happens when a person with HIV gets his/her blood, semen, vaginal fluid, or breast milk inside another person's body. There is no risk of getting HIV from the person's urine, sweat, tears, saliva, or vomit unless there is also blood in it.

A person of any age, sex, ethnic group, religion, economic background, or sexual orientation can get HIV. It is not who you are. It is what you do that puts you at risk. Anyone who shares needles, shares works to inject drugs, or has unprotected sex (sex without a condom) with someone who has HIV is at very high risk for getting infected. A mother with HIV can also pass the **virus** to her baby during pregnancy, during birth, or by breast feeding.

It is not possible to tell if people have **HIV** by looking at them. People can have HIV for many years and not know they have it. They can also pass

it to others without knowing it. That is why it is so important for people to get tested to find out if they have HIV.

People with **HIV** who look and feel healthy, or have very **low or undetectable** (un dē tekt´ i bul) levels of **virus**, can still pass HIV to others.

(See **HIV: The Basics**, How is my child's immune system watched? Measuring the amount of HIV in your child's blood: viral load, page 1–8.)

## How does HIV affect a person's health?

When people first get infected with **HIV**, they may or may not feel sick. Some get flu-like **symptoms** (simp´ toms), they may get a fever, sore throat, swollen glands, or a skin rash. These symptoms will go away without treatment, but HIV stays in their blood where it grows and begins to destroy their **immune system**. People with HIV can have it for many years before their immune system gets weak and other symptoms appear. After symptoms appear, people with HIV will feel better with treatment. People with HIV may get sick more often and have illnesses that are harder to treat than people who do not have HIV. Sometimes people with HIV may get very sick.

People who have HIV may not have any symptoms for years.

Infants who were born with **HIV** or got HIV from their mother's breast milk may have **symptoms** that include:

- slow to grow and gain weight.
- slow learning to walk and talk.
- frequent **diarrhea** (dī a rē' a).
- swollen glands.
- yeast infections (**thrush**).
- enlarged liver and spleen.
- **pneumonia** (nū mō' nē a), a lung infection.
- other infections that healthy children do not usually get.

Infants with **HIV** may get sick more often and have illnesses that are harder to treat than other infants.

There are tests that show if someone has HIV.

## How do people know they have HIV?

**HIV** is most often **diagnosed** (dī ag nōst') in adults and in children over 2 years old by tests that look for **HIV antibodies** (an' tē bod ēz). HIV antibodies are substances the **immune system** makes to fight HIV. If the test finds HIV antibodies, the test result is **HIV positive**. This means the person has HIV.

At birth, all infants will have **HIV antibodies** in their blood if their mothers have **HIV**. Until infants are 6 to 18 months old, they have their mother's HIV antibodies. To find out if an infant has HIV, a blood

test called a **PCR** (polymerase chain reaction) is done. A PCR test is different from an **HIV antibody test**. Rather than look for HIV antibodies, a PCR test looks for HIV in an infant's blood. In almost every case, the test can tell if the infant has HIV by the time he/she is between 1 and 4 months old. If HIV is found, the PCR test will be positive. This means the infant has HIV.

### Special Note for Foster Parents:

Make sure to keep your caseworker informed about follow-up doctor visits for **PCR testing**.

## How does HIV attack a person's immune system?

When **HIV** gets inside a person's body, it attacks his/her **immune system**. (The immune system fights infections and diseases.) The immune system has many kinds of **white blood cells** to fight infections. HIV finds the white blood cells, called **CD4 cells**. HIV gets inside the CD4 cell and makes copies of itself. Then, HIV kills the CD4 cell and the new HIV copies find other CD4 cells to get inside and start the cycle again.

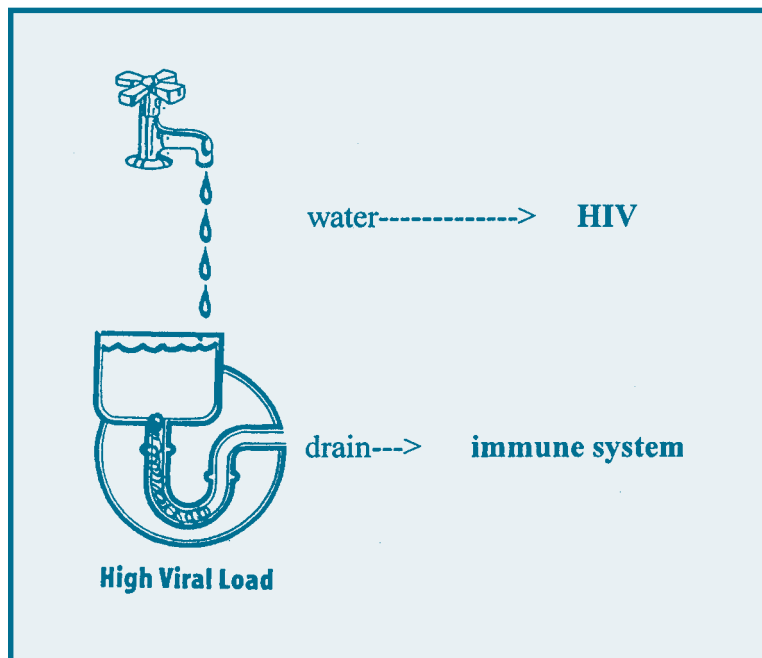
The **immune system** tries to control **HIV** by making more **CD4 cells**. But when the immune system cannot make CD4 cells fast enough, the amount of **virus** in the body goes up and the number of CD4 cells goes down. Because the immune system can no longer control HIV, the person can become sick. A weak immune system has a hard time fighting

HIV kills immune system cells that help the body fight infections and diseases.

The immune system becomes weak when it cannot make enough CD4 cells to fight HIV.

germs, even the germs that are around us all the time. These infections might last longer, be more severe, and return more often in someone with a weak immune system.

The picture below shows what happens in your child's body when **HIV** attacks your child's **immune system**. Think of the running water as HIV making copies of itself. Think of the drain as the immune system (**CD4 cells**) working to get rid of the **virus**. The clogged drain, or weak immune system, cannot get rid of HIV fast enough. The water goes up in the sink just the way the amount of HIV can go up in your child's blood. When this happens, your child has a high **viral load**.



*Adapted from "Your Child, Your Family, and HIV" published by the National Pediatric & Family HIV Resource Center at the University of Medicine and Dentistry of New Jersey.*

## How is my child's immune system watched?

You and your child's doctor(s) will watch your child's health in many ways. Your child's doctor will look for signs and **symptoms** of infections or other problems by ongoing health check-ups and blood tests. These will tell the doctor if the **HIV** is getting stronger or weaker. They will also help the doctor find a problem early when it may be easier to treat.

### Ongoing medical check-ups

Your child's doctor and clinic visits are important. These visits help the doctor or nurse see how your child is doing. Ongoing visits also help the doctor or nurse find health problems when they may be easier to treat. The doctor or nurse will give your child a physical exam and talk with you and your child, if old enough, about changes in your child's health and behavior. He/she will ask you about how your child is doing at home, day care, or school. He/she will also ask about changes in your child's eating habits, sleeping habits, activity level, etc.

**Whenever you see a sudden change in your child's behavior, call the doctor. A sudden change may mean that your child needs help for a physical or mental problem.**

Your child's doctor will use ongoing check-ups and blood tests to watch your child's health.

Your child's ongoing health check-ups are important. These check-ups can help the doctor or nurse find health problems when they may be easier to treat.

### Special Note for Foster Parents:

As noted above, if you see sudden changes in your foster child's behavior, call the doctor and keep your caseworker informed.

Your child will get blood tests from time to time to measure how much virus is in his/her blood.

## Measuring the amount of HIV in your child's blood: viral load

One of the goals of treating **HIV** is to keep the amount of **virus** in your child's body as low as possible. To see how much virus is in your child's blood, a **viral load** test will be done from time to time. Based on the test result, the doctor will know:

- if medicine is needed to help control HIV.
- if the medicine already being taken is controlling HIV.
- if other medicine is needed to control HIV.

The test information will help the doctor suggest treatment options. When your child has a very **low or undetectable viral load**, he/she may not feel sick at all or may have fewer serious infections and illnesses related to **HIV**.



**Anyone with HIV, even if they have a low or undetectable viral load, can still pass HIV to others if their blood, semen, vaginal fluids, or breast milk get inside another person's body.**

Your child will also have blood tests done from time to time to check his/her immune system.

## Measuring your child's immune system: CD4 cell counts

Another way to see how well your child is doing is to check the number of **CD4 cells** he/she has. The CD4 cell blood test tells the doctor if your child's **immune system** is weak or strong. If his/her immune system is weak, the doctor may suggest medicines to help prevent some serious infections.

By looking at both **viral load** and CD4 cell numbers, the doctor can find out a lot about your child's health.



## Checking your child's blood

A **complete blood count (CBC)** is usually done at each doctor or clinic visit. The **CBC** is a blood test that counts the number of your child's **red blood cells, white blood cells, and platelets**.

- Red blood cells carry oxygen to cells in the child's body.
- White blood cells fight infections.
- Platelets help control bleeding.

Changes in your child's blood count can be caused by many things, such as **HIV**, another infection, or by a **side effect** from medicines.

## Checking your child's other body systems

Other blood tests will be done from time to time to see how well your child's kidneys, liver, and other body systems are working.

If your child has a health problem that cannot be **diagnosed** with blood tests, other tests may be needed. **X-rays, ultrasounds, CT scans** (computerized tomography), **MRIs** (magnetic resonance imaging), and **PETs** (positron emission tomography) are tests that show the doctor what is going on inside your child's body.

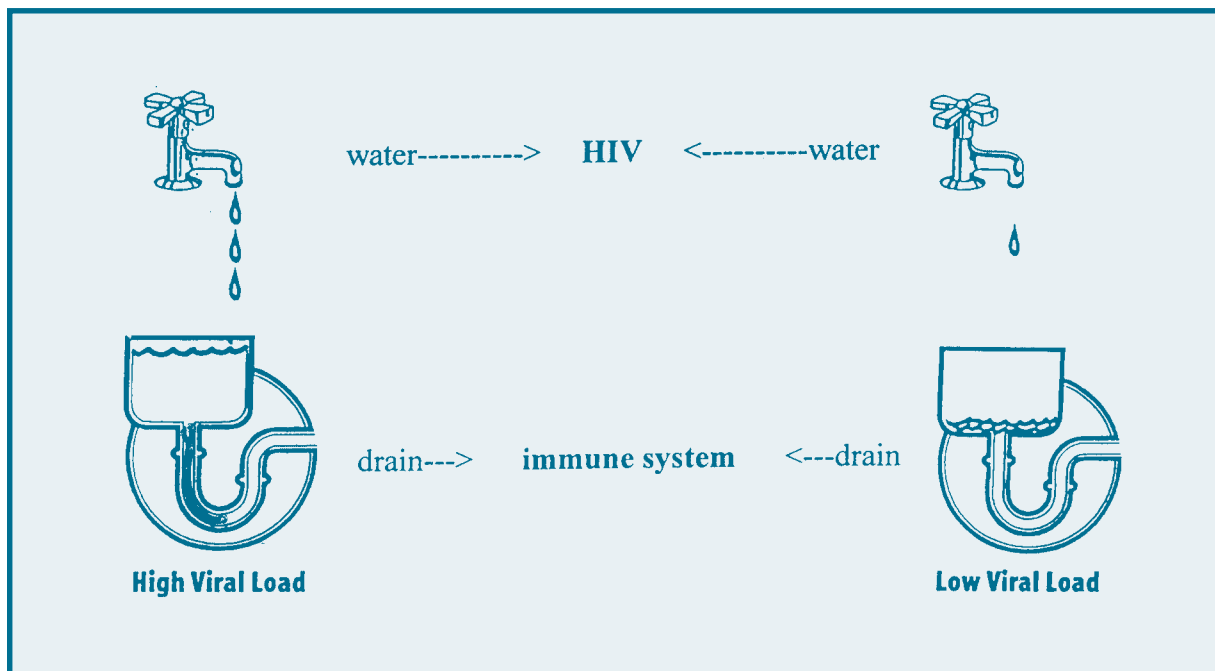
Your child's doctor may have other tests done to find out the cause of a health problem.

## What are the goals in treating HIV?

The goals in treating **HIV** are to:

- lower the amount of **virus** in your child's blood.
- increase the number of **CD4 cells** in your child's **immune system**.

The sinks below may help show how HIV treatment works. Think of the running water as HIV making copies of itself. Think of the drain as the immune system (CD4 cells) working to get rid of the virus.



*Adapted from "Your Child, Your Family, and HIV" published by the National Pediatric & Family HIV Resource Center at the University of Medicine and Dentistry of New Jersey.*

The drain on the left shows **HIV** making many copies of itself. The clogged drain, or weak **immune system**, cannot get rid of HIV fast enough. The water goes up in the sink just the way the amount of HIV can go up in your child's blood. When this happens, your child has a high **viral load**.

The drain on the right shows what happens when **HIV** treatment is working. HIV stops or slows down making copies of itself. The unclogged drain, or strong **immune system**, can get rid of HIV. So the water goes down in the sink just the way the amount of HIV can go down in your child's blood. When this happens, your child has a **low or undetectable viral load**.

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## How do medicines slow down or stop HIV?

Experts have made medicines that work to stop **HIV** from getting inside **white blood cells (CD4 cells)** or work to stop HIV from making copies of itself. These medicines are called **antiretrovirals** (an tī´ ret rō´ vī rals). “Anti” means against, and “retro viral” means the **virus**. Antiretroviral medicines can lower the amount of HIV in your child's blood. When the amount of HIV in your child's blood is low, it is much harder for HIV to make copies of itself. This means:

- your child's medicines are working.
- your child's **immune system** is stronger.
- your child will have fewer illnesses.

Antiretroviral medicines can slow or stop HIV from making copies of itself.

The doctor will recommend antiretroviral medicines that are best for your child.

## Which medicines are best to take?

In the beginning, there was only one medicine to fight **HIV**. So there was no choice about what medicine to take. Now, there are many medicines, and it is harder to decide. A group of HIV experts looked at all the research studies and came up with guidelines or plans. These plans help your child's doctor decide which medicines are best for your child.

Deciding which medicines are best for your child depends on his/her:

- past and present medical problems.
- **antiretroviral medicines** taken in the past.
- ability to take each medicine on time.
- ability to take medicine in liquid, pill or powder form.
- ability to deal with the way the medicine tastes or feels in his/her mouth.

HIV will try to change itself so it can grow stronger.

## Why do HIV medicines stop working?

**HIV** is very smart. If given a chance, HIV will try to grow stronger. HIV will grow stronger very quickly when your child's:

- HIV medicines are not taken correctly.
- HIV medicine **doses** are missed.
- HIV medicines do not work.

When **HIV** grows stronger, your child's HIV medicine may stop working. HIV may be **resistant** (rē zis' tant) to the HIV medicines your child takes. This means:

- your child's medicines can no longer control HIV.
- HIV will make more copies of itself.
- your child's **immune system** will become weaker.
- your child may have more infections and illnesses.



**Remember the running water and clogged drain on page 1-6. The clogged drain, or weak immune system, cannot get rid of HIV fast enough. The water goes up in the sink just the way the amount of virus goes up in your child's blood.**

**Taking medicines everyday can be very hard.** But for the medicines to do their best to control **HIV**, it is important for your child to take every HIV medicine **dose** correctly and on time.

Your child's doctor or nurse should be called if there is a problem taking any of the medicines. You, your child, and your child's doctor or **pharmacist** (far' ma sist) can work together to get the best medicine schedule for your child.



**If your child has a problem taking any of the medicines as directed, call the doctor or nurse.**

### Special Note for Foster Parents:

If your foster child has a problem taking any of his/her medicines, call the doctor or nurse and your caseworker.

Some medicines can help prevent illnesses before they start.

A child with HIV who has a weak immune system may get infections and illnesses that healthy children do not get.

## How are some infections and illnesses prevented or treated?

The best thing to do is prevent problems before they start. Sometimes, this can be done by giving your child medicines before an illness starts. Whether or not a preventive medicine is given depends on your child's health and **immune system**. Many times, your child's **CD4 cell** count is used to help decide if preventive medicine is needed and when to start. Preventive medicines may be used for illnesses such as **PCP** (Pneumocystis carinii pneumonia), **MAC** (Mycobacterium avium complex), **herpes** (her' pēz), and **thrush**.

A child with a very weak **immune system** may need help to fight:

- serious infections, such as lung infections (**pneumonia**), blood infections (**sepsis**), and sinus infections (**sinusitis**).
- **measles**.

## What other illnesses or problems do children with HIV sometimes get?

Children with **HIV** may get illnesses or have problems caused by:

- HIV.
- a weak **immune system**.
- medicines.

### Anemia

**Anemia** (a nē' mē a) is common for children with **HIV**. Children are **anemic** (a nē' mik) when the number of their **red blood cells** fall below normal. Red blood cells are important because they carry oxygen to different parts of the body. Children who are anemic may be tired and pale or have no **symptoms** at all. Anemia is **diagnosed** by a blood test. Children most often become anemic from a low iron level, or from one of the **antiretroviral medicines** they are taking. If the anemia is caused by antiretroviral medicines, the doctor may treat the anemia by changing the medicine. If the anemia is caused by low iron levels, the doctor will treat it with iron vitamins.

### Herpes simplex virus

**Herpes simplex virus** is also common among children with **HIV**. This **virus** causes common cold sores. The herpes simplex virus causes painful sores in and around the mouth of a child with HIV. Sometimes, when first infected with the herpes simplex virus, or when a child's **immune system** is

weak, this virus can cause many painful blisters and a fever. The sores often make it difficult to eat and swallow. Herpes simplex virus can be treated, but may also come back. Usually when the infection returns, there are fewer sores in and around the child's mouth.

## LIP

**LIP (lymphocytic interstitial pneumonitis)** is a serious lung disease that starts with shortness of breath, wheezing and coughing. The cause of **LIP** is not known. A chest **X-ray** may help the doctor make a **diagnosis**. LIP is usually treated with **steroid medicines**, as well as **antiretroviral medicines** to control the **HIV**. With treatment, LIP will improve greatly.

## Shingles

**Shingles** are caused by the same **virus** as **chicken pox**. After having chicken pox, the virus can come back months or years later anywhere in the body and is often very painful. On a small area of the body, the skin breaks out in a rash or small blisters much like the chicken pox. Inside these little blisters is the chicken pox virus. Chicken pox can be spread to another person who has not had the chicken pox by touching these blisters. Shingles usually go away in 1 - 2 weeks but can last longer and be more severe when the child's **immune system** is weak. Shingles can come back either at the same place or a different place on a child's body.



## Fat redistribution

**Fat redistribution** or **lipodystrophy** (lip ō dis´ trō fē) is a change in the way a person's body stores fat. These changes may include:

- losing fat in a person's face, arms and legs.
- gaining fat in a person's stomach or at the base of his/her neck.

The cause of lipodystrophy is still being studied. If lipodystrophy is bothering your child, talk to your child's doctor.

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## How are scientists finding new treatments for HIV?

Scientists are still working hard to find new treatments and a cure for **HIV**. Research studies called **clinical trials** test new medicines and combinations of medicines to see which ones work the best and which ones are the safest. These studies are offered by the **AIDS Clinical Trials Group (ACTG)**. Without clinical trials, there would be no medicines to fight HIV. Medicines that are studied in clinical trials are used very carefully. Before anyone can be in a clinical trial, he/she must fit the study requirements. Once in the study, the person must agree to follow the rules of the study. A person can stop a clinical trial at any time if he/she does not want to continue.

As a parent or **guardian**, you must give permission for your child to be in a clinical trial. Again, the medicine and the study can be stopped if you feel

New medicines for treating HIV are being tested in clinical trials.

the medicine is not helping or hurting your child. No matter if your child is in a clinical trial or not, good medical care will be given to him/her.

**Special Note for Foster Parents:**  
A foster parent cannot **consent** to his/her foster child joining a **clinical trial**. Call your caseworker about getting consent.

## Notes

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