

# *A Family's Guide to Living with HIV*

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Elaine Cox, M.D.  
Denise Shalkowski, R.N.

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INDIANA UNIVERSITY SCHOOL OF MEDICINE  
JAMES WHITCOMB RILEY HOSPITAL FOR CHILDREN



INDIANA UNIVERSITY  
SCHOOL OF MEDICINE



Riley Hospital *for* Children  
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The Ryan White Center for Pediatric Infectious Disease  
James Whitcomb Riley Hospital for Children  
Section of Pediatric Infectious Disease

CONTACTS

Elaine Cox, M.D.  
Assistant Clinical Professor of Pediatrics  
Medical Director of Pediatric HIV/AIDS Services

Denise Shalkowski, R.N.  
Pediatric Infectious Disease Nurse Specialist

Linda Dye  
Administrative Assistant

ADDRESS

ROC 4380  
Riley Hospital for Children  
702 Barnhill Drive  
Indianapolis, IN 46202

PHONE

(317) 274-7260

FAX

(317) 278-0860

[www.rileyhospital.org](http://www.rileyhospital.org)

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DEDICATION

*This booklet is dedicated to our patients and families  
who continually teach us the truly important things in life.*

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## *Introduction*

Welcome to the Ryan White Center for Pediatric Infectious Disease. We are pleased to welcome you and your child to the clinic and hope to make this a positive experience for your entire family.

In the HIV/AIDS clinic, our mission is to promote a lifestyle of wellness and prevention, as well as treatment of the virus. We always try to remember that there is more to the child in our clinic than just their disease. We also know that the entire family is affected by HIV and that it requires everyone for successful treatment. Therefore, we treat on a comprehensive Family-Centered Care model, attending to medical, emotional, and social concerns of all family members involved. HIV has affected our entire society. Worldwide, 42 million people are estimated to be living with HIV/AIDS. Of these, 3.2 million are under 15 years of age. In the United States, according to the Centers for Disease Control, there were 816,149 reported cases of HIV in the United States. Of these, 9,074 cases of AIDS were in children under the age of 13. It is clear that our entire community is affected by this disease, not just individual families.

At the Indiana University School of Medicine and James Whitcomb Riley Hospital for Children, we are committed to providing state-of-the-art care to our patients, their families, and the community. We hope the Ryan White Center for Infectious Disease provides you with a place that meets all the needs your family encounters while dealing with the diagnosis and treatment of HIV in your child.



## *What is HIV?*

There are more than 2 million viruses around. Some cause colds and other illnesses like the flu or chickenpox. HIV (human immunodeficiency virus) is a virus. HIV is the only virus that can cause AIDS. This particular type of virus is called a retrovirus, and the medications used to fight the virus are called *antiretrovirals*. You may be diagnosed with HIV and not have AIDS. There are various stages of HIV, with AIDS generally being the most advanced stage. Many individuals can be infected and contagious with HIV for a period of time and not know that they are HIV positive. This is possible because they do not show any symptoms of the disease, and may not realize that they have been exposed. HIV makes people sick by attacking the body's immune system. The immune system is the part of the body that defends against infection and disease. The CD4 cell (or T4 cell) is also known as a helper cell. It helps the body fight infections that can lead to illness. This is also the main cell destroyed by HIV. Once the virus enters the body, it targets the CD4 cell, multiplies, and then destroys the CD4 cell. As the amount of virus in the body increases, more and more CD4 cells are destroyed and can no longer fight off illnesses. The individual then begins to have symptoms and gets sick. The amount of time it takes from becoming infected to developing symptoms varies from person to person. Some patients will develop symptoms within months of infection and some will take years. The immune system in infants and very young children is still immature, and therefore these children tend to develop symptoms more quickly than newly infected adults.

## *Transmission of HIV*

HIV is passed from one person to another through blood-to-blood contact between people. This mainly occurs during unprotected sex (vaginal, anal, or oral) or through sharing needles or syringes with someone who is infected with HIV. In children, however, the way HIV is passed varies depending on the age of the child. More than 95% of children under 13 years old who are diagnosed with HIV are infected during pregnancy or birth from exposure to an infected mother. In many cases, these women did not know that they were infected with HIV until their baby or child was diagnosed. Babies can also be infected after birth through breastfeeding. Older teenagers tend to be infected through sexual or IV drug exposures. Sexual transmission can occur between heterosexual or homosexual

contacts. In the early days of the epidemic, blood transfusions accounted for a large number of infections. Today, all blood donations are screened for HIV and there is almost no risk for contracting HIV from a blood transfusion.

The following body fluids have been proven to spread HIV:

- blood
- semen
- vaginal fluid/birth canal fluid
- breast milk

Casual contact through closed mouth kissing has not been shown to spread the virus. Although the risk is low, open mouth kissing or French kissing may cause contact with blood and could cause the virus to spread although the risk is minimal.

HIV **cannot** be transmitted through casual contact, which means it is not risky to shake or hold hands, hug, kiss; share locations such as offices, classrooms, or locker rooms; share facilities such as kitchens, bathrooms, or laundry rooms; use public facilities such as drinking fountains, restrooms, or doorknobs; swim in public pools; eat food prepared or served by a person with HIV.



## *Diagnosis of HIV*

HIV can be diagnosed in several different ways. The most common screening test for HIV is called an ELISA. This test checks for antibodies (the body's response to infection) against HIV. This test can be run on either blood or saliva, but tends to be more reliable on a blood sample. The purpose of this test is to screen and not miss any possibly infected person, but there will be occasional false positive tests. Since this can occur, any positive ELISA test will need to be confirmed by a more complex test called a Western Blot. This test takes a much closer look at the antibodies to confirm the diagnosis. This test may take 3-7 days to run and to confirm the diagnosis.

In very small babies, a viral load test that actually measures the amount of virus rather than an antibody response may be more accurate and may be obtained to confirm the diagnosis. A mother will pass her HIV antibodies to the baby. It can take months for the mother's antibodies to clear in the baby's system. The viral load test is done in order to determine if the virus itself is present in the baby's system. The viral load can show quickly if the virus is present in the baby. If virus is detected in the baby, the baby is infected. This results in quicker diagnosis of the baby and allows for early treatment. For all other patients, the viral load test is not used to make a diagnosis since it is expensive and is used instead to monitor the disease in known HIV positive patients.

## *The Clinic Visit*

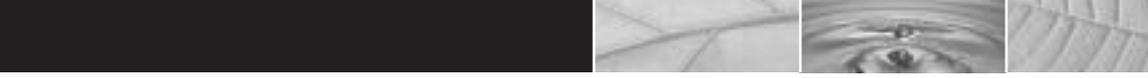
Once HIV is diagnosed, it is very important to have frequent follow up visits with a doctor who specializes in the treatment and management of HIV. This is usually an infectious disease doctor. It is recommended that young children and adolescents see a pediatric infectious disease specialist. Sometimes it will be necessary for your infectious disease doctor to call on other specialists to assist in the management of complications that may arise from the HIV.

During a typical outpatient clinic visit, your child will be weighed and measured. This is very important as the HIV may slow a child's growth. Vital signs will be monitored since medications can affect these, particularly blood pressure. Your child will then be examined by the doctor. Other specialists that may meet with

the family include the dietary specialist or nutritionist, social worker or a doctor from a different specialty. After the examination, it is usually necessary for most children to have laboratory or blood tests drawn. These tests are to monitor the amount of virus activity in the child and how much destruction is occurring to the immune system. Other blood tests are performed to monitor for side effects of the HIV medications. HIV medications can cause serious side effects on body organs, such as the liver and pancreas. It is extremely important for your child to be examined and to have labs monitored on a frequent basis. The frequency of visits will be determined by your health care team.

The following blood tests are those most frequently monitored:

- **Complete Blood Count (CBC)**- This test monitors the number and function of red blood cells, white blood cells, and platelets.
  1. White Blood Cells—these cells are produced by the immune system and help defend the body against infection. There are several types of white blood cells and each one works differently. A high white blood cell count might be a sign of infection somewhere in the body. A low white blood cell count might be the result of HIV infection or another serious illness or disease.
  2. Hemoglobin—this is a measure of red blood cells in the body. Red blood cells deliver oxygen throughout the body. A low red blood cell count might indicate anemia, which can cause a person to feel tired or have decreased energy. Anemia can sometimes be caused by a chronic or longstanding disease such as HIV or by the medications used to treat HIV such as AZT.
  3. Platelets—platelets are produced by the bone marrow. They help the blood to clot. Some antiretroviral medications can cause a low platelet count.
- **The Blood Chemistry Screen**- Sodium, potassium, chloride, bicarbonate, phosphate, calcium, and magnesium are all electrolytes. Electrolytes are substances in the body that play an important role in the operation of the cells in the body and heart. A person with HIV who is having diarrhea or vomiting can have an electrolyte imbalance. The BUN and creatinine are tests to evaluate the function of the kidneys. The kidneys are responsible for



getting rid of the body's waste products through the urine. Many medications are processed through the kidney and passed through the urine. This can affect kidney function. Liver function is also monitored (SGOT/SGPT) since the liver also helps process many of the medications. The pancreas can also be irritated by the HIV and/or its medications, and its function is monitored by checking the enzymes amylase and lipase levels in the blood.

- **The Immune Function Screen**—this group of tests will measure the amount of HIV in the body as well as its effect on the immune system. This will help determine when to start medication and then will determine the effectiveness of the medications.

1. **CD4 or T4 count**—the CD4 cell (also called the T4 or helper T cell) is one type of white blood cell that is an important part of the immune system. They help to protect the body against infection. The CD4 cell leads the attack against infection. HIV infects the CD4 cell making it unable to fight infection. The HIV then begins to destroy other T cells. When the CD4 cell count gets low, the immune system is being weakened. The lower the CD4 cell count, the more likely the child will get sick.

Other things can affect the CD4 cell count as well such as stress, illness, and recent immunizations. Because of this, the doctor does not make medication changes based on just one CD4 cell measurement, but looks at the trend over a few measurements obtained at different times. However, if the CD4 cell count remains low over several lab draws, it may indicate progression of disease or that the medications are no longer effective. This might require a change in medication. Understanding the meaning of T cell counts can be difficult since they can vary as mentioned above. Normal counts also depend upon the age of the patient, so interpretation of counts should be done with your doctor.

2. **Viral Load**- The viral load (also called the PCR) measures the amount of virus found in the body. As the disease worsens, the amount of HIV in blood and body tissues increases. The viral load is reported in “copies”. If there is so little HIV in the blood that it is not detected by

this test, it is reported as undetectable (<400 copies). However **that does not mean that the virus is not present anywhere in the body or that the patient is cured.** Even when HIV is not spilling over into the blood, it is still present in other body sites and tissues including the central nervous system, the spleen, and lymph nodes. As the disease progresses untreated or as the virus becomes resistant or less responsive to medication, the viral load will rise.

When evaluating for treatment, the doctor will look at the CD4 count as well as the viral load and symptoms to decide on a management plan. Generally, routine blood tests are ordered every 1-3 months for monitoring. This may be done more frequently during changes in the treatment plan or as the disease progresses. Although blood tests can be an uncomfortable experience for a child, they are very important in helping to monitor the progression of the HIV, immune function, body organ function, and the success of medications and their side effects.

### *Initiating Therapy*

There is currently no medication that will cure HIV. However, with good medical care, many patients are able to remain healthy for long periods of time and lead productive lives, including attending school and holding a job. Without treatment, however, the virus will continue to multiply and, as it does so, it will weaken the immune system. Once the immune system is weakened to a certain critical point, you or your child will be more likely to develop potentially life-threatening infections.

Children who maintain a close relationship with their doctor and who have strong family and friend support have a very good chance at achieving and maintaining a healthy lifestyle. Although antiretroviral medications are usually necessary at some point to control the progression of HIV disease, these medications can be difficult to use and have significant side effects. This requires that your child be scheduled for a clinic visit appointment every 1-3 months. Occasionally more frequent visits will be necessary when first starting or when making any medication changes.



The decision to start treatment in a child with HIV is difficult and requires thought and commitment by the patient, family, and doctor. Babies with HIV who are less than 1 year of age require immediate treatment. This is because small babies and children have immature immune systems and are therefore at much greater risk of developing life-threatening illnesses. Infants also have much higher viral loads and poor control of the HIV in their body. They often require treatment with 3 medications and very frequent monitoring by the doctor.

Sometimes, children are diagnosed when they are preschoolers or teenagers. They may have had HIV since birth and their mother's HIV status was likely unknown if she was not screened before giving birth. Often the mother's HIV infection is not diagnosed until the child becomes ill and the diagnosis is made on the child. Also, some older children and teenagers do become infected at an older age and may not be diagnosed until they have been HIV positive for a period of time. In these children, the decision to begin medications will be based on many factors.

In a child who is HIV positive, is over 1 year of age, but has no symptoms of disease, the decision to treat is based on several factors including T4 count, viral load, and a readiness of the patient and family to commit to therapy. This decision is made carefully because treatment can result in many different side effects. The child and family must be ready and willing to work through these and the doctor and care team must be prepared to support the child and family in this process.

Some children have HIV infection that is slowly progressing. These children are termed as "slow-progressors". They have no symptoms of being sick and their immune systems remain healthy in spite of the HIV. In the few children who do fit this pattern, the decision to treat may be delayed until the disease progresses.

The medical team may decide not to treat a patient who is in a situation where they will not be able to maintain the medication schedule as long as the child is not suffering from the symptoms of the disease. Treatment will be required in any child with: illness from their disease, a low CD4 count or a high viral load. While the acceptable levels of immune function and viral load vary with age, generally the lowest acceptable CD4 count in an older child or teenager is 350 cells and any viral load over 35,000 to 50,000 is often the most allowed before starting therapy.

Once the decision is made to begin treatment, it is critical that children are compliant with the schedule, which **means taking every dose of every medicine at the scheduled time**. This is critical to maintaining the effectiveness of the medications and the long term health of the child. **Skipping doses of medication can cause the virus to become resistant to the medication. When that occurs, the drugs will no longer control the progress of the HIV disease and the immune system will be weakened and eventually destroyed.** Resistance to one medicine may result in resistance to other medications, even some the child has never taken before. This is called *cross resistance*. This limits the medication options available in future treatment.

Treatment with antiretroviral medications is called HAART. This stands for Highly Activated Antiretroviral Therapy. It is an aggressive approach at attacking HIV from different sides at the same time. This is done by using combinations of medications in groups of 2-7. Treatment of HIV disease using one medication or *monotherapy* is rarely recommended in children or adults. Each medication works differently in controlling the HIV. Once treatment begins, it is extremely important to be compliant and take all the medications as prescribed. Studies have shown that resistance to the medications can occur quite easily. Antiretrovirals taken less than 100% of the time can lead to resistance. If the HIV sees medications on and off or sees them one at a time, it may figure out how the medicine works and change itself in some way to become resistant.

Another important part of being compliant is keeping all scheduled appointments with your doctor. This allows the care team to evaluate how effectively the medications are controlling the HIV. This is determined by talking to your child and family, by performing an examination on your child, and monitoring blood tests. Side effects and compliance will be evaluated at each visit. It is critical that your child and family be considered a part of the care team and are able to discuss your concerns with the rest of the care team openly. We hope to provide support, resources, and encouragement as each family struggles with road blocks to maintaining a healthy lifestyle. To help ensure a child's compliance, we try to start medications that are effective but with the least side effects, that fit into busy schedules, and that are tolerable in taste. Patients and families are encouraged to



call for information and support at any time but particularly in the first few weeks of starting therapy when side effects may be at the worst.

Once therapy is started, blood will be drawn at 3 to 4 week intervals. This will help monitor the effectiveness of the medication as well as side effects on other body organs. The maximum effect of the medications on the HIV viral load will generally be seen after 8-16 weeks of therapy. The goal is to reach an undetectable level, but this is achieved in only about 50% of patients. The other half may not reach undetectable but may have their HIV viral load decreased to a point where it does not weaken the immune system as quickly. It is also important to remember that an undetectable viral load does not mean the virus is cured and that levels may go up and down slightly from one measurement to the next. If the medications are effective, it may take months or even years to see the CD4 count increase to higher levels.

The viral load may not decrease with medications or it may decrease for a period of time but then go back up to very high levels. The cause of this will need to be determined. There are generally four reasons the viral load will be high:

- 1) Receiving immunizations during this period,
- 2) An illness or infection,
- 3) Not taking the medications
- 4) Resistance of the virus.

Not being compliant with the HIV medications will cause resistance to quickly occur, but even the most compliant people will eventually develop resistant virus over time.

It is also important to know that other medications may interfere with the antiretrovirals and change the way they work in the body. This may require an adjustment of the dose. Please inform the care team of any other medications including over the counter drugs your child is taking on a regular basis or even every once in a while. If you are given a prescription or over the counter medication by another care provider, please check with the care team to make sure it will not interact with the antiretrovirals **before you start to take the new**

medication.



## Medications

### • General Information

The medical team will want to review your medication list at each clinic visit. Please bring your medications with you to each clinic visit. This is very important as sometimes doses must be adjusted to account for your child's growth.

It is also important you report all side effects that your child has to the nurse or doctor at your visit so that they may be evaluated and changes made if necessary. If side effects occur that are unexpected or excessive, the medical team should be notified immediately by telephone.

The medication information sheets will give you information specific to the particular medications your child is taking. These will discuss interactions with other medications, the effect of food on the medicine, and likely side effects.

Remember that antiretroviral medications, particularly liquid forms, may not be readily available at your pharmacy and may need to be ordered by your pharmacist. You should **always** have a minimum 4 day supply at home to be certain you do not run out of medication in case it needs to be ordered by the pharmacy. This supply will also account for other possibilities such as bad weather or spillage.

### • Infants and Young Children

Antiretroviral medications are given in powder or liquid form to children too young to swallow pills. The ability to swallow pills varies from child to child and even some adults are unable to take drugs in pill form. As of this time, there are only nine medications available in liquid or powder form, which again emphasizes the importance of *compliance*. If the medications are not given appropriately, the virus will become resistant and the medications will no longer work against the virus. Since the medications are usually used in combinations of 3 or more, we could quickly run out of liquid options if resistance develops. This would limit our ability to change and use medications until the child is older and able to swallow pills. Also, early resistance may cross over and cause resistance to some of the pill medications even if your child has not been on those before.

## • Measuring Liquid Medications

Liquid medications are measured by using a syringe or medication cup. Teaspoons and tablespoons used at home are often not accurate. We prefer that these not be used to measure medication doses. The nurse or pharmacist can assist you in obtaining a supply of syringes or medication cups. These can be washed and reused.

Occasionally a medication will be packaged with a dropper. To use the dropper, place the dropper in the bottle and squeeze the rubber top. Lift the dropper from the bottle and read the amount off the dropper. To get to the correct dosage, gently squeeze the top of the dropper until the medication is in line with the desired dose written on the dropper. **Do not switch droppers from one medication to another.** Often the dosing measurements can only be used for a specific medication. Do not use a dropper with a medication unless the dropper comes in the package with the medication.

The nurse or pharmacist will review all new medications with you. She will also show you how to measure medications using a syringe or medication cup.

When using a syringe, remember to measure the dose by lining up the top of the black line of the plunger with the desired dose or number on the syringe. Remove any large air bubbles. Be careful when obtaining a new supply of syringes since each type measures differently. For children less than one year of age, we prefer that liquid medications be measured with a syringe rather than a cup.

Measuring cups are useful in giving medication to older children. In order to accurately measure a dose of liquid medications, place the cup on a flat surface and keep your eye level with the cup. Pour slowly to the desired dose.

Liquid medications often have a bad taste, sometimes even bitter. Most pharmacies now offer a choice of added flavoring. This may not cover the awful taste. Some caregivers try adding formula to medication but this is not the preferred method. If you must use this approach, limit the amount of fluid to one ounce. Otherwise, if your child refuses the bottle, you will not be able to determine if the baby received the entire dose of medication. Also, some medication may stick to the sides of the bottle or cup and the baby may not receive the full dose. Therefore, for these reasons and the fact that formula or other fluids often do not



disguise the poor taste, it is best to not use this method when giving medications.

Realizing that every child is different, we are offering a list of suggestions of things to give before or after the medication. You may need to try several different things to ease the administration of medication for your child. Some suggested approaches follow.

- **For infants less than 4 months:**

- a. Using a needleless syringe, squirt the medication slowly into the side or the back of the mouth. Have a pacifier or bottle of formula to use between and after medications.

- **For infants 4 to 12 months:**

- a. Same method as above.
- b. A half ounce of diluted fruit juice may be given between or after medications.
- c. Teaspoons of baby food can be given between or after medications.

- **For children 12 months to 3 years:**

- a. Fruit juice or cold milk between and after doses
- b. Popsicles
- c. Chocolate or strawberry syrup
- d. Yogurt
- e. Chocolate pudding

- **For children 3 years and older:**

- a. Any of the above options
- b. Peanut butter-use only in children 4 years and older and use care to avoid choking
- c. Jelly
- d. Honey (never give honey to a child less than 1 year of age)
- e. Ice cream
- f. “Pixie stix”-use only in children 6 years and older
- g. Ice chips-use only in children 6 years and older
- h. Life savers or other hard candy-use only in children 6 years and older

## • Measuring Powder Medications

To measure powder medications, please speak to the nurse or pharmacist for directions.

## • Tablets

Antiretroviral pills tend to be very large in size. Some tablets can be cut in half or crushed for those who cannot swallow such large pills. Other types of tablet medications will lose their effectiveness if cut or changed in any way. If you have difficulty in swallowing pills, speak to your doctor or pharmacist for directions.

## • Suggestions for Giving Medications

### 1. For Babies and Toddlers:

- a. hold the child in your arms with the child's right arm under your left arm around your back.
- b. hold the child's head tilted back firmly between your right arm and chest.
- c. put the medicine in corner of the child's mouth toward the back and along the side of the tongue; give small amounts at a time to avoid choking.
- d. when all of the medicine is given, hold and comfort your child; offer a pacifier, bottle, or cup.
- e. this can be frustrating—do not yell or show anger.
- f. if you are having difficulty giving medications, the nurse can demonstrate the procedure for you in the clinic.

### 2. For Older Children:

- a. never ask your child if they want to take the medicine—it is not optional; be firm in telling your child it is time for medicine.
- b. offer a choice of liquid or food to take after medication.
- c. some children will cooperate better using a reward system such as stickers.
- d. do not threaten or punish—be patient.
- f. keep explanations simple; explain to your child that the medications must be taken to continue to feel good and be able to play.



g. if in spite of all your efforts you are not able to get your child to take the medicine, call the office and ask to speak to the nurse.

If your child vomits the medication within 20 minutes after giving the dose, please repeat the dose. If your child vomits more than 20 minutes after giving the dose, do not repeat the dose since we do not know how much of the dose has been absorbed. If your child continues to vomit or vomits after every dose of medicine, please contact the office.

If you miss a dose of medication, take it as soon as possible and then continue with your regular schedule. Do not re-time medicines after a missed dose. If it is less than 2 hours until the next dose, wait and take that dose at the regularly scheduled time. **Do not double up and take 2 doses of the same medication at the same time. This could increase possible side effects.**

## *Specific Medications*

There are currently four families of HIV medications. The medicines are grouped into these families based on the way they work on the virus. The medications are usually used in combinations from different families. In this section, they are divided up into individual families and each drug is discussed in detail.

Remember that in children, medications are dosed based on the child's size. Therefore, the doses have to be adjusted and increased as the baby or small child grows up.

- **Nucleosides**—these medications were the first HIV drugs available and are the ones that people are the most familiar with. These medications are usually the easiest to tolerate but are not as effective as some of the other drug families. They are referred to as the backbone of therapy since they are almost always part of the treatment plan.

1. AZT—also called zidovudine and zidovudine.

- a. Dosing: AZT can be taken as a 100 mg capsule or a 300 mg tablet. It is also available in a liquid form. It is taken 2-4 times per day and can be taken with or without food.
- b. Side Effects: rare but may include rash, fever, nausea, vomiting, low blood count, diarrhea, and headache.
- c. Discuss with your doctor if you have liver or kidney problems or if you are pregnant or planning a pregnancy.
- d. Comments: contact your doctor if you experience rash, fever, chills, weakness, or if you are feeling unusually tired.

2. 3TC—also called lamivudine or epivir.

- a. Dosing: Epivir comes as a 150 mg or 300 mg tablet that is light blue in color and is also available as a liquid. It can be given once or twice daily with or without food. The liquid is always given twice a day.
- b. Side effects: Side effects are very rare with 3TC but can occasionally include headache, nausea, diarrhea, tiredness, or irritation of the body organs including the pancreas and liver which can cause belly and



back pain, nausea and vomiting, and sometimes fever. 3TC can also cause an imbalance of the chemicals of the body (a condition called lactic acidosis). Blood tests are used to monitor for these conditions.

3. D4T—also called stavudine or zerit.

- a. Dosing: Zerit comes in 15 mg, 20 mg, 30 mg, or 40mg tablets that are red in color. It is also available in a liquid form. It is taken two times per day and can be taken with or without food.
- b. Side effects: Include nausea, vomiting, diarrhea, rash, headache, and tingling or pain of the legs (a condition called peripheral neuropathy). It can irritate the pancreas, liver, and chemical balance of the body as described above.
- c. Comment: Rarely are patients treated with D4T and AZT together since AZT can reduce the ability of D4T to fight the HIV.

4. DDI—also called videx or didanosine.

- a. Dosing: Videx comes as a capsule, chewable tablet or liquid. The pill forms of the medicine are light blue or white in color. It is usually given once or twice a day. The liquid form is always given twice a day. Videx should be taken on an empty stomach, either 1 hour before a meal or 2 hours after a meal.
- b. Side effects: Include nausea, headache, diarrhea, and tingling or pain of the legs. Videx is also one of the medications that frequently irritates the pancreas (causing a condition called pancreatitis), as well as liver irritation and an imbalance of the body chemicals. Please report any side effects to the doctor. Lab tests are used to monitor for these problems and if these side effects occur, it may result in stopping the medication. Videx may also affect the nerves in the eye, causing blurred or colored vision.
- c. Comment: Children taking videx and stavudine together have a greater chance of having these side effects.

5. Abacavir—also called ziagen.

- a. Dosing: Available as a 300 mg tablet which is green in color or as a liquid. It is taken twice a day and may be taken with or without food.

- b. Side effects: Rash, nausea and vomiting, diarrhea, decreased appetite, decreased sleep, headache, and tiredness.
  - c. Comments: Taking abacavir can produce a severe allergic reaction. Watch for rash, nausea and vomiting, diarrhea, decreased appetite, decreased sleep, headache, and tiredness.
  - d. Comments: Taking abacavir can produce a severe allergic reaction. If your child develops a rash, stop the medication immediately and call the doctor's office immediately.
6. Tenofovir—also called viread.
- a. Dosing: Tenofovir only comes as a tablet form. It is white in color and is usually taken once a day. Tenofovir works best when taken on a full stomach.
  - b. Side effects: nausea, vomiting, diarrhea and gas, some fatigue, feeling jittery, or feeling like you are moving in slow motion.
  - c. Comment: Most side effects improve within 5-7 days after starting the medication.
  - d. Comment: When tenofovir is taken with videx, the patient must be monitored carefully since the level of the videx in the blood may go up and cause increased side effects.
7. Trizivir—this is a combination of 3 medications all from the same family including abacavir, 3TC, and AZT. All three medications come together in one pill.
- a. Dosing: Trizivir only comes in tablet form. It is yellowish in color and is given two times per day. It can be taken with or without food and is given to children usually only if they weigh more than 88 pounds.
  - b. Side effects: Rash, nausea, vomiting, diarrhea, abdominal pain, decreased appetite, decreased sleep, increased liver enzymes, muscle pain.
  - c. Comments: See above comments on AZT and abacavir.
8. Combivir—is a combination of AZT and 3TC.
- a. Dosing: Combivir comes only in tablet form and is only used in children old enough to swallow a tablet and who are big enough to require the dose of each medicine in the combivir tablet. It is white in color



and is taken twice a day. Combivir can be taken with or without food.

b. Side effects: Include the side effects listed for AZT and 3TC.

c. Comment: When taking combivir, patients should be closely monitored if they are also taking other medications, especially gancyclovir, interferon, or zert.

9. Emtriva—also known as emcaltricabine.

a. Dosing: Emtriva comes only in a capsule form. It is given as one 200 mg capsule per day.

b. Side effects: Include headache, diarrhea, nausea, and rash. Lactic acidosis and severe liver dysfunction have been reported but are extremely rare.

c. Comment: Emtriva may also be useful in treating patients co-infected with Hepatitis B virus. It is usually not useful in patients that are known to be resistant to epivir.

- **Non-nucleoside reverse transcriptase inhibitors (NNRTIs)**—This family of medications is used in combination with the nucleosides and are slightly stronger and have more side effects. The HIV virus can develop resistance to these medications fairly easily if the medications are not taken exactly as prescribed. Once a person develops resistance to one of the medications in this family, they often will be resistant to all the medications in this family, even those they have never received.

1. Nevirapine—also called viramune.

- a. **Dosing:** Viramune comes as a 200 mg tablet that is bluish in color. It can also be given in liquid form. It is usually given 1 time per day for the first week and then increased to twice per day after that. It can be given with or without food.
- b. **Side effects:** Severe rash, nausea, headaches, liver irritation, diarrhea and vomiting.
- c. **Medications that can cause problems when they are taken with viramune** include birth control pills, rifampin, rifabutin, and methadone.
- d. **Discuss with the doctor before taking the medication if your child has liver problems** including hepatitis or if they are pregnant or planning to become pregnant.
- e. **Comment:** Rash is most common in young children and usually happens when the dose is doubled in the second week on the medication. If you get a rash, the medication should be stopped and the doctor notified immediately.

2. Sustiva—also called efavirenz.

- a. **Dosing:** Sustiva comes in different size capsules called geltabs, which are brownish in color. It can take several pills to equal the right dose in any patient and may be a combination of 50 mg, 100 mg, 200 mg or 600 mg geltabs. This medication is taken only one time per day. It is not generally used in children less than three years old or 29 pounds and it cannot be used in patients who are unable to swallow a fairly large pill. It may be given through a feeding tube placed in the stomach, although not easily. It can be taken with some foods but high



fat foods should be avoided two hours before and after the dose.

- b. Side effects: Rash, nausea, vomiting, dizziness, headache, change in moods, decrease in sleep, abnormal or vivid dreams, and difficulty concentrating.
- c. Medications that should not be taken with Sustiva include cisapride, terfenadine, loratidine, midazolam, triazolam.
- d. Medications that need to be monitored closely when taken with Sustiva include clarithromycin, methadone, rifabutin, rifampin, warfarin, seizure medications, itraconazole, ketoconazole, protease inhibitors (see below), or herbal remedies such as St. John's Wort. Please talk to the health care team if the patient is using any of these medications.
- e. Comment: Sustiva is sometimes given with benadryl to avoid rash. Due to this and some of the side effects of Sustiva, it is usually given at bedtime. Any female taking Sustiva should use birth control if they are sexually active since it could cause birth defects in an unborn baby. If a patient discovers she is pregnant while on Sustiva, she should contact the care team immediately but **should not stop the medication on her own without a new plan in place.**

• **Protease inhibitors**—This family of medications is considered the strongest available medications for HIV and have the most side effects. They are used in infants or when children's HIV is poorly controlled.

1. Ritonavir—also called norvir. This medication can be used as the only protease inhibitor of the drug panel or can be used in combination with other protease inhibitors (saquinavir) or to boost the strength of other protease inhibitors (kaletra).

a. Dosing: Ritonavir is available in a 400 mg or 600 mg blue capsule. It is also available in a liquid, but the taste is extremely bitter. This medication should be taken after eating and on a full stomach.

b. Side effects—Nausea and vomiting are the most common side effects and can often occur just with smelling or tasting the medication; other side effects include diarrhea, decreased appetite, abdominal pain, change in taste, headache, rash, fat accumulation in the body (known

- as lipodystrophy), and high blood sugars.
- c. Medications which should not be taken with Ritonavir include rifabutin, cisapride, terfenadine, amiodarone, flecamide, and some seizure medications.
  - d. Discuss with your doctor before starting the medication if your child has liver or kidney problems or if you are planning to become pregnant.
  - e. Comment: When using the ritonavir/saquinavir combination, the medications should be taken 2 hours apart.
2. Saquinavir—also called fortovase, this medication is almost always used in combination with another drug in this family in an effort to maximize its effectiveness.
- a. Dosing: Saquinavir is only available in a rather large gelatin capsule. It is pinkish in color and is usually taken three times per day. Saquinavir should be taken with a high fat meal.
  - b. Side effects: Include diarrhea, abdominal pain, nausea, headache, high blood sugar, rash, and fat deposits in the body.
  - c. Medications that should not be taken with this medication include astemizole, terfenadine, cisapride, midazolam and triazolam.
  - d. Medications that should be closely monitored when taking saquinavir include clarithromycin, ketoconazole, other HIV medications including viramune and other protease inhibitors, rifampin, and rifabutin.
    1. Talk to your doctor before starting saquinavir if you have diabetes, are pregnant or may become pregnant.
  - e. Comment: If taken with ritonavir, take the two medications at least 2 hours apart.
3. Nelfinavir—also called viracept. This protease inhibitor is often used in small infants and children.
- a. Dosing: Nelfinavir comes as a 250 mg tablet that is light blue in color or a powder form that can be mixed with water, milk, formula, or soft food. This medication should be taken with food, but avoid giving with acidic foods or juice such as orange or apple juice because this can



cause a bitter taste.

b. Side effects: Diarrhea, nausea, fat deposits, and high levels of fat in the blood.

c. Medications which should not be taken with Nelfinavir include: cisapride, terfenadine, astemizole, amiodarone, quinidine, midazolam, or triazolam.

d. Comment: If your child is taking a fungus medication called ketoconazole or if you or your child are taking birth control pills, please notify the physician so doses can be adjusted if necessary.

4. Crixivan—also called indinavir; this medication is very potent.

a. Dosing: Crixivan is made only in capsule form and is therefore only used in patients who can swallow pills. It comes as 200 mg, 400 mg, or 800 mg off-white capsules. This medication should be taken on an empty stomach which means one hour before or two hours after a meal. Children taking crixivan should also increase their water intake while taking crixivan to decrease the chances of developing kidney stones. Adults should be cautious in drinking alcohol while taking this medication.

b. Side effects: Nausea, vomiting, diarrhea, rash, headache, kidney stones, liver irritation, fat depositis in the body, and belly pain.

c. Medications that should not be taken with crixivan include rifampin, rifabutin, INH, ketoconazole, clarithromycin, clotrimazole, quinidine, and birth control pills.

d. Before starting crixivan, inform the doctor if your child has diabetes, kidney problems, history of kidney stones, or if she is or may become pregnant.

e. Comment: Although this medication works best on an empty stomach, children who are having nausea and vomiting may do better if they take crixivan with a light, low fat snack.

5. Kaletra—(also called Lopinavir/Ritonavir combination), this drug is boosted, meaning it is kind of a super strength protease inhibitor. It is two protease inhibitors combined into one pill. It is sometimes saved for people that have been on many different medications over a long period of time

but whose viral load continues to increase and whose CD4 count continues to fall. This is called salvage therapy.

- a. Dosing: Kaletra is available in a liquid or soft gel capsule form. The liquid tastes very bitter and is often difficult for young children to swallow. It is often best given through a feeding tube placed in the stomach. The capsules are orange in color and are 133 mg doses. It generally takes 1 to 3 capsules to give an entire dose. This medication is given 2 times per day and should be taken on a full stomach.
- b. Side effects: Nausea and vomiting, diarrhea, feeling tired, and headache.
- c. Many medications should not be taken if a person is taking Kaletra including allergy products, cisapride, versed, some blood pressure medications, halcyon, viagra, lipitor, mevacor, or zocor.
- d. Medications that should be monitored while taking Kaletra include seizure medications, metronidazole, and disulfiram.
- e. Before taking this medication, let the doctor know if your child has liver problems including hepatitis, diabetes, hemophilia, or if the patient is pregnant or may become pregnant.
- f. Comment: While Kaletra may be difficult to use, it is a very good medication. Often, the nausea and vomiting will decrease after the first few days to a week of therapy.

6. Amprenivir—also called agenerase.

- a. Dosing: Agenerase comes as a 50 mg or 150 mg capsule that is blue in color. It is also available as a liquid but is rarely used in children less than 4 years old. It is given twice a day and can be taken with or without food. Fatty foods should be avoided when taking this medication.
- b. Side effects: Rash, diarrhea, nausea, vomiting, mood changes, deposits of fat in the body, tingling around the mouth, and changes in taste.
- c. Comment: Some medications that should not be taken with agenerase include halcyon, cisapride, ergot medications used for migraine headaches, versed, and a medicine for tic problems called orap. Other medications require close monitoring when taken with agenerase,



include rifabutin, ritonavir, viagra, St. John's wort, rifampin, drugs to lower cholesterol, seizure medications, steroids, birth control pills, and vitamin E. There is a new form of Amprenavir now available called fosamprenavir that requires less numbers of pills to be taken. Ask the health care team about this option if you are on agenerase.

7. Reyataz—also known as atazanavir.

- a. Dosing: Reyataz only comes in a capsule form. The capsule comes in a 200 mg size and the usual dose is 2 capsules one time per day. Reyataz can be boosted or supersized in certain people by adding Norvir to increase the strength of its effects. When boosting is appropriate, the dose is two 150 mg capsules of Reyataz and one 100 mg capsule of Norvir once a day. Reyataz should be taken with food, usually a complete nutritious meal, to ensure that the medicine is appropriately absorbed into the body.
- b. Side effects: Jaundice, which is a yellowing of the skin and eyes caused by a build-up of bilirubin by the liver. It seems that the high bilirubin levels seen with Reyataz do not cause any other health issues or problems other than the yellowing.
- c. Comment: Reyataz can interact with many other medications including acid reflux medications, antibiotics, chemotherapy medications, migraine medications, antihistamines including cold and allergy medications, heart and cholesterol medications, birth control pills, and even other HIV medications and herbal remedies. It is very important that the health care team and the pharmacist review all such medications before you start Reyataz since some medications should not be used with it and the doses of others may need to be changed to make sure they stay effective but are not toxic.

- **Fusion inhibitors** are the newest family of medications. Fusion inhibitors keep the HIV from holding on to the CD4 cells. So far there is only one drug in this family available for use but many more are being studied by scientists.

1. T20—also called Fuzeon. It is given with the other medications listed above

in people that have been through many of the other medications and who have a lot of resistance to the other medicines. It is also given to people who have virus levels out of control in spite of medications (known as salvage therapy). It is not routinely used for treatment of people who have many other medication options left, at least not at this time.

- a. Dosing: Fuzeon is a white medication that is mixed with sterile water and then given with a needle by injection twice a day. It is not available in any other form.
- b. Side effects: Include pain, swelling, bumps, redness, or bruises at the point where the medication was injected. Also, rash, fever, nausea, vomiting, chills, low blood pressure, and liver irritation. There may also be a higher risk of pneumonia in patients on fuzeon.
- c. Comment: Fuzeon should not be taken by anyone pregnant or who may become pregnant or is breastfeeding.



## *Side Effects of Medications*

### • Nausea and Vomiting

All HIV medications have side effects and most of them are related to the gastrointestinal (also called GI) tract. The GI tract is one of the body's first lines of defense and also where medications are turned into their active form. The most common effects are nausea, vomiting, and diarrhea. As the body adjusts to medications, most of the symptoms will improve over time. However, if vomiting is severe and continuous, your child may become dehydrated or suffer from poor nutrition. If these symptoms persist or become frequent, please notify the care team.

When trying to manage nausea, vomiting, and diarrhea, it is important to read the information that the pharmacist gives you with each medication. Often, a small snack with the medications will help with the problems. Some medications need to be taken on an empty stomach to help the body absorb them into the bloodstream so they may begin to fight the HIV. Some other tips to help decrease nausea and vomiting associated with taking medications include:

1. Eating small frequent meals
2. Eating bland foods
3. Breathing deeply and slowly through nausea

### • Diarrhea

Diarrhea is defined as having loose watery stools more than three times per day. Infants less than one year of age who have diarrhea for more than two days should be reported to the office. Some tips to help manage diarrhea include:

1. Avoid foods high in fiber such as cereals, raw vegetables, and fruits except bananas.
2. Provide frequent small meals consisting of bland foods.
3. Encourage clear liquids such as Pedialyte for infants or Gatorade. Avoid excessive amounts of plain water. Avoid fruit juices, caffeine containing drinks, and milk. Liquids should not be bubbly and should be served close to room temperature and not hot or cold.
4. Often times, doctors will recommend a BRAT diet during diarrhea which stands for Bananas, Rice, Applesauce, and Toast.

Diarrhea left untreated can cause dehydration and, if left untreated for a very long time, can result in malnutrition. Diarrhea may be caused from lots of different sources including medication side effects, infections, or lactose intolerance (which means the inability to digest milk products). If the diarrhea is a side effect of the medication, it may get better with time. If not and the child cannot tolerate the symptoms, a change in medication may be considered or additional medications may be added to decrease the symptoms.

- **Fatigue**

More than half of the people diagnosed with HIV experience fatigue or extreme tiredness at some point during their disease. This fatigue may be related to the HIV infection itself, especially if it is poorly controlled. Fatigue can also be caused as a side effect of medication, such as a low red blood cell count, or with an associated infection. Some ways to fight fatigue are to eat well-balanced, nutritious meals, regular exercise, and getting adequate rest for about the same number of hours each night. Firm bedtimes in young children and a firm wake-up time in teenagers should be maintained.

- **Weight Loss and Wasting**

Weight loss may result from advanced HIV infection (AIDS), side effects of medications, or from associated infections. Wasting occurs when the body loses some of its muscle because food is not being absorbed well by the body and the body fails to keep the muscles fed. Fat and protein, which make up muscle tissue in the body, get broken down by the body for energy when food is not available or is poorly absorbed. This process leads to wasting.

Other causes of weight loss or wasting include loss of appetite, or vomiting and diarrhea, or from increased energy needs of the body known as increased metabolism. The body will have an increased metabolism or increased energy needs during times of illness such as HIV infection. This may make it difficult to take in enough calories to meet all the body's energy needs. The dietitian is an important member of your health care team and is very important in recognizing early signs of weight loss and heading off problems with wasting. The doctor and dietitian will evaluate your child's nutritional well being with examinations and laboratories when necessary.



- **Peripheral Neuropathy**

Peripheral neuropathy is pain that is felt in the hands, legs, and/or feet. It may be constant or come and go. Some of the HIV medications can cause this to happen. If the HIV disease advances to later stages or AIDS, it can also cause this problem. Symptoms of peripheral neuropathy include numbness, decreased feeling to pain or temperature, extreme sensitivity to touch, tingling or burning sensations, loss of balance and/or coordination, muscle weakness, pain, or cramping. Sometimes, a medication may need to be stopped if the symptoms are severe. Concerns over peripheral neuropathy should be reported to the health care team at each clinic visit.

- **Immune Reconstitution Syndrome**

Often times as a person's immune system begins to recover after the medications begin to work, they will initially feel tired, achy, or in general worse than they did before starting medications. This occurs as the immune system is reconstituted which means that it occurs as the CD4 count rises toward more normal levels. This likely occurs due to the person having the ability to react to certain infections that were in the body that went unnoticed since the immune system was too weak to fight against them previously. Often times, this will require time and patience to resolve but there may be occasions where further evaluation for infections and possible treatment may be necessary. Please alert the health care team if your child experiences any of these problems.

## *Changing Medications*

As the viral load, CD4 count and symptoms are monitored, it may become apparent at some point that there is a need for a change in therapy. Since the goal of treatment is to lower the viral load to the lowest possible point, increases in the viral load measurement signal an increase in viral activity. One cause of this increase can be due to noncompliance. However, even children who have had good compliance with therapy can have a virus that becomes resistant to current medication. This resistance occurs because the virus can change or mutate. It is important to understand that antiretroviral medications can decrease the amount of virus in the body but they can never completely get rid of all the virus in the body. The HIV will find refuge in sanctuary sites or hiding places in the body, such as the solid organs of the body like lymph nodes and other places. The virus that is present in the body will continue to multiply. The less virus that is around, the less quickly the virus can multiply and mutate. Therefore, the goal of treatment must be to keep the viral load as low as possible.

Medications work differently in each person. The medication's ability to be absorbed and *metabolized* by the blood stream can affect its ability to fight the virus. In evaluating the medication's effectiveness, the medical team will be looking at trends in the viral load and CD4 count. One single set of labs should never be used in determining treatment decisions. A blood test called genotyping will be done to help determine the treatment course. Genotyping can test for viral mutations. It gives information regarding which medications are showing resistance to the virus.



## Complications of HIV Infection—Opportunistic Infections

*Opportunistic infections* are germs that take the opportunity to infect someone with a poorly functioning immune system. Although these infections can occur during any time of HIV infection, they are most likely to infect a person with AIDS or a very low CD4 count.

### • Pneumocystis Carinii Pneumonia (PCP)

PCP is the most common opportunistic infection seen in children with HIV. However, it can affect people of all ages with HIV who have low CD4 counts. PCP is a life-threatening disease and once a person develops PCP, they are diagnosed with AIDS for the rest of their lifetime.

PCP is a type of lung infection or pneumonia. The most common symptoms come on slowly and appear as tiredness, fever, cough, and eventually, difficulty breathing. A chest x-ray can show pneumonia but to identify which type of germ is causing that illness may require additional tests. The good news is that there is treatment available. However, people who develop PCP often will be very sick and may require a ventilator to help them breathe.

To avoid getting PCP, children who have had the disease before or those who have very low CD4 counts for their age will receive an antibiotic called Septra or Bactrim to hopefully keep them from getting PCP. This is called *prophylaxis*.

### • Thrush

Infants and children who have HIV are more likely to develop a condition of the mouth called thrush. This is a yeast infection of the mouth that can be seen on the tongue and the inside of the cheeks. It appears as white patches on the inside of the mouth that look like left over milk. It can often be quite painful, causing the child to have difficulty eating and drinking. A bland diet may be easier for the child to tolerate. It should also be noted that thrush can occur in babies with a normal immune system or normal CD4 counts.

Thrush is treated with a liquid medication called Nystatin. When giving this medication to an infant or young child, half of the dose should be given in each side of the mouth. Pacifiers and nipples from baby bottles and pacifiers should be

boiled each day to decrease the chances of re-infection. Older children should be encouraged to swish the medication around the mouth and then to swallow it. If the medication does not get rid of the thrush other medications may need to be used.

The same germ that causes thrush can also cause a vaginal yeast infection. This may cause burning and itching around the vagina and a thick white discharge. It may also be seen as small raised bumps in the diaper area of an infant. There are creams and suppositories available to treat this type of infection, but the best way to prevent this problem is good control of HIV infection by being compliant with medications. Another place that this germ can cause problems is in the esophagus (or the tube that connects your mouth to your stomach). This is called *candidal esophagitis* and may be associated with symptoms like painful swallowing and burning of the chest. It should be reported to the health care team so further tests can determine if it is present. When a child has candidal esophagitis, it can be a very serious medical problem and requires extensive treatment.

- **Lymphoid Interstitial Pneumonitis (LIP)**

*LIP* is a “silent” form of pneumonia or lung inflammation that is sometimes seen in children who are over one year of age and who are HIV positive. It occurs when there is an inflammation of the lungs but it is not caused by a particular germ. This inflammation can limit the oxygen supply in the lungs. It is a progressive problem and there is no specific treatment for LIP. How fast it progresses is different for each person. As the problem gets more advanced, the individual may not be able to get as much oxygen and may feel winded with exercise and get a bluish discoloration of fingernails and toenails. LIP is most likely to be serious in patients with very low CD4 counts or a virus that is poorly controlled.

- **Cryptosporidiosis**

*Cryptosporidium* is a germ that can sometimes cause severe diarrhea and fevers in people with a weak immune system. There is no good treatment available for this illness. Since it is found in contaminated food or water, it is best to avoid it by only drinking tap or bottled water that has been treated or by eating only foods that are properly prepared.



- **Mycobacterium Avium Complex (MAC)**

MAC is an infection that is seen in people with very advanced HIV/AIDS. These people have very high viral loads and very low CD4 counts. Symptoms can be vague and generally develop rather slowly over a few weeks. The symptoms include fever, weight loss, night sweats and feeling tired. The bacteria that causes MAC is found all over the environment, in water, and even in some animals. If a person has a CD4 count less than 50, it may be necessary to take an antibiotic to try and prevent getting sick with MAC. This is called antibiotic prophylaxis.

- **Herpes Viruses**

There are several different germs in the herpes family. As a matter of fact, it has been estimated that 80% of all people have been infected with some kind of herpes virus by the age of 40. Therefore, most people infected with HIV are likely to develop some kind of herpes virus at some point in their life.

Herpes simplex virus can show up as either cold sores, infections of the eye, or genital infections. Varicella (the virus responsible for chicken pox and also a member of the herpes virus family) infections can show up as either very serious chickenpox or as shingles. People with weakened immune systems can get very severe infections with these germs. *Therefore, it is very important if your child is exposed to chicken pox that you call the office immediately.* There is a shot that we can give to try to prevent the child from getting chicken pox or from getting an extremely severe case. The shot must be given within 96 hours of the exposure. For children who get herpes infections or chicken pox, it is important that you notify the care team immediately since there is a medication called acyclovir that can be used to treat the illness. Acyclovir can be given by mouth or by IV depending on how serious the infection is.

*Cytomegalovirus or CMV* is one of the herpes viruses that can affect different organs of the body but most often affects the eyes. A warning sign of CMV infection in the eyes is the increased complaint of “floaters” in the eye. While CMV is very common in all people it usually only causes significant problems in people with HIV who have CD4 counts less than 100. Symptoms of CMV include fever, muscle pain, weight loss, and low white blood cell count. There is a medication called *gancyclovir* that can be used in treatment of CMV. Once treatment is started,

it usually must be continued for life.

- **Histoplasmosis**

*Histoplasmosis* is a disease that is caused by a fungus. It lives in the soil and is spread by bird and bat droppings. It is very common in the state of Indiana. Most of the time, histoplasmosis does not cause illness in healthy people. In people with an abnormal immune system, histoplasmosis can be very severe and affect any organ in the body. The symptoms include fever, weight loss, cough, and swollen lymph glands. It is important that all people with low CD4 counts avoid activities that increase their chance of getting histoplasmosis. This includes activities that disturb the soil such as digging or raking, or being exposed to bird or bat droppings such as playing in an uncovered sandbox or exploring caves. Since fungus germs often live in the soil, construction sites or houses undergoing remodeling should be avoided.

- **Toxoplasmosis**

*Toxoplasmosis* is a common infection among people living with HIV/AIDS. It usually affects the nervous system, particularly the brain. Although people who are HIV negative can get this infection, you are much more likely to get sick from it with a weakened immune system. The most common symptoms are headache, confusion, and fever. Other symptoms may include seizures, falling, and nausea.

Toxoplasmosis can be spread by eating undercooked meat or by contact with infected cat stool. The infected cat may not appear sick. To protect yourself from getting toxoplasmosis, meat should be cooked to 150 F or until it is no longer pink in the center. Red meat such as steak or hamburger is also safe if it has been frozen for at least 24 hours, or if it is smoked or cured. Chicken, eggs, or other fowl are almost never a risk for toxoplasmosis. Hands should be washed well after touching any raw meat or after any gardening or outdoor activities. All fruits and vegetables should be well washed before eating them raw.

If there is a cat in the child's household, special precautions should be taken, although it is not **always** necessary to give up your cat. Someone who is not infected with HIV and is not pregnant should take responsibility for changing the litter box *every day*. If a child infected with HIV must change the litter box, gloves should be worn and hands washed with soap and water right after changing the



litter. If a person with HIV cannot find someone to take over these duties, keeping the cat should be reconsidered. It is best to keep a cat indoors to prevent it from hunting and picking up germs. If you adopt a new cat, it should be older than one year and be documented to be healthy by a veterinarian. Stray animals should be avoided.

If a child has a CD4 count of less than 100, *antibiotic prophylaxis* may be started depending on the age of the child and risk of getting the disease. If a child becomes ill with toxoplasmosis, there is antibiotic treatment available. Once the diagnosis of toxoplasmosis has been made, medication will need to be continued for life.

#### • Other Opportunistic Infections

There are some other infections that take the opportunity to cause illness when someone has a weakened immune system. These include: tuberculosis and cervical or anal disease such as dysplasia or even cancer. Therefore, periodic tests or examinations will be done by the health care team to look for these other problems in those people at risk.

## *Special Issues in HIV*

### • Infection Control

All liquid waste, such as urine or vomit that has blood in it should be flushed down the toilet. Be careful not to splash liquids as they are being poured into the toilet. Paper towels, sanitary pads and tampons, wound dressings and bandages, diapers and other items that have blood on them and cannot be flushed should be placed into a plastic bag, sealed and then placed into a second plastic bag before placing in the trash.

Any surface that has body fluid containing blood on it should be thoroughly cleaned using a solution of 1 tablespoon of household bleach per quart of water. The solution should be made fresh each time it is needed.

Schools must follow the guidelines for infection control set up by the CDC (Center for Disease Control) and should dispose appropriately of any materials used at school.

### • Immunizations

Indiana currently requires that children receive many vaccinations in order to be admitted into the school system, including the measles vaccine. This vaccine is a “live” vaccine and usually given as MMR—(measles, mumps and rubella). A live vaccine actually has the germ in the shot, although it is a very weakened form of the germ that is unlikely to cause problems in a healthy individual. However, in a person with a weakened immune system, the shot may cause problems including giving the person measles. People may have the MMR if they have had a CD4 count over 1000 for a few months. Before any child with HIV receives this vaccine, the health care team should be notified to be sure it is safe. Since vaccines are given by a primary medical doctor, your doctor may need to contact the HIV team to ensure the child’s safety.

Since all states started requiring the MMR for children, the disease of measles has become very rare. Occasionally a case may be seen, usually carried in from another country. If your child is exposed to someone with measles, please contact the doctor **immediately**. Even children who have received two doses of the MMR vaccine may not be safe. Once exposed, the child will need to receive an injection



of a medication called gammaglobulin to give extra protection in order to prevent them from getting measles. **This is extremely important since measles can be a life-threatening illness.**

If the child is going to school and has an immune system too weakened to receive the MMR, a letter can be sent from the clinic to the school excusing the child from the vaccine for medical reasons. This can be done without disclosing HIV status if necessary.

The chickenpox vaccine is also a live vaccine and can only be given to children with HIV who have high CD4 counts. This vaccine can give children chickenpox, particularly in those with a very low CD4 count. If your child is exposed to someone with chickenpox or shingles, please contact the health care team **immediately**. The child will need to receive an injection of gammaglobulin in order to prevent becoming sick with the chickenpox. This medication must be given within 96 hours of exposure to be effective and can sometimes take several hours to obtain. Anyone who is HIV negative living in the household who has not already had chickenpox should receive the vaccine to decrease the chances of bringing home a case of the chickenpox.

#### • Travel

Although travel to other areas, particularly to other countries or trips involving exotic activities such as scuba diving or caving can increase the risk of infections, not all travel plans have to be abandoned. With good advance planning, many trips can be made. Before traveling, it is important to talk with the health care team including the travel medicine expert about health risks in the area being visited. These experts can give you advice on how to keep yourself healthy when you travel to places where certain illnesses are known to be a problem. They may also be able to identify places where it might not be safe for you to travel. It is also important to identify where travelers can seek health care while they are in another location. Some travel problems which can be anticipated, such as traveler's diarrhea, can be discussed with these experts.

It is also important to remember that there are many germs that can be carried by insects and control of these bugs varies in other regions of the US and the world. A good insect repellent and appropriate protection with mosquito netting and

clothing is important.

There may be a need for special medication or vaccinations before traveling. Some other areas of the world also have special health rules for visitors. It is important to know what these are and to make sure all the rules are followed. If you have medical insurance, check to see what it covers when you are away from home. Many insurance plans, including Medicaid, have limited or no benefits when traveling outside the United States, including for Make-a-Wish trips. Make sure all paperwork is up to date, in order, and that proof of insurance is included.

When traveling, do not eat raw fruit or vegetables that you do not peel yourself, raw or undercooked seafood or meat, unpasteurized dairy products, unpasteurized fruit juice, or anything from a street vendor. Also, do not drink tap water, drinks made with tap water or ice if you are traveling outside of the US. Food and drinks that are generally safe include steaming hot foods, fruits and vegetables that you peel yourself, bottled drinks, hot coffee or tea, beer, wine, and water that has been vigorously boiled for 1 minute.

In many places, animals may roam around more freely than they do in the area where you live. Always wear shoes and protective clothing and sit on a towel to avoid direct contact with sand or soil. Avoid swimming in ponds, lakes, or the ocean with CD4 counts less than 250.

It is very important to take medicine with you when traveling. Be sure that you have plenty of medicine for your trip and at least 2 extra days in case of delays. When flying, medication must be in its original container with the pharmacy label intact. All medication should be carried on to the airplane to avoid a disaster in the event of lost luggage.

#### • School

According to the current Indiana state law and in every other state, families do not have to tell the school or anyone else in the education system of their HIV status. HIV testing is not required for any purpose.

The decision to share HIV information with the school is different for every family



and must be made on an individual basis. When the decision is made by the family to inform the school of a person's HIV+ status, that information must be kept confidential by the school staff so that it does not lead to discrimination or the child being treated differently in any way. School personnel and the public are often not educated about HIV and how it is spread, so they become fearful and may treat a person with HIV differently.

Schools have very strict guidelines with regard to immunizations and require certain ones be received before attending. According to Indiana law, the school can refuse entry to a child who has not received these vaccines including the live MMR which may not be safe in children who are HIV+ (see the section on immunizations). An exception can be made by the school if a medical condition is the cause for a vaccine not being given. The school will require a letter from the doctor to verify this. If a family has chosen not to disclose the child's HIV status to the school, a letter sent to the school will give a diagnosis of immune deficiency. This may alert the school staff that a child has a medical condition they do not know about and may result in the school trying to get more information about the health of the child. The clinic will not release further information unless it is requested by the family.

If a family does disclose the child's HIV status to school staff, it is against the law for that information to be shared with anyone who does not need to know. "Under the terms of the federal Civil Rights Act of 1991, which also prohibits discrimination on the basis of a disability, a school could be held liable for monetary damages if school authorities are aware of harassment aimed at a person with HIV infection and who do not intervene to stop it or prevent it from continuing to occur. (Page 13)"

The federal law and the Supreme Court of the United States consider HIV infection and AIDS to be "disabling conditions." Many children with HIV will also have learning difficulties. Under section 504 of the Americans with Disabilities Act, any child who has special learning needs will have a yearly IEP (individualized education plan). The IEP is decided by the child's guardian and a committee from the school. A child with HIV who attends a public school may also request testing to identify if learning difficulties are present.

The risk of HIV transmission at school is small. No special safety precautions are

required to protect others. All schools are required to use appropriate infection control measures, such as gloves when touching materials containing blood, proper disposal of materials containing blood and handwashing. These measures should be used with all students, regardless of HIV status. There is an extremely small risk of HIV transmission when vomit, urine, or stool contains blood. The school has policies in place for cleaning surfaces that come into contact with these body fluids. All students, regardless of HIV status will be required to cover any bloody or oozing skin sore.

Much concern exists over children who bite. The risk of HIV transmission from a bite is very small because the amount of HIV in saliva is very low. Bites rarely result in blood to blood contact. However, any child that bites repeatedly may need a disciplinary plan to address the issue. It is **never** appropriate to bite your child back to discourage this behavior.

It is important when a student has a chronic medical condition or a weakened immune system that the school post appropriate alerts about illnesses going around the school and communicate them to parents so that appropriate steps can be taken to protect the students who are HIV+. This will be done much more readily if the school is aware of the underlying diagnosis.

The same rules apply to daycare settings as schools. If your child is going to an accredited daycare center, they will have the same laws and guidelines as schools. If your child is going to an in home daycare, make sure that it is licensed and that all safety requirements are met. Visit the home to ensure there are no health hazards to your child such as smoking or exotic pets or chronically ill caregivers present. Ask if they use universal precautions as required for licensure. If you are not comfortable doing so, you do not have to disclose your child's HIV status.

#### • Recess and School Sports

Children with HIV can participate in recess, gym class, and sporting events. By law, the school must allow a student with HIV participation in these activities. Cuts, scrapes, and nosebleeds can be fairly common in some sporting events. The risk of passing HIV to another person during a sporting event is very small. However, it is likely that there will be more blood exposure in sports such as



football, hockey and wrestling and that should be taken into consideration by the family when thinking about participation in these sports.

Any equipment with signs of blood should be cleaned with fresh bleach solution and allowed to dry before re-using. Any blood soaked clothing should be replaced even during the event. Such items should be brought to the attention of the trainer by any athlete that notices blood on equipment. Any child who has signs of bleeding should be removed from the activity until the bleeding has stopped and the wound has been covered. These rules should be applied to all participating athletes regardless of HIV status.

Swimming in a school pool is usually safe for children with HIV whose CD4 counts are over 250.

Any child who is casually playing by riding a bike or scooter should wear a helmet and proper shoes to avoid injuries. This rule should be in effect for all children regardless of HIV status.

#### • Safe Food and Water

Germs in food and water that can make someone with HIV sick include *Salmonella*, *Campylobacter*, *Listeria*, and *Cryptosporidium*. They can cause diarrhea, upset stomach, cramps, fever, headache, body aches, blood stream infections, *meningitis* or *encephalitis*. People with HIV may become extremely ill with these germs and may have a difficult time recovering.

##### 1. Tips to keep drinking water safe include:

- a. Don't drink water directly from lakes, rivers, streams, or springs.
- b. Unless you are certain your tap water is safe, avoid drinking it or using ice from a refrigerator icemaker. Well water should be tested prior to use (contact the state health department).
- c. Always pay attention to special notices issued by local health departments regarding the safety of tap water.
- d. Consider boiling or filtering your water or drinking bottled water if unsure or if your CD4 count is extremely low. If you decide on this option, drink only bottled water when away from home.

- e. Remember that boiling is the best way to kill germs in the water. Heat your water to a rolling boil for one minute. After the boiled water cools, put it in a clean pitcher or bottle with a lid and store in the refrigerator. Use the water for drinking, cooking, or making ice. Water bottles and ice trays should be cleaned with soap and water before use.
2. It is also important to keep food safe from contamination before eating it, especially with very low CD4 counts. Some helpful tips include:
- a. Eggs are safe to eat if they are well cooked. Cook eggs until the yolk and white are solid and not runny. Do not eat foods that may contain raw eggs, such as Hollandaise sauce, cookie dough, homemade mayonnaise, or Caesar salad dressing. If you prepare these foods at home, use *pasteurized* eggs found in the dairy case of your market rather than regular eggs.
  - b. Raw fruits and vegetables are safe to eat if you wash them carefully first. Wash and then peel the fruit that you will eat raw. Increased risk of illness occurs when eating raw alfalfa sprouts and tomatoes so wash these especially well.
  - c. Meat and poultry such as chicken or turkey and fish can make you sick if they are raw, undercooked, or spoiled. Cook all these until they are no longer pink in the middle. If you use a meat thermometer, the temperature in the middle of the meat should be 165 F. Fish should be cooked until it is flaky. After handling raw meat, poultry or fish, wash your hands well with soap and water before you touch any other food. Thoroughly wash cutting boards, cooking utensils, and countertops with soap and water after they have contacted raw meat, poultry or fish. Do not let uncooked meat, poultry, or fish or their juices touch other food or each other. Do not let them sit out at room temperature for more than a few minutes. Keep them in the refrigerator until you are ready to cook them.
  - d. Read food labels carefully when shopping for food. Be sure that all dairy products and fruit juices purchased have been pasteurized. Do not buy food that contains raw or undercooked meat or eggs if it is not meant to be cooked further. Be sure the “sell by” date has not passed.

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- e. Put packaged meat, poultry or fish in separate plastic bags to prevent their juices from dripping onto other groceries. Check the package the food comes in to make sure it isn't damaged.
  - f. After shopping, put all cold and frozen foods into your refrigerator as soon as you can. Do not leave food sitting in the car. Leaving such food out for only a short while can give germs a chance to grow.
3. Eating at restaurants can be safely managed if a few safety issues are addressed.
- a. Order all food well done. If meat is served pink or bloody send it back to the kitchen for more cooking. Fish should be flaky, not rubbery, when cut.
  - b. Order fried eggs cooked on both sides. Avoid “sunny side up”. Scrambled eggs should be cooked until they are not runny. Do not order foods that may contain raw eggs such as Caesar salad or Hollandaise sauce. If you are unsure about the ingredients in a dish, ask the waiter before ordering.
  - c. Do not order any raw or lightly steamed fish or shellfish, such as oysters, clams, mussels, sushi, or sashimi. All fish should be cooked until done.
  - d. Avoid eating at salad bars whenever possible. The food may have been sitting out awhile and many people may have touched the food or the serving utensils.
  - e. When eating while traveling in a foreign country, avoid fruits that you do not peel, salads, cooked foods that have cooled, non-boiled water, or ice.

### • Swimming

While it is not necessary to take all the fun out of things, it is important to know that certain activities can increase your risk of infection, especially in people with lowered CD4 counts. Swimming is an activity that may increase a person's chances for infection, especially if it is done in lakes, ponds, or the ocean. Swimming in pools with chlorine is safer but still can be a risk for people with a weak immune system. It is also best to avoid hot tubs as the warm water often helps bacteria

grow that can then make people sick. Sandals or other shoes should be worn around pools, in public showers, or on the beach.

#### • Pets

Animals can carry infections that can be harmful to human beings. Such infections include many discussed elsewhere in this book (cryptosporidiosis, toxoplasmosis, MAC) and others such as cat scratch fever. These diseases can give you problems like severe diarrhea, brain infections, and skin lesions. When making the decision to bring a pet into your home, it is important to discuss it with the health care team before purchasing the pet. While we are not recommending that you get rid of pets you already have, we do caution against bringing new and particularly young pets into your home. If you already have a pet, please make sure it gets regular check-ups at the vet.

Younger animals such as kittens and puppies pose a greater risk of infection to the person with HIV. **Do not purchase a pet that is younger than 6 to 12 months of age.** If you are getting a pet from a pet store, animal breeder, or animal shelter, check the sanitary conditions. If you purchase an animal, have it checked out by your veterinarian to make sure it is healthy and all its shots are up to date. Do not purchase an unhealthy pet and if you get it from the pound or a pet store, please check the conditions and license of these facilities.

There are several ways to protect your child or yourself from infections spread by animals:

1. Always wash your hands well with soap and water after playing with or caring for animals. This is especially important before eating or handling food.
2. Do not let your pet lick your mouth, any open wounds or cuts you may have. If you have medical devices such as a tracheostomy or IV, do not let the cat play with or lick these items.
3. Have your pet's nails clipped frequently so it cannot scratch you and de-claw if possible. If you are scratched or bitten, immediately wash the wounds well with soap and water.
4. Be careful about what your pet eats and drinks. Feed your pet only pet food or cook all meat thoroughly before giving it to your pet. Don't let your pets



eat raw or undercooked meat, drink from toilet bowls, or get into the garbage. Don't let your pets hunt or eat other animals or their droppings.

5. Don't ever touch the stool of any animal.
6. Ask someone who is not infected with HIV and who is not pregnant to change your cat's litter box daily. If you must clean the box yourself, wear vinyl or household cleaning gloves and immediately wash your hands well with soap and water.
7. Avoid reptiles such as snakes, lizards, iguanas, and turtles since they can be carriers of a germ called *salmonella*. If you touch any reptile, immediately wash your hands with soap and water.
8. Avoid exotic pets such as monkeys, ferrets, or other wild animals such as raccoons, bats, and skunks as they may have many germs. Even animals such as rabbits and squirrels may have *rabies*.
9. Do not approach or handle any pet not known to you.
10. While it is not always necessary to get rid of pets, certain pets may need to find a new home. It is best not to get any new pets once the diagnosis of HIV is made without discussing it with the health care team first.

#### • Nutrition

Good nutrition and maintaining body weight by taking in enough healthy calories is an important goal. A dietitian from the health care team will be scheduled to meet with you and your child in the clinic one to two times per year or more frequently if necessary. The dietitian can also be scheduled at your request any time you have questions or concerns.

Good nutrition is important for several reasons. Good nutrition is absolutely necessary for the body to heal. Poor nutrition can increase your child's chances of developing an infection. Poor nutrition and infection will hurt the immune system, making it unable to work well so that it can keep your child healthy.

There are many causes of poor nutrition in children with HIV:

1. As discussed earlier, nausea and vomiting can add to poor nutrition.
2. Diarrhea can be a side effect of medication or can be caused by infection. If left untreated, diarrhea can lead to dehydration, malnutrition, and wasting.
3. Loss of appetite due to mouth sores or pain from swallowing caused by thrush, herpes infection or other infections can lead to a decrease in calories taken by the patient. Foods that are salty, spicy, crunchy or dry may cause pain and make them more difficult to eat. When someone has one of these problems, it is best to try foods that are soft, smooth, and served cold or at room temperature. If a patient is complaining of one of these problems, treatment is usually needed and the doctor should be notified.
4. Sometimes poor nutrition is related to being unable to buy food secondary to a lack of money. If this is a problem, please contact the health care team so that one of the social workers can work with you to see if assistance is available.
5. As HIV disease advances, it puts more stress on the body and requires an increase in energy to do all its usual work. This is called increased metabolism. If calories are not increased to meet this new energy need, weight loss will occur. People with fever and infection will also have increased metabolism and need extra calories.
6. Sometimes, people eat enough healthy calories, but because of the HIV and its associated problems, the body is not able to use those calories properly. This is called *malabsorption*. If this condition occurs, an evaluation by the doctor and dietitian is necessary to help find the cause.
7. Sometimes, people may not find eating as enjoyable as they once did because they can have a decreased sense of taste due to medications or infections. In this case, it may be necessary to increase the appetite with medications called appetite stimulants.



Malnutrition can lead to weight loss and wasting syndrome. Often in the more advanced stages of HIV/AIDS, the body will burn up calories very fast. If a person is unable to eat enough calories no matter how hard they try, supplements may be necessary. The dietitian can suggest things to help with weight gain including the following:

1. Drink milk with meals instead of juice, tea, water, or soft drinks. Milk has more calories and protein. Choose whole milk over low fat milk. If you do not like milk, try milkshakes, chocolate milk, buttermilk, egg nog, or ice cream and cheese.
2. Use milk instead of water to make soups and hot cereals.
3. Add calories to milk by mixing it with dry powdered milk or Carnation Instant Breakfast.
4. Nonfat dry milk powder can be added to a lot of foods to give them more protein and calories. Adding the powder will not change the taste of the food. Try adding it to meatloaf, hamburger patties, casseroles, macaroni and cheese, cereal, scrambled eggs, mashed potatoes, milkshakes, and pudding.
5. Use ice cream as a snack or dessert.
6. Cheese added to foods will increase calories. Cheese can be added to eggs, meatloaf, hamburger, spaghetti, mashed potatoes, vegetables, salads, soups, chili, and toast. You can also add extra cheese to pizza, macaroni and cheese, or to casseroles if trying to gain weight.
7. Peanut butter can be added to the following foods: on top of pancakes or waffles, apples, bananas or pears, blended into milkshakes, served with celery, cookies, or crackers. Remember, peanut butter should not be given to children under two years of age due to risk of choking.
8. If there is no vomiting or diarrhea associated with the weight loss, the following tips may be useful. Add salad dressings to baked potatoes or use as a dip for vegetables. Add sour cream to potatoes, vegetables, chili, salad, and soup. Whipping cream can be added to pies, fruit, puddings, and other desserts. Gravy and cream sauces can be added to meats and vegetables.
9. All children should be given daily vitamins. In children who are very young, a liquid vitamin will be prescribed. Older children should take Flintstones

Complete vitamins.

It is important to remember that children can become quite picky about food and that there are certain developmental stages where food intake naturally decreases. To avoid making an issue of weight gain, never force feed. If a child refuses to eat, other methods such as tube or IV feeding may need to be explored with the health care team.

It is also important that children do not get overweight if possible. Good nutrition and exercise are important to keep this balance. If a child is overweight, we do not encourage weight loss usually. Rather, we encourage efforts to maintain the weight at its current level while height continues. If you have questions, they can be addressed with the dietitian.

#### • Care of the Teeth and Mouth

Children with HIV have more cavities, tooth decay, and gum disease than other children—about 30% more. People with low CD4 counts cannot keep all the germs that commonly live in the mouth under control. This allows those germs to do more damage to teeth. Children who eat and drink a lot of sweets, who drink from a bottle in the crib, and those past one year of age are at even greater risk for teeth problems. Many liquid medications, even those for HIV, may be flavored with sugar at the pharmacy.

Sometimes, children with HIV are delayed in getting teeth. This can happen with both baby and adult teeth. They may also get thrush or white patches of fungus in their mouth, usually on the insides of their cheeks. This can do damage to teeth as well and requires medication. It is also important to prevent re-infection by boiling pacifiers and nipples each day until the white patches disappear. Cold sores may also be painful, damage teeth and require medication.

The American Dental Association currently recommends that a dentist see children within six months of the appearance of the first tooth. Parents can help maintain care to the teeth, mouth, and gums by doing the following:

1. Keep regular visits to the dentist.
2. Brush your child's teeth with them after every meal or dose of medication until they are able to do this on their own. Use very small amounts of



toothpaste until your child is able to spit it into the sink. Swallowing large amounts of fluoride from toothpaste is not healthy.

3. If the child is an infant, brushing may be very difficult. Cleaning a tooth or gums with a damp cloth may be helpful.
4. Children should never take a bottle of milk with them to bed. This will allow the milk to coat the teeth and pool in the mouth leading to cavities.
5. Tooth sealants are used by dentists to cover teeth in order to help prevent cavities. Please discuss this with your dentist. If you do not have a dentist, please ask the health care team for a referral.

### • Sexuality

While it may be difficult, it is important to have serious discussions with teenagers who may be thinking about becoming sexually active. This is extremely important in HIV positive teenagers who are considering becoming sexually active.

For all teenagers, having sex for the first time is a very big deal. This is truer for the HIV positive teenager. The potential partner must be told of the teenager's HIV positive status before sexual activity is initiated. Precautions should be discussed and taken before any sexual activity occurs. Not all potential sex partners will remain interested after being informed of the HIV status which may lead to feelings of isolation and sadness or anger. Support for the teenager should be provided by the family and health care team.

When both partners are infected with HIV, it is still not safe to engage in unprotected sex. Research has shown that HIV positive people can be and often are re-infected or *superinfected* by different strains of HIV, like giving them a double dose of infection. This can cause more rapid weakening of the immune system and more rapid progression to AIDS.

### • Reproductive Health Care

There are certain gynecological (GYN) conditions that occur more often in females that have HIV or AIDS. According to a recent report, 42% of women infected with HIV were also dealing with some form of GYN disease. Some of the more common conditions include chronic or repeated yeast infection (called

candidiasis) and abnormal periods. Other conditions such as vaginal warts caused by Human Papillomavirus (or HPV), abnormal Pap smears, and pelvic inflammatory disease (or PID) are seen more frequently in sexually active females with HIV. Women and girls with a lowered CD4 count are more likely to develop a GYN condition and this condition may not respond easily to treatment. A discussion of each of these conditions is below, but the most important message from your health care provider is that good communication is of the utmost importance when dealing with such issues. Reporting any signs or symptoms that are worrisome or that don't seem normal will help maintain your health. Ongoing GYN concerns will likely result in consultation with the adolescent specialist or gynecologist.

1. **Yeast Infections:** Vaginal candidiasis or yeast infection is the most common GYN condition known. As mentioned earlier, candidiasis can also occur in the mouth (oral) and/or in the esophagus or throat. All females have yeast in their bodies. When this yeast grows extensively, it can lead to a candidal infection. Several things that can cause this to occur include taking antibiotics, tight fitting pants, being overweight, diabetes, and poor hygiene. Symptoms of vaginal yeast infection include itching, burning with urination, burning or pain during sex, and/or having a white vaginal discharge. Frequent yeast infections may be the first symptoms of HIV. Babies and toddlers may develop candidiasis that first appears in the diaper area. It often looks like a raised red rash. This rash may be seen in older people too. This usually requires treatment with a prescription medication. The inside of the mouth should be examined as well. Often babies and toddlers who have candidiasis in their diaper area may also have it in their mouth.
2. **Menstrual Changes:** Women who have HIV or AIDS are more likely to have changes in their menstrual cycle or periods. This may be related to the disease itself or the antiretroviral medications. These women and girls may have periods that have a lighter or heavier flow. They may also have irregular periods or more frequent periods or may not have any periods at all. Any female who is having heavy bleeding, irregular bleeding, or painful periods should contact their health care team.
3. **Sexually Transmitted Diseases:** Genital herpes is a sexually transmitted disease. There are two types of herpes virus. Type 1 occurs most frequently



in the mouth or on the lips and is often called a “cold sore”. Type 2 most often occurs in the vagina, around the penis, or in surrounding areas. It causes painful ulcers or sores. After the ulcers have healed, the virus remains in the body in a dormant or resting stage forever. People with the virus will have repeated outbreaks of painful sores from time to time. The frequency of these outbreaks is different for each person. In people that also have HIV, as the CD4 count drops, outbreaks may be much more frequent. Although there is not a cure for herpes infection, there is medication that can help decrease the number of painful days. Once a person has this virus, they can pass the virus to others even when the sores are not present. The infection occurs during skin to skin contact such as sexual intercourse or when kissing someone in an area where they have an open sore. Genital herpes can also be transmitted to a newborn baby from its mother at the time of delivery. If you have ever had genital herpes and are pregnant, it is very important to notify the health care team so appropriate medication and delivery methods can be investigated.

Genital warts are another virus that can be transmitted during sex. People who are HIV positive are at high risk for contracting genital warts. These warts look like small white or skin colored growths. Although there is treatment available, warts may be difficult to get rid of in an HIV positive person. Often, repeat treatments are needed. For females, the virus can also lead to an abnormal Pap smear due to a condition called cervical *dysplasia*. This condition occurs when the cells of the cervix change. These cells can progress to cancer if not found and treated. Females who are HIV+ are more likely to develop dysplasia and these changes may progress to cancer more quickly. There are no symptoms with early dysplasia, but vaginal discharge and bleeding may occur at a later stage of the disease. **The Pap smear is the test that is used to diagnose cervical dysplasia and/or cervical cancer. Pap smear testing should be done as soon as an HIV positive female becomes sexually active.** Any woman who is HIV positive and who develops genital warts or an abnormal Pap smear will need frequent follow-up testing.

Other sexually transmitted diseases include syphilis, pelvic inflammatory

disease (or PID), chlamydia, gonorrhea, and trichomonas. Any vaginal discharge, burning with urination, abnormal bleeding with a period, lower belly pain, or any other unusual or worrisome symptoms should be reported to the health care team. Many of these STDs may not be associated with any symptoms. All sexually active HIV positive females and males may need to be routinely screened for these concerns.

4. **Birth Control:** If you are having sex or are planning on sexual intercourse, it is very important that you discuss this issue with your health care team. They will be able to give you information on birth control options. Antiretroviral medications frequently cause an interaction with birth control pills causing it to be less effective in preventing pregnancy. There is also the concern over safe sex practices to decrease the chances of giving HIV to a sexual partner. Information regarding safe sex practices is available from the health care team. A consultation with the adolescent specialist to address all these concerns should be done before sexual activities are initiated.
5. **Pregnancy and Family Planning:** Pregnancy can be very hard on the HIV positive female without good planning. While there are many issues to talk through before deciding to have a baby, one of the most important is to plan for continued good management of HIV during the pregnancy and to prevent transmission of the HIV to the newborn baby. This requires that CD4 counts and viral load be under very good control and that safe practices are used to become pregnant. Medications will be required to keep the baby from getting HIV. An obstetrician that is familiar with HIV will be necessary. Please ask the health care team for further discussion of family planning.

In the event of an unplanned pregnancy, please inform the health care team as soon as possible so that the health care needs, as well as emotional support, can be provided for the pregnant teenager and the unborn baby.

#### • Depression and other Psychiatric Concerns

Many people will experience some periods of sadness or depression during their years growing up. This is also true of children and teenagers who are positive for HIV. Sometimes the depression may be caused from feelings of fear or isolation if



other people find out that the person is HIV positive. Sometimes, fear of AIDS or dying can be a factor. People can get depressed over knowing that they may be dependent on medications or may be ill frequently for the rest of their lives. Some medications can cause depression or other psychological issues as well. These feelings are natural and must be addressed. Parents may also experience depression over their child being perceived as ill or some guilt they may feel over the child being infected.

It is important to treat depression. If a person is chronically depressed, they are less likely to take their medications correctly and to take good care of their health. This may result in them being sick more often or progressing to full blown AIDS more quickly. Caregivers who are depressed may not be able to provide the best possible care for their child. If you and/or your child is experiencing any of the symptoms of depression including extreme or constant sadness, inability to take part in fun activities, poor eating, or sleep problems, please notify the health care team so evaluation and possibly treatment may begin. There are many parts to treating psychiatric issues that arise including counseling and medication or even hospitalization if necessary.

#### • Disclosure

*Disclosure* or telling people that you or your child are HIV positive is very difficult. Even telling a child who was infected at birth that they are HIV positive can be very hard on both the parent and the child.

Families take many different approaches to tell their child that they are HIV positive. Many parents feel that if a child knows that they are HIV positive from a very young age, they adjust better. However, young children often tell private information without knowing that the parent does not want the information known to everyone. Some parents prefer to wait until the child is older and can understand more about HIV. It is the policy of our clinic to let the parents decide how and when a child should be told about their HIV status. The health care team will not tell a child unless requested to do so by the parent or caregiver. However, we are available to help and support this decision in any way possible. It is important that the child find out their HIV status from someone they trust and someone who knows what they are talking about so all questions may be

accurately answered.

For disclosure to the rest of the world, there are laws that state that no one has to disclose their HIV status to anyone except to health care providers and sexual partners. This is to guarantee that health care providers can fully evaluate the patient and order appropriate tests and treatment. Sexual partners must be informed so that precautions can be taken to protect themselves from infection.

Situations arise where it becomes a good idea to disclose your child's status to a select group of people. If someone is taking your child to an activity that is high risk to their health, the chaperone should be notified. If your child is bringing medication into a facility or to someone's house, the adult chaperone should be notified. All other disclosure should be decided by the patient and family, although medical research has shown that patients who have a few people in their support group who know their HIV status tend to stay healthier for longer periods of time.

While it should not happen and is against the law, there may be times when telling someone your HIV status may result in them treating you badly, hurting your feelings, or *discriminating* against you. This usually comes from fear of other people about things they do not know very much about. Please feel free to share such experiences with the health care team so that we may offer support and suggestions.



## *Care Coordination*

Care coordination is a personalized case management system in which a social worker meets with your family to offer assistance, guidance, and advice. The relationship between you and your care coordinator is a partnership. The care coordinator assists you, but you maintain control over the life choices that affect your family. Your care coordinator cannot solve your problems, but can provide you with assistance to help reach a solution.

If you are followed in the clinic, you will meet with our care coordinator on-site and it will be determined which care coordination program will assist you depending on where you live. Once that site is identified, you will complete an intake with the care coordinator and you will need proof of HIV status, which can be obtained from your child's doctor. You and your care coordinator will identify areas of concern, establish a care plan, and attempt to meet all these needs. All of the services are available free of charge.

Benefits of care coordination may include obtaining insurance to help pay for HIV medications, assisting with finding affordable housing, or providing referrals to other programs that can help your family. Your care coordinator is a valuable part of your health care team and can be a resource and an advocate for you as you navigate the various and often complex social service programs.

In our clinic, we firmly believe that care coordination is **essential** for long-term success and health when dealing with the many factors associated with the diagnosis of HIV. Please involve the care coordinator with any issues that may come up.

## *Health Insurance and Government Assistance Programs*

In the state of Indiana, there are several types of health insurance coverage and government supported assistance programs. These programs vary by state and can be navigated with you by your care coordinator.

The first and most traditional insurance is that offered by a company or a business to their employees. In general, only the employee, spouse, and children are eligible for this type of insurance coverage. There are many programs and each has different benefits available. Most companies require the employee to pay a portion of the insurance premium. Most insurance policies have what is called “in-network” or “primary care providers.” It is very important to know if your insurance has such a requirement because the insurance company may not pay for a visit or for labs if the doctor and/or hospital are not in-network providers. Or, the insurance company may pay at a lower rate leaving you to pay the rest of the bill. Many insurance companies also have in-network pharmacy providers for medications. Many insurance policies offered by employers have a pre-existing condition clause. This means that any health condition diagnosis (such as HIV or AIDS) may likely not be covered under the policy for a certain number of days or months.

By law, an employer cannot refuse insurance coverage to any employee who is covered by the group plan and meets the eligibility requirements. In other words, an employee cannot be denied insurance coverage by a group plan based on a pre-existing health condition such as HIV. An employer also cannot require an employee to pay an increased rate for insurance based on a pre-existing condition. All employees are expected to pay the same amount of money for the same type of coverage.

If you leave your job, you may be able to continue your health insurance under what is called “COBRA” coverage. COBRA allows for you to continue health insurance for a specific number of months. However, you will be expected to pay the full amount of the monthly premium. If you do not pay the premium on time, this insurance can be cancelled.



The second type of insurance offered in the state of Indiana is called Medicaid or a sub-program of Medicaid called Hoosier Healthwise. These are government funded programs that provide health insurance to U.S. citizens who are residents of the state of Indiana. Each state has its own program, so if you live outside Indiana you will need to explore similar programs in your home area. You must meet income guidelines in order to receive benefits from such programs. Medicaid is offered primarily to pregnant women and children or those who are deemed by the state's definition to be disabled. Your social worker or care coordinator can help guide you through the application process if you qualify for these programs. There are many different Medicaid plans and many of them require that you choose a doctor who is your primary care provider (PCP). This type of system requires that you obtain a referral to a specialist including the person who treats HIV. If you do not follow the system and obtain the appropriate referrals, we may not be allowed to continue providing care to you or your child. If you do not choose your own primary care provider, one will be assigned to you through the Medicaid office.

Once a year, you will receive paperwork from the Medicaid office that will need to be completed on time to continue receiving Medicaid coverage. Otherwise, there may be a period of time when you or your child will not be able to obtain medications. It is important to remember that taking the antiretroviral medications less than 100% of the time may allow the virus to become resistant to the medications.

Approximately half of children infected with HIV at birth will have a condition called encephalopathy. This condition affects the brain and can lead to learning disabilities and/or some form of cerebral palsy (CP). One type of Medicaid coverage that provides additional benefits under such circumstances is called Medicaid Disability. A patient must be able to provide medical documents that prove that he or she is disabled and that this disability affects the ability to care for themselves. The care coordinator can help determine if you qualify for this type of coverage.

Another program that may be available to children is called Children with Special Health care Needs (CSHCN). This is a program that can help pay for medical care

of children with chronic medical conditions. Although the diagnosis of HIV does not by itself qualify a child for such assistance, associated issues such as developmental delay may. In order to be eligible, you must be a U.S. citizen, resident of the state providing the program, and you must meet medical and financial guidelines. The income guidelines are higher than those for Medicaid. There is a CSHCN office in the hospital that can help you through this process.

Children who have disabilities related to the diagnosis of HIV may be eligible for expanded programs through the Medicaid system. The Medicaid Waiver provides money for certain types of equipment and other services that may not be covered under other health insurance plans. This waiver program is not income dependent but there is a waiting list to get on the program. The Indiana Area Council on Aging is responsible for managing this program as well as a program called CHOICE. The CHOICE program can provide respite or relief services to families who meet the income guidelines.

Your child may also qualify for Social Security benefits or SSI if they meet certain disability guidelines and if the family meets income requirements. This program provides money to the household to help pay living expenses.

For those families that do not qualify for Medicaid and/or CSHCN, parents may purchase private health insurance, which is usually quite expensive and may not be available to those who have been diagnosed with HIV/AIDS. One such program is Indiana Comprehensive Health Insurance (ICHIA). This is a health insurance plan that is available in our state for people who cannot obtain health insurance from any other source and who do not qualify for Medicaid. Although it may be expensive to buy, it is certainly less expensive than paying for health care and medications out of pocket.

For those patients who live in Marion County in Indiana, there is a program through Wishard Hospital called Wishard Advantage. This program is for people who cannot afford private insurance and who do not qualify for Medicaid who meet the eligibility requirements. It is available to people who are not citizens of the United States.



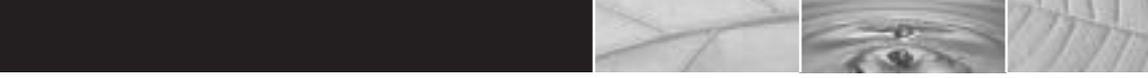
The HIV Medical Services Program is a program that provides health care to people who are HIV+ and who meet eligibility requirements. This is a program for people who do not and cannot receive private insurance benefits and who do not qualify for Medicaid. In order to be considered for this program you must: 1) have applied for Medicaid and received a denial for this program 2) be a resident of Indiana for 365 straight days and 3) meet income guidelines. This program is administered by the Indiana State Department of Health. Applications may be obtained through your care coordination site. This program also requires that you apply to ICHIA. Once you are approved for this program, you will have a 90 day pre-existing condition period. This means that the program will pay for all medical care except that related to HIV for that time. During this period, you will receive medication from the AIDS Drug Assistance Program (ADAP) which is a program that is supported by the drug companies that make the medications. You will also receive limited health care services through the Early Intervention Plan (EIP). After 90 days, all health care will be provided through the Health Insurance Assistance Plan, including the care for HIV. The ADAP and EIP programs will be discontinued.

This information may seem overwhelming and like a maze, but it is extremely important that coverage is in place to avoid any interruptions in medication delivery. Your care coordinator can help you sort through the various programs in order to determine the ones that will best fit your family's needs and those for which your family will qualify.

## *AIDS (Acquired Immunodeficiency Syndrome)*

HIV infection worsens over time, at a faster rate if there is poor compliance with medications, but at some point in all patients. How quickly each virus multiplies and how quickly it can then weaken the immune system varies from one patient to the next.

HIV is the virus that causes AIDS. A person with HIV is given the diagnosis of AIDS once they develop a CD4 count of  $<200$  or one or more of the conditions listed in Appendix A. These are known as AIDS defining criteria. Once a person is given the diagnosis of AIDS, they will keep that diagnosis forever even if the CD4 count or medical condition improves. Once a person is diagnosed with AIDS, it becomes more likely that opportunistic infections will develop, which are usually life-threatening. Many opportunistic infections do have medication available for treatment but without help from the body's own immune system, they may be difficult to clear. This can result in serious problems or even death for the patient. The goal of HIV treatment is to avoid allowing the disease to progress to AIDS.



## *Appendix A — AIDS Defining Criteria*

CD4 count <200

Pneumocystis carinii pneumonia (PCP)

Candidiasis of bronchi, trachea, or lungs

Invasive cervical cancer

Coccidioidomycosis, disseminated or extrapulmonary

Cryptococcus

Cryptosporidiosis

Cytomegalovirus

HIV encephalopathy

Herpes simplex with ulcers that have lasted longer than 1 month

Pneumonitis or esophagitis secondary to herpes

Histoplasmosis, disseminated

Isopsoriasis

Kaposi's sarcoma

Burkitt's lymphoma

Immunoblastic lymphoma

Brain lymphoma

Mycobacterium avium complex (MAC) or other mycobacterium species

Tuberculosis

Recurrent pneumonia

Progressive multifocal leukoencephalopathy

Recurrent Salmonella sepsis

Toxoplasmosis of the brain

Wasting from HIV

## Appendix B — Glossary

**Americans with Disabilities Act** - a law that protects people with disabilities against discrimination. It provides “equal opportunity” for individuals with disabilities in housing, employment, transportation, government services and programs, etc.

**Amylase** - an enzyme produced in the pancreas and salivary glands. Increases in the blood amylase may be an indication of pancreatitis.

**Anemia** - a decrease in the normal amount of red blood cells or hemoglobin. People with anemia may feel tired and fatigue easily.

**Antibodies** - a substance produced by the body to fight germs.

**Antiretrovirals** - the group of medications used to treat HIV/AIDS.

**Burkitt’s lymphoma** - a type of cancer found in the T and B cells of the immune system.

**Candidiasis** - yeast or fungal infection that can occur anywhere in the body. On the skin appears as a raised red rash; in the mouth looks like curdled milk.

**Cat Scratch Disease** - an illness caused by a cat scratch that results in swollen lymph glands, fever, and chills.

**Coccidioidomycosis** - an opportunistic infection of the lungs caused by a fungus that normally lives in the soil. Infection occurs when strong winds disrupt the soil and then the unseen spores are breathed into the lungs. This fungus is usually found in the southwestern United States (California, Arizona, and Texas). People with CD4 counts that are very low are more likely to develop infection with this fungus.

**CD4 Cell (AKA T4 cell)** - the part of the immune system that is attacked by HIV. People who are infected with HIV often have too few CD4 cells. CD4 cells play an important role in the way the immune system works. Also called T-helper cell, helper cell.

**Compliance** - following health care team’s instructions. It is extremely important to take each and every dose of medication as prescribed. Anyone taking less than 100% of their medications can develop resistance of the virus against that medication and possibly other medications as well.



## Appendix B — Glossary continued

**Confidential** - private. Confidential information can be shared **ONLY WITH YOUR PERMISSION**.

**Cross Resistance** - resistance to other medications from the same class of drugs.

**Cryptococcosis** - the most common cause of meningitis in people with AIDS. Usually found in people with extremely low CD4 counts. Symptoms include fever, headache, nausea, and vomiting. The infection can spread to other parts of the body. The yeast that causes this infection is found in the soil. People become infected when the soil is disturbed and the unseen spores are breathed into the lungs.

**Cryptosporidium** - an organism that enters the gut and causes diarrhea, pain, and weight loss.

**Cytomegalovirus (CMV)** - a virus that can affect many parts of the body and cause a variety of infections including pneumonia, diarrhea, and retinitis (eye infections).

**Disclosure** - giving information to others. Information regarding HIV status can **ONLY** be given with permission from the patient or guardian.

**Discrimination** - when someone is treated differently than others based on their HIV status.

**Dysplasia (cervical)** - changes from normal in the cells lining the cervix or uterus. These changes are not cancerous but can often lead to cancer.

**Encephalitis** - inflammation of the brain which can lead to seizures and death.

**Encephalopathy** - a condition that occurs in the brain that affects its development. In children, encephalopathy may result in developmental problems such as cerebral palsy.

**Extrapulmonary** - occurring outside the lungs.

**Gammaglobulin** - medication made from blood products that may be given after exposure to chicken pox or measles in an effort to avoid or lessen the disease.

## *Appendix B — Glossary continued*

**Gastrointestinal Tract** - the tube that extends from the mouth to the anus in which the movement of muscles and the release of hormones and enzymes digests food. Includes the mouth, esophagus, stomach, duodenum, small intestine, large intestine, rectum, and anus.

**HAART** - stands for highly activated antiretroviral therapy.

**Helper Cell** - a type of T cell that helps in the immune response. The HIV attacks these cells in the body.

**Hepatitis** - inflammation of the liver that can be caused by a viral infection or can be caused by other things including certain types of antiretroviral medication.

**Heterosexual** - a person sexually attracted to persons of the opposite sex.

**Histoplasmosis** - the most common fungal infection in the states of the Mississippi Valley (including Indiana). The yeast that causes this infection is found in the soil. People become infected when the soil is disturbed and the unseen spores are breathed into the lungs. It may spread outside the lungs to other parts of the body.

**Homosexual** - a person sexually attracted to persons of the same sex.

**Immune System** - the part of the body that fights germs and helps to prevent infection. It includes white blood cells and CD4 cells.

**Kaposi's Sarcoma** - the most common form of cancer in people with HIV. Rarely occurs in children. This type of cancer affects the blood vessels. It appears as purple, pink, or red spots, patches, or raised areas on the skin. These "lesions" usually are found on the face, neck, chest, or back but can also occur in the internal organs.

**Lipase** - an enzyme in the body that measures the function of the pancreas. Elevations in lipase may indicate pancreatitis.

**Lipodystrophy** - a condition caused by antiretrovirals. It causes loss of fat tissue in certain areas of the body and fat accumulation in others.

**Listeria** - a bacteria usually found in contaminated food. Listeria can cause death in people with weakened immune systems.



## Appendix B — Glossary continued

**Lymphoid Interstitial Pneumonitis (LIP)** - a lung disease that may develop in children with HIV infection. This condition can cause permanent damage to the lungs. It is diagnosed by x-ray.

**Lymphoma** - a form of cancer that occurs in the T and B cells of the immune system. Not often seen in children but does sometimes occur.

**Malabsorption** - the process that occurs when food nutrients are not absorbed by the body.

**Meningitis** - inflammation in the brain caused by a virus or bacteria. Symptoms include high fever, headache, loss of appetite, and severe neck pain. In infants, symptoms typically include irritability, fever, and poor feeding.

**Metabolism** - the process that occurs when the body generates energy. HIV can cause the body to work harder and to use more calories for energy. People with high viral loads usually have an increase in metabolism and usually have a hard time taking in enough calories to keep up with the body's needs.

**Monotherapy** - treatment with only one medication. Rarely used in the treatment of HIV.

**Mutate** - to change in form. This happens when HIV changes itself to become resistant to medications.

**Mycobacterium Avium Complex (MAC)** - a condition caused by a type of bacteria that enters the body through the gut and other organs. Symptoms include fever, weight loss, abdominal pain, loss of appetite, diarrhea, fatigue, and anemia.

**Nutritionist** - a person who specializes in diet and nutrition. Often called a dietitian.

**Opportunistic Infections** - an infection that occurs because of a weakened immune system. May be difficult to treat.

**Pancreatitis** - Inflammation of the pancreas. Some of the antiretroviral medications can have this condition as a side effect. This condition needs to be closely monitored.

## *Appendix B — Glossary continued*

**PCR** - a test that measures the amount of HIV in the body (also caused viral load).

**Peripheral Neuropathy** - a condition that affects the nerves of the body especially those of the legs and feet. Symptoms may include numbness, weakness, burning, or loss of reflexes. These symptoms should be immediately reported to the health care team.

**Pneumocystis Carinii Pneumonia(PCP)** - a lung infection that causes fever, dry cough, and difficulty breathing. This can be a very serious infection. In people with very low CD4 counts, medicine may be given to try and avoid this infection.

**Progressive Multifocal Leukoencephalopathy(PML)** - a serious life-threatening opportunistic infection that affects the brain. It is rarely seen in children.

**Prophylaxis** - measures that are taken to prevent disease.

**Resistance** - in the treatment of HIV/AIDS, the virus may develop certain ways of avoiding the effects of medication and make the medication no longer work. The virus can then continue to multiply in the body.

**Retrovirus** - a type of virus. HIV is one.

**Roadblocks** - something that blocks or prevents you from a task such as taking medication.

**Salmonella** - a bacteria that can cause “food poisoning” and fever from contaminated foods.

**Sexually Transmitted Diseases** - an illness or infection transmitted during sexual contact. Includes HIV, chlamydia, genital herpes, genital warts, gonorrhea, syphilis, and yeast infections.

**Shingles** - an infection caused by the same virus that causes chicken pox (herpes zoster). After a case of chicken pox, the virus stays in the body and will later appear as shingles. This can occur when the immune system is weakened. Shingles is an extremely painful condition that causes inflammation of the nerves.



## Appendix B — Glossary continued

**Superinfection** - re-infection with a second strain or type of an illness.

**Sushi** - raw fish usually served with cold rice.

**Thrush** - yeast infection of the mouth. Usually looks like patches of white. Can be painful and does require treatment with a prescription medication.

**Toxoplasmosis** - an infection that enters the brain and causes flu-like symptoms such as fever, headache, seizures, and swollen lymph glands. Symptoms may last several weeks.

**Tuberculosis** - a highly contagious infection that attacks the lungs and other parts of the body. A skin test can be done to indicate infection.

**Viral Load** - the amount of HIV in the body.

**Wasting** - rapid weight loss.



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