


LEGAL AID OF 
WESTERN MISSOURI

AIDS LEGAL ASSISTANCE PROGRAM



Legal Handbook For Persons With HIV

AIDS programs · benefits · legal rights

*Handbook made
possible by a grant
from the Heart of
America Community
AIDS Partnership*

Introduction

This is the third edition of the Legal Handbook for Persons with HIV/AIDS. Many changes have occurred since this handbook was first published in 1992. The most notable and hopeful is the progress made in treatment for the condition, which has improved the quality and duration of life for those living with HIV.

In this handbook we attempt to set out practical and legal information and advice in the areas we have found to be of most interest to those with an AIDS or HIV positive diagnosis. We hope it will provide the reader with a basic understanding of legal rights, available government benefits, and planning options. However, the law is subject to change. This handbook is not a substitute for the advice and counsel of an attorney, and we urge those with legal questions to consult with the Legal Aid office in their area or a private attorney.

Legal Aid of Western Missouri (LAWMO) has made a commitment to provide legal services to low income persons with AIDS and to those who are HIV positive. LAWMO offers free legal counsel and representation to low income clients in many areas of the law including public benefits, housing, family law, consumer, immigration, employment, education, medical assistance, and municipal court cases. For low income individuals with AIDS or who are HIV positive, LAWMO attorneys will also draft living wills, simple testamentary wills and durable powers of attorney and will assist with the execution and recording of these documents.

If you are in need of legal assistance and live in Missouri, please call our office at **(816) 474-6750** to have an initial intake completed or for referral to the appropriate office. You do not need an appointment and you do not have to come to LAWMO's office to make an initial application. Our normal office hours are 8:30 a.m. to 5:00 p.m., Monday through Friday. The office is located at **1125 Grand, Suite 1900, Kansas City, Missouri 64106**. Our web site is **www.lawmo.org**.

If you live in Johnson, Wyandotte, Miami, Franklin, or Linn Counties in Kansas you may call Kansas Legal Services at **(913) 621-0200**, for information on legal assistance available to low income persons or referral to other sources for help. In Douglas County, Kansas, call the Douglas County Legal Aid Office at **(785) 864-5564**.

No person eligible for services shall on the grounds of race, color, religion, national origin, gender, handicap, veteran status, age or sexual orientation, be excluded from participation in, be denied the benefits of, or be otherwise subject to discrimination for any service provided by Legal Aid of Western Missouri.

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Public Benefits

If you are no longer able to work or your income is reduced, there are some federal and state programs that are available to help you. These programs have complex eligibility requirements which are presented below in a very simplified manner. We have provided some suggestions to help the application process go more smoothly and to help you identify and understand the different programs:

■ A. Social Security and SSI Disability

The Social Security Administration, a federal agency, determines eligibility for both Social Security and Supplemental Security Income (SSI) Disability. Both programs have the same rules regarding the definition of disability, but the benefits and other eligibility requirements differ. For the purposes of receiving Social Security or SSI disability benefits, disability is defined as an inability to engage in any “substantial gainful activity” (SGA) by reason of a medically determinable physical or mental impairment that can be expected to last or has lasted for a continuous period of not less than 12 months or can be expected to result in death.

If you are turned down for any of these programs, in most cases you may appeal. You must do so within strict time limits. You may contact Legal Aid of Western Missouri (816) 474-6750, to assist you with the appeal. If you live in Kansas, call Kansas Legal Services at (913) 621-0200. Some cases, which may be fee generating, would be referred to private attorneys, but Legal Aid can usually answer questions about the appeal process and in some cases represent you at a hearing.

1. Programs and Application

To be eligible for Social Security benefits (not SSI) you must be an insured worker, i.e.

you must have worked and have paid a minimum amount of money into Social Security through the FICA deductions on your wage stub. These cash benefits are awarded in an amount based on what you have paid into Social Security up to a maximum monthly amount. There is a five month “waiting period” after your disability (as defined by Social Security) begins before you can begin receiving benefits.

Supplemental Security Income (SSI) disability benefits are available only to the financially needy. They are cash benefits issued to bring an individual’s monthly income up to a minimum level (as of January, 2001, \$530 per month). Very simply stated, to qualify for SSI benefits your income from any source must be very low. In addition, your assets must be under \$2,000 (2001 figure), excluding your home, one car, and household goods and personal effects valued at less than \$2,000.

To be eligible for either SSI or Social Security disability, you must apply. If you are too sick to go to your local Social Security office, you may apply by phone or a worker may come to your home or hospital. The sooner you apply after you become unable to work, the better, as this process can be quite lengthy.

When you apply for Social Security benefits, try to have available the following

information; but, if you do not have it, go ahead and apply and ask for help getting the information together.

- Social Security Number, card, and certified copy of birth certificate
- W-2 forms from your employers for the two prior years
- A list of your employers for the last 15 years
- Names of previous or current spouse, children, and their Social Security numbers. (If you are found disabled, your children may also be eligible for benefits on your account)
- A list of all your doctors, addresses and phone numbers, dates of treatment
- A list of hospitals and clinics, addresses and phone numbers where you have been treated, date and type of treatment
- A list of your medications, with dosages, why they are needed, their side effects and effectiveness
- A list of reasons explaining why your condition prevents you from working, physically and mentally
- A signed letter from your treating physician with your diagnosis, the basis for the diagnosis and the date

If you believe you may also be eligible for SSI benefits, take all of the above, plus,

- Proof of current income, if any
- Bank statements or account numbers and balances
- Car registration, life insurance policies, etc.
- List of household expenses

Take a friend or family member who can help you provide information about your condition. Do not withhold information or misinform any government agency about your condition, your income, or your assets. Your benefits could later be reduced or totally withheld when the agency finds out. They do check the information you provide.

Having this information available will help the initial application process go more quickly.

2. Proving You are Eligible for Social Security Benefits

After providing the information listed above, you may still be denied benefits. You can and should continue with your claim through the appeals process. **BE SURE TO APPEAL AS DIRECTED IN THE NOTICE OF DENIAL OF BENEFITS WITHIN 60 DAYS OF THE DATE OF THE NOTICE.** The procedure for appeal can differ depending upon whether you are newly applying for benefits or are being terminated from benefits. Read your Social Security letter completely to determine what type of appeal you should request. The Social Security Office should help you with this. If you have been receiving benefits and the Social Security Administration (SSA) is trying to terminate

your benefits, you must appeal within 10 days and also request that your benefits continue (if you wish) to avoid loss of benefits during the sometimes lengthy appeals process.

A person with an AIDS diagnosis may be presumptively eligible for Social Security if he or she is not working. In general this requires having HIV plus one of a group of opportunistic infections, such as pneumocystis pneumonia. Your CD4 count and viral loads are factors considered by the SSA, but are not the determining factor in the decision about whether or not you are disabled.

A person with an AIDS-related condition who does not meet stringent initial screening requirements for disability must prove to Social Security that his or her disability will keep him from working at any job (not just his past work) for at least 12 months. Currently this process can be very lengthy unless you are already very ill. Be patient and enlist the assistance of a lawyer, friends and your physician in convincing Social Security that you cannot work. Other health problems not related to your HIV status, such as prior injury, depression or other mental health diagnosis, should be brought to Social Security's attention. Medical documentation of your health problems is very important for disability claims.

We suggest that as soon as you become unable to work, or are having difficulty working, you should begin keeping a diary showing your daily problems with HIV-related symptoms, such as fatigue, diarrhea, sweats, fever, recurring infections, skin problems, weight loss and mental problems

(depression, forgetfulness, alcohol abuse). Try to associate these with your inability to work. This kind of diary could help you, your physician or your attorney prove to Social Security your inability to work.

You should be aware that Congress passed a law making persons whose drug or alcohol addiction is a contributing factor material to the determination of disability ineligible for Social Security or SSI disability benefits. If you have a dual diagnosis, you may wish to consider the effect your addiction will have on your eligibility before you apply.

■ B. Medicare

Medicare benefits for those under age 65 are available only to Social Security recipients who have been disabled according to the Social Security Administration's rules for 24 months plus the five-month waiting period. Different levels of payment of medical bills are available. Medicare does not cover prescription costs, although other programs might. If you are financially needy, the state may pay your Medicare premium; otherwise, it is deducted from your Social Security benefit amount. Unless you know you are covered by other insurance or benefits for the duration of your illness, do not reject Medicare benefits as it may be difficult and costly to choose to receive them after your initial period of eligibility.

■ C. Medicaid

Medicaid is a federally subsidized program administered by the state for low-income persons and their families who have no significant assets and cannot work or who

qualify on some other limited bases. Medicaid benefits cover many medical services, including most prescriptions, visits with physicians who accept Medicaid and hospital charges. The agency where you apply for Medicaid in Missouri is the Division of Family Services (DFS). In Kansas, the agency is called Social and Rehabilitative Services (SRS) and Medicaid is referred to as MediKan. Generally, if you are eligible for SSI benefits, you are eligible for Medicaid. However, there may be different limits on the kind or value of some assets or resources you may own. If your income is over certain Medicaid limits, you may be eligible on a “spend down” basis, which means that if you incur “x” number of dollars in medical bills per quarter, Medicaid will pay the rest. In Kansas, the spend down period is 6 months. The “spend down” amount is similar to a deductible on an insurance policy, but varies depending on your income. Medicaid and MediKan (Kansas Medicaid) cover many families in a wide variety of programs including some for working individuals and families. If you are uninsured, APPLY FOR BENEFITS and let the agency determine your eligibility. If you are denied and you disagree with the decision, call your local Legal Aid office immediately for assistance with an appeal.

■ D. Medication Programs

Special programs provide assistance for medication prescribed by the physician of an eligible HIV positive client. Generally these programs are available only to those who are uninsured or under insured for their prescription medication. Kansas and Missouri have significantly different

eligibility requirements which may change frequently as funding for the program changes. The number and kind of medications which are covered also vary between the states and may change from time to time. For access to this program, contact a Ryan White Case Manager at a local AIDS service organization or the Kansas City Health Department, (816) 513-6230, for assignment of a Case Manager.

■ A. Temporary Assistance Benefits, General Relief and Food Stamps

1. Temporary Assistance Benefits

Each state receives funds from the federal government to operate a Temporary Assistance program. The program is administered by the Missouri Division of Family Services (DFS) or in Kansas, Social and Rehabilitative Services (SRS). The purpose of Temporary Assistance benefits is to provide cash assistance to needy families so that they may care for their children in their own homes. If your family is approved for Temporary Assistance benefits, you will also be eligible for Medicaid or MediKan.

Temporary Assistance benefits are now focused on providing a time limited period of cash assistance to families and assisting them in job preparation and work activities. These benefits may be available for families with low income and few resources if there are minor children in the home who are deprived of parental support due to death, incapacity, absence of one parent, or unemployment of a parent. The Temporary Assistance program now encourages the maintenance of two parent households.

Certain relatives caring for minor related children may also be eligible for Temporary Assistance benefits for the children, even if the relative's income would exceed the usual Temporary Assistance income maximums of the state agency. In addition, an individual who is awarded custody of a child through the Courts, or is the legal guardian of a child, may be eligible for Temporary Assistance benefits for the child.

Have this information available when you apply:

- Birth certificates for any children; or in Kansas, a doctor's statement showing pregnancy of six months duration
- Social Security numbers for the applicant and any dependents
- Information on income and resources
- Some form of identification to prove who you are. In Kansas, the SRS requires a picture I.D. for all adults
- In Kansas, the SRS may also require utility bills, proof of residence, proof of alien status or citizenship, child care bills and receipts, and insurance policies.

The caseworker for DFS or SRS has an obligation to advise Temporary Assistance applicants of the information needed to process the Temporary Assistance application and to assist the applicant in obtaining the information needed to determine eligibility. Absent extreme or unusual circumstances, a determination of an applicant's eligibility should be made within 30 days and, if approved, the

applicant should receive benefits within 45 days.

2. General Relief (Missouri) and General Assistance (Kansas)

General Relief and General Assistance benefits are funded totally by the state governments. The programs are administered by state agencies. The purpose of the programs is to provide cash assistance and medical coverage to individuals who are unable to work due to a physical or mental disability. If you are approved to receive this assistance, you will also be eligible for Medicaid.

People who are prohibited from engaging in any job for which they are qualified due to a medically determinable physical or mental impairment may be eligible for this assistance. This impairment must be expected to last at least ninety days in Missouri, and in Kansas for 12 months or be expected to result in death. In certain instances, General Relief benefits are also available for people who are victims of fire, flood, or other natural disasters. Be aware that the amount of monthly cash payments that may be received from General Relief is very low in Missouri, \$80 per month as of January, 2001. In Kansas, the maximum General Assistance payment is \$196.00 per month and varies from county to county.

Take the following information with you when you apply:

- Some form of identification to prove who you are (in Kansas it must be a picture I.D.)
- Information regarding your doctors, hospitals, medications

- Information on income and resources
- Your Social Security number
- In Kansas, SRS may also require proof of residence, proof of alien status/citizenship, medical bills and receipts, life insurance policies, utility bills, etc.

3. Food Stamp Benefits

Food Stamp benefits are administered by state agencies, but they are funded solely by the federal government. The amount of Food Stamp benefits received by any household will vary depending upon the size of the household and the income of the household members.

The following may be eligible for Food Stamps: (1) Disabled and elderly individuals or families who have net income below a standard set by the federal government (2) Individuals or families who have gross income below a standard set by the federal government.

MANY INDIVIDUALS WHO WOULD QUALIFY FOR FOOD STAMP BENEFITS ARE NOT RECEIVING THOSE BENEFITS. IF YOU BELIEVE YOU MAY QUALIFY FOR BENEFITS, APPLY.

Take the following information with you when you apply:

- Proof of your identity (picture I.D. required for adults in Kansas)
- Your Social Security number and those for your dependents living with you
- Information on income and resources

- Information on your rent and utilities
- Proof of your medical expenses if you are disabled or elderly
- Additional information may also be required in Kansas, such as proof of residence, alien status/citizenship, child care bills and receipts, insurance policies, etc.

Food Stamp benefits can be issued in Missouri through a Benefit Security Card. The Benefit Security Card is used at the grocery store to purchase only food items. Food stamp benefits cannot be used to purchase certain items, including certain foreign meat items, toilet tissue, soap, detergent, shampoo, cigarettes, alcohol, etc. In Kansas, Food Stamp benefits are issued through an electronic benefit card as well.

Food Stamp benefits should be issued within 30 days of the date of application for those individuals who are not destitute. Generally, individuals who have extremely limited income and resources within the specific provisions of the agency's criteria should receive food stamp benefits within five days of the date of application.

4. Where You Should Apply for Temporary Assistance, Food Stamps and General Relief benefits

Apply at the office of the Missouri Division of Family Services or Kansas Social & Rehabilitative Services in your county. Since some counties have more than one office, you may wish to call the general information number for each state agency listed in the blue pages of the telephone book to determine which office would be

closest to you. You may also apply for Food Stamps at any Social Security office.

You have the right to apply for benefits the same day you go into the agency's office. You cannot be denied the right to apply for any benefits for which you think you may qualify. If you cannot go into the office of DFS or SRS due to poor health, you may contact DFS or SRS and request that a home visit be made to have an application taken.

5. If You Are Denied Benefits To Which You Believe You Are Eligible

Carefully review any notices you receive from the Division of Family Services or Social and Rehabilitative Services and appeal each denial within the applicable deadlines. If your benefits are terminated wrongly, you must appeal within a very short period of time.

Call the Legal Aid office in your area to see if you qualify for free legal assistance with your appeal. In the Kansas City area, call Legal Aid of Western Missouri (816) 474-6750 for Clay, Platte and Jackson Counties or Kansas Legal Services, (913) 621-0200 in Wyandotte, Leavenworth and Johnson Counties.

■ F. Veterans Benefits

If you are a veteran you may be eligible for a wide range of medical and disability benefits. Contact your local Veterans Administration office for more information. In Kansas City, call the Vet Center (816) 753-1866 or Disabled American Veterans (816) 922-2884 or the Veterans Administration (816) 861-4700 or 1-800-827-1000. You may also call the Legal

Aid office in your area for assistance if you have low income and you feel you were wrongly denied benefits or services by the Veterans Administration or one of the VA Hospitals.

■ G. Housing Assistance

There are a number of housing assistance programs available for qualified persons with HIV. If you need assistance with your rent, mortgage payment or in obtaining housing, call SAVE, Inc., (816) 531-8340. In addition to assistance programs, SAVE, Inc. operates some subsidized housing specifically for persons with HIV/AIDS. Save, Inc. can also assist with other housing related needs, such as utilities, moving and deposit expenses, furniture and supported housing. Good Samaritan Project also may have emergency assistance money available for rent and utilities. Contact your Ryan White case manager for more information.

Because many of these programs are temporary housing assistance programs, if your situation is one where your income will be low or very low for an extended period of time, there are a number of long term federally subsidized housing programs available to qualified individuals. These include:

- public housing: low income housing owned and operated by a local public housing authority (PHA)
- Section 8 Housing Choice vouchers: a public housing authority (PHA) issues a voucher to an individual who then seeks housing in the private housing market and a portion of the rent is paid by the PHA

-
- other federally subsidized developments: these developments are usually privately owned and managed, but rent is subsidized by the Department of Housing and Urban Development.

Listings of public housing authorities and subsidized developments are available at Legal Aid of Western Missouri and the United States Department of Housing and Urban Development.

Usually, you will only pay 30%-40% of your adjusted income for rent in these housing programs. There are requirements for the quality of the housing provided. Eligibility for the assistance is based on your income and a variety of other factors, such as your criminal history and rental history.

When you apply for federally assisted low income housing, it is important that you know that most developments will check your rental history, criminal history and employment, if any. If there are negative factors in these areas, try to get them cleared up or provide an explanation at the time of your application.

You should also be aware that most public or subsidized housing developments and the Section 8 housing choice voucher program have waiting lists. Each housing authority or development may also have preferences for certain classes of applicants. Find out what the preferences are to see if you qualify for one. If so, you may be moved higher on the waiting list. These

preferences may include: head of households who have demonstrated they are working or receiving vocational training; individuals who are disabled (usually according to the Social Security Administration); and elderly or homeless individuals. Each housing authority or subsidized housing development may have a different policy or preferences.

Because these housing assistance programs are government funded, there are special rules regarding when the housing provider can deny your admission or eligibility for a program. There are also due process requirements for terminating your assistance which the provider of the assistance or landlord must follow. The requirements vary depending on the housing program. If you are denied eligibility for housing assistance, your assistance is being terminated or you are being evicted from subsidized housing, you may wish to consult an attorney. The attorney can help you determine if you have a right to a hearing, advise you regarding your rights, or provide representation at the hearing or court proceeding.

Call the Legal Aid office in your area to see if you qualify for assistance.

In Clay, Platte or Jackson Counties, call:

- ◆ Legal Aid of Western Missouri
(816) 474-6750.

In Kansas:

- ◆ Kansas Legal Services
(913) 621-0200.

Employment and AIDS

■ A. Americans with Disabilities Act/ Employment Discrimination

1. Introduction

Generally, federal, state and local laws prohibit discrimination by an employer against an individual because of a disability. A disability is a condition which substantially limits one or more of a person's major life activities. Federal and Kansas law also prohibit discrimination against an individual who is perceived as having a disability. Discrimination occurs when you are treated differently because of a disability or a perceived disability. Courts have held that federal disability discrimination laws do extend their protection to persons with HIV/AIDS, including HIV seropositivity. Section 504 of the Rehabilitation Act (Section 504), a federal law, has for many years prohibited disability discrimination if you are a federal employee, your employer is a federal contractor, or if your employer is a recipient of federal aid. Federal law protection was extended to almost all employees who work for employers with 15 or more employees under the Americans with Disabilities Act (ADA) in 1994.

If you believe you have been treated differently by your employer because of your HIV status or a condition related to being HIV positive, you have the right to file a charge of discrimination against your employer. Federal law also protects you if you are treated differently by your employer because you are perceived or

regarded as having an impairment such as HIV and even if you are treated differently by your employer because of your relationship to or association with a person with AIDS.

It is important to realize that differences in treatment can occur at any point in the employment relationship—when you are hired (or not), promoted (or not), disciplined or terminated and even in the way benefits are provided, particularly insurance benefits. You also have the right to be free from harassment because of your disability. These laws protect you from adverse employment decisions as long as you are able to perform your duties, even if you can only do so with “reasonable accommodation” by the employer. Employers are required to accommodate your illness in many situations and if the employer does not, you may have the right to force them to do so. You may also be awarded back pay, compensatory damages, the promotion which you were denied, or reinstatement to the position from which you were fired.

This law is complex and you should discuss your concerns with the human resources person at your employer or consult with an attorney if accommodation or requests for other assistance are denied.

2. Reasonable Accommodation

Under the Americans with Disabilities Act, “reasonable accommodation” is a modification or adjustment to the application process or the work environment that levels the playing field for applicants or employees with disabilities.

“Reasonable” is not defined, but examples can include:

- making facilities accessible
- restructuring the job, including altering nonessential duties
- modified work schedules or leave
- reassignment or transfer to another position
- acquiring and allowing use of enabling equipment
- removing physical impediments
- adjusting or modifying examinations, training materials or policies.

An employer must provide reasonable accommodation unless it would impose an “undue hardship” which is defined as “action requiring significant difficulty or expense” on the part of the employer. In determining whether a requested accommodation is an undue hardship, courts will look to the cost of the accommodation, the size and financial resources of the employer, both overall and by the facility affected, the type of operation of the employer, and the impact of the proposed accommodation.

Accommodation may also include transfer to a less fatiguing job, or to a job with less risk of exposure to infection, flexible hours, or even the opportunity to work at home. Explore these or the options listed above with your employer if your ability to work is impaired to the extent you need accommodation to continue to work. If you

do need to request accommodation, you may be required to provide medical evidence to support the need for the requested accommodation. An employer, in most circumstances, should not ask for or require that you provide your complete medical records, only those necessary for these purposes.

The ADA does not require:

- the promotion of a disabled employee
- displacement of a current employee, or the creation of a new position
- the elimination of the essential functions of the job, or the reallocation of job functions in a way that increases the hours or difficulty of another employee’s job
- the alteration or reduction of an employer’s standards
- the granting of indefinite leave or the allowance of chronic unscheduled absences
- the provision of the best possible accommodation or the specific accommodation requested by the employee, so long as the accommodation provided by the employer is reasonable
- the creation of a light-duty position
- the ignorance of medical restrictions
- variance from seniority rules pursuant to a collective bargaining agreement.

If you have AIDS, are symptomatic or are HIV positive, beware of the employer who may wish to terminate your employment, segregate you or change your job duties “for your own protection.” Unless the employer can clearly show that you will be harmed by your work or work environment, this may be another form of discrimination.

3. Sexual Orientation and Discrimination

If an employer perceives that you have HIV infection or AIDS because of your lifestyle or sexual orientation, you may be covered by the handicap discrimination provisions of federal and Kansas law. However, neither state nor federal law provide protection against discrimination on the basis of sexual orientation. If you believe that you are being discriminated against because of your sexual orientation and you live in the Kansas City area, consult an attorney. Kansas City, Missouri does have an ordinance making it unlawful for an employer, employment agency or labor organization to discriminate on the basis of sexual orientation. Complaints may be filed with the Kansas City Human Relations Department, (816) 513-1836.

4. Applying for Employment

An employer is generally prohibited from asking in an employment application whether or not you have a specific disease or disability. Doing so may constitute a violation of the state and federal laws protecting disabled persons. However, an employer may ask if you have any condition or disability which would interfere with your ability to do the job for which you are applying and ask you to demonstrate how you will be able to perform the job, with or without reasonable accommodation.

If your employer requires you to have an HIV antibody test as a condition of your employment, this may also be discriminatory under the law, since it would be very difficult to show that an HIV positive status would affect your ability to do most jobs and, therefore, the only purpose would be discriminatory. However, for some jobs, there may be what the ADA calls a “significant risk to the health or safety of others” and the law would allow testing and even difference in treatment. The employer may require a medical exam (including an HIV test) but only after an offer of employment is made and only if all employees in the same job category must have the exam prior to employment and regardless of disability. Information obtained by an employer during such an exam must be collected and maintained on separate forms and in separate medical files and be treated as a confidential medical record. If you have questions about an employer’s request for an HIV test, contact an attorney or the appropriate government agency. (See below).

5. Where to File a Charge of Discrimination Against an Employer

Although you may wish to consult an attorney before filing a charge of discrimination, it is not absolutely necessary. Agencies responsible for carrying out the laws passed by Congress and state legislatures have the means to assist you with your complaint either with or without an attorney.

The Equal Employment Opportunity Commission (EEOC) at Gateway Tower II, 400 State Avenue, Kansas City, Kansas, 66101, (913) 551-5655 will investigate

charges of disability discrimination against employers who have 15 or more employees and state and local government agencies and is responsible for enforcing the Americans with Disabilities Act (ADA). Complaints against private employers must be filed with the EEOC within 180 days of the discriminatory act. If no satisfaction is received from the EEOC, you may pursue your claim as an individual in federal court. You may be awarded a wide range of relief such as reinstatement, back pay, compensatory damages and attorney fees. The EEOC has a web site at www.eeoc.org.

You may also make claims of disability discrimination against a federal employer by filing a complaint with the Equal Employment Opportunity Commission or with the Department of Health & Human Services, Office of Civil Rights, (816) 426-7278. The complaint must be filed within 30 days of the discriminatory act. Complaints about employers who are recipients of federal aid must be filed within 180 days with the agency which provides funds for the particular employer.

If you are an employee of the State of Missouri or the State of Kansas, you should file your complaint with your state agency. If the division of the state government you work for receives federal funds, you should also file a complaint under § 504 of the Rehabilitation Act with the agency who provides the funds.

Missouri law prohibiting disability discrimination is applicable to any employer with six or more employees. The law specifically includes contagious diseases, HIV infection and AIDS, as conditions protected from discrimination, unless the

contagious disease would constitute a direct threat to the health or safety of other individuals. Since it is highly unlikely that AIDS or HIV can be transmitted in the normal employment environment, this law seems to provide adequate protection. You must file a complaint of discrimination under this law within 180 days of the discriminatory act with the Missouri Commission on Human Rights, (816) 889-5100. Since Missouri law does not protect you unless you actually have a disability, do not file your complaint here if you were discriminated against because of a perceived disability or because of your association with an HIV positive person.

Kansas law prohibiting disability discrimination is applicable to any employer with four or more employees. Disability is defined similarly to the definition under federal law, and specifically includes persons who are not disabled but are regarded as being disabled. Complaints of discrimination must be filed within six months of the discriminatory practice with the Kansas Human Rights Commission, (785) 296-3206.

■ B. Family and Medical Leave Act

The Family and Medical Leave Act (FMLA) is a federal law that applies to all employers with 50 or more employees. Eligible employees are those who worked for at least the past twelve months for at least 1,250 hours during that period. Leave may be granted under the FMLA to employees who have a serious health condition that renders them unable to perform the functions of their position. It also may be

allowed to care for a spouse, child, or parent with a serious health condition. A serious health condition is one that requires inpatient care in a hospital, hospice, or residential medical care facility; or continuing treatment by a health care provider.

Eligible employees are allowed twelve weeks of unpaid leave during any twelve-month period. An employee may be required or allowed to substitute accrued paid leave. Leave also may be taken on an intermittent or reduced schedule basis so that an employee may, for example, attend necessary medical appointments. Where an employee requests intermittent leave, an employer may transfer him or her to an available position for which the employee is qualified and better accommodates periods of leave. An employer also may alter an employee's existing job to better accommodate leave. The employee should be prepared to provide medical support for the requested leave from a health care provider in a timely manner.

When you request FMLA leave, make your request in writing and get a written response. Make notes of the dates and content of any verbal communication regarding your leave, and get a copy of your company's FMLA and other leave policies.

In general, an eligible employee is entitled to be restored to the same or equivalent position with equivalent pay and benefits when he returns from an FMLA leave. Under the FMLA, an employer may terminate an employee who is unable to return to work after twelve weeks of leave.

This law is complex and you should discuss your coverage with the human resources person at your employment or consult with an attorney if leave is denied.

■ C. Confidentiality, Testing and Disclosure

The advantages of not disclosing an HIV positive status are apparent to anyone who has witnessed or read about the discriminatory treatment of persons who are HIV positive or who are perceived as such. Consider very carefully before you disclose your HIV status to anyone. Even sympathetic employers may try to terminate your employment to try to control increased insurance costs. Co-workers may disclose the information inappropriately trying to help "explain" absences or illnesses. On the other hand, some employees feel disclosure actually "lightens the load" and makes the work environment better. Clearly, you want to be the person who controls who is told and when they are told. Anonymous testing can put you in the drivers seat, while some confidential testing may not. Questions about maintaining confidentiality may arise even before a person is tested for HIV antibodies and continue as a person seeks new employment, medical treatment or accommodation from an employer because the disease has become disabling.

If you decide to disclose your HIV status to your employer, the Americans with Disabilities Act does provide some protection. The employer is required to treat medical information you disclose or which they obtain from a disability inquiry or medical examination as a confidential medical record. However, in limited

circumstances they can legally disclose the information to supervisors, managers, first aid personnel, and government officials investigating ADA compliance. The employer does not have to request your permission or tell you who they told.

Early detection of the presence of HIV is critical for prevention of the spread of the virus and because early medical intervention promotes a longer life and better quality of life for those who are infected. If you suspect you have been exposed to HIV or are exhibiting symptoms, go in for testing as soon as possible. However, be aware of testing options and consequences as well.

If you believe you have been exposed to the AIDS virus, you may be anonymously tested for the HIV antibody in Kansas City at the Kansas City Free Health Clinic by appointment **(816) 753-5144**. Anonymous testing means you do not provide identifying information to the tester and no third party can access the results. Health care providers in Missouri are required to report anyone who tests positive for HIV to the State Department of Health. In Kansas, health care providers are required to report to the Secretary of Health the name of any person with an AIDS diagnosis for whom they are providing services. All positive HIV test results are reported as well, but not by name. Anonymous and confidential testing are available at most county health departments in Kansas.

Be sure to ask for anonymous testing if this is your wish. The great thing about anonymous testing is that only you are told the results and you have control over disclosure of the information.

1. Missouri

The law of Missouri provides that findings of AIDS, confirmed HIV infection and low CD4 cell counts of persons who have HIV infection must be reported to the Department of Health within three (3) days along with the person's name, address, age, sex, and race. A physician or health care provider must otherwise keep this information strictly confidential because of the doctor-patient privilege and state law. One result of your name being reported to the Health Department may be contact notification according to public health department protocol. Persons who may have been exposed through contact with you may be notified although your name should not be revealed. Another result may be that your medical records may be subject to review by the Department of Health. Information contained in your medical records may be reviewed by your insurer only with your consent.

Missouri state law provides that only physicians, hospitals and those authorized by the Department of Health may perform HIV tests and the tester must provide counseling both before the test and when reporting the results.

There is also provision for anonymous testing sites where a person may go for testing without revealing one's identity to anyone. There are three test sites in the state of Missouri where tests are conducted by number instead of by name and only the number is reported to the State Department of Health. In Kansas City, anonymous testing is available at the Kansas City Free Health Clinic, (816) 753-5144. This option provides only temporary anonymity. Once you begin receiving medical treatment for

your HIV disease, your name, etc. will be given to the Health Department. These test sites are also required by law to initiate contact notification. For example, they may ask you to notify persons you may have exposed to the virus.

The Missouri Department of Health and other persons, agencies, or political subdivisions of the state must keep the tests strictly confidential. However, they may share this information with other public employees who need to know in order to perform their duties and with persons other than public employees who are entrusted with the regular care of persons under the care and custody of a state agency. (For example, the Department of Mental Health.)

Missouri law specifically provides: “unless the person acted in bad faith or conscious disregard, no person shall be liable for violating any duty or right of confidentiality established by law for disclosing the result of an individual’s HIV testing:

1. To the Department of Health;
2. To health care personnel working directly with the infected individual who have a reasonable need to know the results for the purpose of providing direct patient health care;
3. Pursuant to the written authorization of the subject of the test result or results;
4. To the spouse of the subject of the test result or results;
5. To the subject of the test result or results;
6. To the parent or legal guardian of the subject if the subject is an unemancipated minor”.

However, there is no duty or obligation to

report the information to a spouse or other potentially exposed person, parent or guardian, and if the information is released in bad faith, liability for any damage caused may be incurred.

In Missouri, a person who knows he is HIV positive does have an obligation to disclose the information to any health care professional prior to receiving services from the health care provider. Discuss with your health care provider what information will be placed in your file and who will have access to it.

If information about your HIV status is negligently provided to someone and you are injured as a result in Missouri, you may sue the person who disclosed your HIV status and recover actual damages, court costs and attorney fees. Willful violation of the confidentiality protections also entitles you to punitive damages.

2. Kansas

In Kansas, the law regarding confidentiality of testing results is less well defined than in Missouri. The results of an HIV test must remain confidential, except a physician may disclose the information to:

- other health care providers
- emergency personnel
- law enforcement officers
- correctional officers
- the spouse or partner of the person who is HIV positive.

The information then must remain

confidential with those persons to whom it is disclosed. There is no duty or obligation to disclose, but if the information is disclosed in good faith and without malice to the persons listed above, there is no civil or criminal liability for the disclosure. Again, consider carefully whether you want your family physician to do the testing or if another alternative, such as anonymous testing would better serve your needs.

A physician must report the name and address of any person whom he or she knows has AIDS or died from AIDS to the Secretary of Health and Environment. Positive results of an HIV test must be reported by a physician or laboratory director by date, date of birth, sex, race and county of residence, but not by name.

Both anonymous and confidential HIV testing is available at county health departments in Kansas. If you want anonymous testing, be sure and ask for it. Also, make sure the tester knows what anonymous means (i.e., your name won't be on the test). In Johnson County, call the Health Department at (913) 894-2525, and in Wyandotte County call the Health Department at (913) 321-4803.

Private employers in both states who are made aware of a person's HIV positive status should keep the information confidential. Failure to do so could result in harm entitling you to legal redress. Depending on the situation, you could recover damages for a breach of your privacy rights, libel or slander, or illegal discrimination.

■ D. Unemployment Benefits

1. Missouri

Unemployment benefits in Missouri are available to those who are unemployed through "no fault of their own." The general rule is that if you quit your employment, you are ineligible for benefits unless you quit for reasons related to your employment. For example, if you quit because you are unable to perform the work, or if your employer increases your required hours of work and your fatigue or lack of stamina prevent you from working more hours. To regain eligibility after quitting without cause, you must do insured work and earn 10 times your weekly benefit.

You may be eligible for unemployment benefits through the Division of Employment Security if you are forced to leave your job because your physician directs you to quit for health reasons. Be sure to get a signed, dated recommendation to this effect from your physician. You must still be available and able to do other work. It must be the nature of the job that makes you quit, by causing the illness or by aggravating it, not your illness alone.

If your illness is causing absenteeism or other poor work performance, you should discuss the possibility of reasonable accommodation under the disability discrimination laws before it gets so serious you are terminated. Keep in mind your rights under the Family and Medical Leave Act. If you are terminated for misconduct, your eligibility for unemployment benefits may be delayed for several weeks or even denied entirely in some extreme circumstances. If you believe the real

reason for your termination is a disabling condition, you should let the Division of Employment Security (DES) know so they can consider the information.

If you are unable to do the work despite your best effort or due to circumstances beyond your control, this would not be considered misconduct either. In both circumstances the employer could legally terminate you, but if you are able to do other work, you would be eligible for unemployment benefits until you obtain the work or your benefits run out.

You may apply for unemployment benefits at the Division of Employment Security **(816) 889-3101** (Kansas City, Missouri office). If you are denied, you may wish to pursue your appeal rights, which will be described in your notice of denial. Frequently, denials are reversed when all the facts come out in front of the Appeals Referee. If you need assistance with the appeal, call Legal Aid of Western Missouri, **(816) 474-6750**, and apply.

Finally, be aware of your right to privacy with regard to medical information your employer may obtain during the course of your employment. If the employer disseminates this information irresponsibly, you may have legal redress. In Missouri, release of information about your HIV status is specifically prohibited.

2. Kansas

In Kansas, unemployment benefits are also available to those who are involuntarily unemployed. If you quit your employment for a reason which is not considered good cause or if you are discharged for misconduct, you will be ineligible for

unemployment benefits until you have earnings from insured work greater than three times your weekly benefit amount. Misconduct in Kansas is defined as willful and intentional action which is adverse to the employer's interests, or carelessness and negligence which is of such degree it evidences wrongful intent or evil design.

If you quit due to an illness it will be deemed for good cause if: (1) you immediately notify the employer that a physician has advised you not to work and you provide proof of same, (2) the employer consents to an absence due to illness and (3) you later become able to return, try to return and the job or a suitable alternative is not available.

It is also good cause to quit if you leave due to harassment by the employer or another employee if the employer has knowledge of the harassment.

Generally speaking, repeated absence may be considered misconduct if it is without good cause. If you have been employed for a year or more, in some cases you may have a right under the Family and Medical Leave Act (FMLA) to take time off periodically, without pay.

You may apply for unemployment benefits at the Division of Employment, **(913) 281-3000** (Kansas City, Kansas) or **(913) 642-8484** (Overland Park, Kansas). If the initial decision is against you, you have the right to appeal within 15-16 calendar days as described in your notice. If you need legal assistance with the appeal, call Kansas Legal Services at **(913) 621-0200**.

■ E. Returning to Work

If you have not been working because you are disabled and you are also receiving SSI or Social Security disability benefits, there are some Return to Work programs which allow you to test your work readiness without losing your eligibility for these benefits. The programs are different for SSI than for Social Security disability benefits.

If you engage in any work activity while you are receiving Social Security or SSI disability benefits (SSD or SSID), you have an obligation to report the nature and extent of your work and the amount of your income. You should report any improvement in your abilities and health. You may also call Social Security before beginning work to discuss your options and responsibilities.

The Social Security Administration will periodically conduct continuing eligibility reviews to determine whether you are still disabled or your medical condition has improved. These may occur on a random basis or in response to a certain event, such as a report of work activity. For both SSI and Social Security, if you are no longer disabled, your eligibility for benefits ceases. Generally speaking, if you are working and earning over \$740 a month (2001 figure), then you are not considered disabled by the Social Security Administration, without further evidence of medical improvement.

You can, however, take advantage of work incentive programs if you believe you are ready to return to work or you want to test your ability to work. Under these programs you may:

- Be entitled to retain your Medicare or Medicaid coverage even after you return to work.
- Continue to receive your full monthly benefit amount, even if you are no longer disabled according to the Social Security Administration rules, so long as you are participating in an approved vocational rehabilitation program.

Under either disability program, Social Security or SSI, if you become unable to work again within 60 months of the time your benefits were terminated due to work activity, you may request reinstatement within the five-year period and receive benefits for six months while your case is reviewed by the Social Security Administration. These benefits would not be considered an overpayment if you are found not disabled, and will continue if you are found disabled.

SSI benefits are reduced by any income you receive while eligible. The first \$20 of income from any source is disregarded. The next \$65 of earned income is also disregarded. After that, for every \$2 of earned income you have, your SSI benefits are reduced by \$1, until you max out at \$975 (2001 figure) and your benefit equals zero. You continue to remain eligible for benefits so long as you are disabled, you are receiving at least \$1 in SSI benefits, and you meet all other income and resource tests. If your wages drop below \$975 in a month, you would again receive the adjusted SSI benefit if you keep the Social Security Administration advised of your income.

Under the SSI work incentive programs, you may set aside some of your income

under the PASS program and it would not count towards reducing your income. This program requires that you have a written plan showing how you intend to reach your goal of working before you begin setting aside the funds. The set aside funds must be used for education or things that will aid you in your work.

Social Security disability benefits continue so long as you are disabled per Social Security Administration rules. However, if you earn over \$740 per month (2001 figure), you are considered to be doing substantial gainful activity (SGA), and the Social Security Administration presumes you are no longer disabled, unless you can show otherwise. Under the work incentive program, you are allowed a trial work period of nine months during which you may work and receive your full disability check. You only get nine months of trial work during a 60 month time period. There is then a three month grace period, where you still get a check. Trial work period months are any month you earn over \$530 (for 2001). If you do any SGA after this time, you are no longer eligible unless a review by the Social Security Administration reveals that your work is not SGA.

If your Social Security benefits are stopped because you are working, for the next 36 months if your earned income drops below SGA levels you can receive a check. However, you must still be disabled and your benefits must not have been terminated because of medical improvement. For instance, your disability benefits are stopped in January of 2001, but in March, June and July, your earnings are less than \$740. For those months, you will receive a check, and for any other month during the 36 months after January 2001, as long as your medical condition remains disabling by Social Security standards.

These programs can be complicated and any kind of work activity may trigger a review of your disability. You may want to consult an attorney before returning to work. Once you make a decision to work, you should contact the Social Security Administration first to determine what work incentive programs are available for you.

For more information on the work incentives program, ask for a copy of the "Redbook on Work Incentives Program" from you Social Security Administration office or see it online at:
www.ssa.gov/work/ResourcesToolkit/redbook.html.

Discrimination and AIDS

■ A. Housing Discrimination

The Fair Housing Amendments Act of 1988 and Section 504 of the Rehabilitation Act of 1973 give strong federal protection against discrimination because of disability by those who rent, sell or finance housing. The definition of disability is the same as for employment discrimination and HIV infection is specifically included by regulation. If a landlord, mortgagor or real estate agent treats you differently by evicting you, denying you financing, initiating foreclosure or by “steering” you to certain housing, etc., you may have a valid claim of discrimination if the difference in treatment is because of your HIV status or perceived status as a person with HIV.

Federal regulations also provide that if you are living in a facility which receives federal funding, it must provide reasonable accommodation to residents of the facility to ensure they have equal access to the development. These may include:

- permitting an assistive animal
- making modifications necessary for the use of a wheelchair in the individual unit or common areas
- providing a bedroom for a live-in aide.

If the housing provider does not receive federal funds, the housing provider may not refuse permission to the resident to make reasonable modifications at the resident’s expense.

All housing providers must make reasonable accommodation by changing

their policies or practices so a person with a disability may use and occupy the dwelling. Examples include providing an assigned parking space near the disabled person’s door or allowing the person to pay rent by mail when the policy is payment at the office.

To avail oneself of a reasonable accommodation, the resident must ask for it. Some disclosure of the nature of the disability may be necessary to show it is needed. Otherwise, it is generally unlawful for a housing provider to make inquiries about whether an applicant or any person who will reside there has a disability or about the nature or severity of the disability. There are limited exceptions to these rules if the housing is designed to provide housing for those with disabilities.

This law also makes illegal any policy of a landlord prohibiting unrelated adults from sharing an apartment if such a policy would deny housing to a tenant who needs an attendant because of a disability. The law does not apply to owner-occupied housing with four or fewer units.

Again, federal law may be applicable even if you do not have HIV or an HIV-related disability. If you are perceived to have AIDS because of your sexual orientation or lifestyle and housing discrimination results, you are also protected by the Fair Housing Act. If your lawsuit is successful, both federal and state law provide for attorney fees to be paid by the party you sue, plus any resulting damages to you because of the discrimination.

You must file a complaint of discrimination within one year of the discriminatory act

with the Department of Housing and Urban Development, (913) 551-6958, or you may file a civil action in federal court within two years of the discriminatory act.

Missouri and Kansas law provide for similar protection against disability discrimination in housing. Complaints of discrimination in Missouri under state law must be made within 180 days of the discriminatory act with the Missouri Commission on Human Rights (816) 889-5100. Complaints of discrimination in Kansas under the state law must be filed with the Kansas Human Rights Commission within one year of the discriminatory act, (785) 296-3206.

■ B. Education Discrimination

The Education of the Handicapped Act and Section 504 of the Rehabilitation Act of 1973 provide protection from education discrimination to children and adults with AIDS or HIV infection. The law provides that children with disabilities are to be educated with children who do not have a disability to the maximum extent appropriate. For a child diagnosed with HIV infection who is otherwise able to attend school and benefit from the experience, it would be difficult to imagine a situation where the child should be treated much differently from other school age children. Schools must be accessible and usable by students with disabilities.

If an HIV positive child becomes very ill, the school must take action to accommodate the illness including providing special assistance at the school or home teachers.

The Missouri State Board of Education has

issued Policy Guidelines to individual school districts. School districts are urged to regularly review their policies for dealing with communicable diseases for effectiveness and legality.

The recommended policy requires all school staff to routinely observe universal precautions to prevent exposure to disease causing organisms. Students or staff infected with bloodborne pathogens, such as hepatitis B or C or HIV are specifically allowed to attend school or perform their duties without any restrictions based solely on the infection. The district, under these guidelines, could not require any medical evaluation or test.

The guidelines provide that student and employee confidentiality rights must be strictly enforced and only those who determine fitness of a student to attend school and those who may need to know the identity of the child to provide health care would have a need to know.

Kansas law is silent on the question of the admission of HIV positive children to schools, but federal laws would be the same for both states.

In some situations you must first follow the administrative process provided by the local school board before asking a court to provide relief from a decision about how the student will be educated. You may also have an immediate right to take a handicap discrimination complaint into court and get an injunction to force the school district to comply with the law. Both the Rehabilitation Act and the Americans With Disabilities Act provide protection to you and your child against disability

discrimination. If you or your children are being discriminated against, you should consult a lawyer before making any decisions. Federal law provides that the school district may have to pay your attorney if you succeed.

■ C. Public Accommodation Discrimination

Another important effect the ADA has had is the broadening of protection to persons with disabilities in the area of public accommodations. Although Section 504 of the Rehabilitation Act prohibits discrimination on the basis of disability by recipients of federal funds (including most hospitals, nursing homes and other medical providers who received Medicaid or Medicare) the law is not well known and has been poorly enforced.

The ADA extends protection against disability discrimination to all places where the public is welcome including:

- hotels
- housing
- restaurants and bars
- entertainment establishments
- stores and rental service
- museums
- public transportation
- recreational facilities
- education facilities
- social service agencies

Service facilities would include insurance offices, funeral parlors, and health care providers. Day care centers, homeless shelters, substance abuse centers and health clubs must also provide service in a non-discriminatory manner.

You may not be denied an equal opportunity to participate in the goods or services offered by these establishments in the most integrated (or least segregated) setting which is appropriate. Examples of denial of equal access include the refusal of a nursing home bed to a person with HIV or the segregation of HIV patients in hospital, or to a particular chair in a dentist's office. The preferences of other consumers at the establishment do not justify difference in treatment. Legitimate safety concerns not based on stereotypes or generalizations may mean an individual could legally be excluded from a particular activity. For example, refusal of service by a health care provider might be appropriate if referral to a specialist is made. Failure of a health provider to treat a patient may in some instances rise to the level of medical malpractice. In these instances, you should seek assistance from an attorney as soon as possible as the time limit for filing a lawsuit is relatively short.

Insurance discrimination, another area where your HIV status may cause differences in treatment, is discussed in PART II, Employment and AIDS.

If you are treated differently by a place of public accommodation, you may file a complaint with the U.S. Attorney General, or you may personally file an action in federal court. At the state level, the Missouri Commission on Human Rights (MCHR), (816) 889-5100, and the Kansas Human Rights Commission, (785) 296-3206, accept complaints about disability discrimination by public facilities and will investigate your complaints. You must file your complaint within 180 days of the discriminatory act. In Missouri, if your

complaint has merit, the Commission may order the facility to cease the discriminatory action, pay actual damages, pay your attorney fees or require the offending place to pay a civil penalty. You may also have the right to bring a personal action in state court, but you must file a complaint with the MCHR first. The Kansas Human Rights Commission is authorized to conciliate the disagreement and if this fails, order the discriminatory practice to cease and award

damages for pain and suffering in an amount not to exceed \$2,000. Attorney's fees are not available.

You should also complain to state or local health departments about discriminatory or unprofessional treatment by health care providers. This may result in disciplinary action against the health care providers or, at the very least, educate the provider about the appropriate treatment of an HIV client.

Things to Consider:

Insurance and Estate Planning

■ A. Getting and Keeping Insurance

Anyone who needs health care today knows that even routine exams and medications can be very costly. For a person with AIDS or HIV positive, the recurring, lifetime expenses are very high. Since this expense would deplete most personal resources, the usual source of funds to cover these costs are private health insurance, employer-provided group health insurance and government health care programs such as Medicare and Medicaid.

Health, disability or life insurance may become difficult or impossible to obtain for persons who have AIDS, have tested HIV positive, or are in high risk groups. In some instances, insurers may legally deny you insurance on the basis that you have tested HIV positive or have an AIDS related medical condition. If you already have insurance, you should make every effort to maintain the insurance.

If you are HIV+ or think you may be, review your coverage for health, life and disability insurance and determine if it is sufficient to meet your needs. The following information may provide some guidance in your decision making process.

1. Obtaining Insurance

There are a limited number of ways to obtain health, life or disability insurance if you are a person with HIV/AIDS. Insurance companies may legally ask whether you have been positively diagnosed or if you

have been treated for AIDS or HIV infection so long as questions about other high risk medical conditions are also asked.

In Missouri, the insurer may require an HIV antibody test prior to insuring you only if your medical history suggests exposure to the virus.

However, it is against Kansas and Missouri law for an insurer to ask questions about your sexual orientation, or use your marital status, living arrangements, occupation, medical history, beneficiary designations, or the fact that you have sought AIDS counseling to deny you coverage or increase your insurance premiums. Both Kansas and Missouri require that counseling must be provided. You must be advised of the nature of the test and you must be administered a confirmatory test if the initial result is positive. If you agree to the test and it is positive, the information that you have a “non-specific blood abnormality” may be reported to the Medical Information Bureau (MIB) and all other insurers who are MIB members will then have access to the information. Most insurance applications ask you to give permission to release information to the MIB. Otherwise this information is strictly confidential and may not be released to anyone without your express written permission. You may wish to be anonymously tested prior to applying for insurance if you suspect you are positive. If the insurer requires a test, insist on having the test done where both pre-test and post-test counseling are available.

The insurer may legally deny you coverage if you advise them you are HIV positive or their test reveals that you are, unless you have had group health insurance (including Medicaid or Medicare) for 18 of the 20 months prior to an application for an individual policy. You must also be currently uninsured and have exhausted any COBRA benefits which were available to you to avoid denial of insurance.

If you do not meet these guidelines, and even though limited protections against discrimination on the basis of sexual orientation or lifestyle exist, you may want to take extra precautions. To protect yourself, shop carefully for an insurer, request information (anonymously, if you wish) on their HIV testing policy, their coverage for AIDS related medical conditions, etc. Ask your physician not to place unnecessary references to your lifestyle, sexual orientation, or requests for information about AIDS in your medical file.

One way to get private health insurance if you are currently uninsured is to try to get employment with an employer who has “open enrollment” insurance for new hires. Almost all group plans have “open enrollment” since the effective date of HIPAA in 1997. This means you will not be rejected for health insurance because of your HIV positive status. However, you may not be covered for pre-existing conditions, unless you have prior “creditable coverage” as defined by the Health Insurance Portability and Accountability Act (HIPAA). Medicaid and Medicare are counted in prior “creditable coverage” as is insurance under any other group plan. For each month of creditable

coverage you had prior to your new employment, the plan’s pre-existing condition exclusion will be reduced by one month so long as there was no break in coverage longer than 63 days.

Most health insurance plans cannot deny coverage for more than 12 months due to a pre-existing condition. Under HIPAA, insurers of group plans cannot impose any pre-existing condition exclusion for workers except in the case of medical conditions for which medical advice, diagnosis, care or treatment was recommended or received within the six-month period before your enrollment date — your first day of coverage or, if there is a waiting period, the first day of your waiting period.

If you are denied coverage for HIV related conditions under a “pre-existing condition” clause, seek legal assistance if you were not diagnosed as HIV positive or having a related condition at the time your insurance policy went into effect.

Other options may be available if you are unable to get health insurance. Medicaid or MediKan may be available if you have very low income or if you are unable to work because of your disability. These medical benefits are available on a much wider basis than previously. If you are uninsured, APPLY FOR MEDICAID benefits for yourself and your family. If denied, contact Legal Aid. You may check to see if high risk insurance is available as well (although the coverage may be poor and the premiums high). If you are a veteran, you may be eligible for treatment at your area Veterans Medical Center. Contact your Ryan White Case Manager or the Kansas City Missouri Health Department for other options for

your health care expenses.

Life insurance policies may be available on a “no questions asked basis”, but will have a low pay off or no benefit if the insured dies within two years. Contact an insurance broker to find out more.

Finally, do not try to obtain insurance by misrepresenting your medical condition or withholding information. Otherwise, when you make a claim on an HIV-related condition, the insurer may find out you were dishonest. Your insurance may be canceled just when you need it most. If your insurer returns your premiums and attempts to cancel your policy, seek legal advice or file a complaint as indicated below before cashing the check.

If you are denied insurance, if coverage is denied under an existing policy, or if your insurer is slow to pay your claims, you are entitled to know the true reason. First, ask for this information, then if you believe your rights under the law have been violated, you may file a complaint with the Missouri Division of Insurance, P. O. Box 690, 301 West High Street, Jefferson City, Missouri 65102, (314) 751-2640, or 615 E. 13th Street, Room 512, Kansas City, Missouri 64106, (816) 472-2381. In Kansas, file the complaint with the Department of Insurance, 420 S.W. 9th, Topeka, Kansas 66612, 1-800-432-2484. You may also take your complaint to an attorney as you may have a private cause of action against the insurance company.

2. Keeping Insurance You Already Have

An employer or insurance company cannot terminate your insurance solely because you have been diagnosed with AIDS or are HIV

positive. You are entitled to insurance like any other employee and should consult an attorney immediately if your employer or insurance company reduces or terminates your insurance. You should become familiar with your employer’s long and short-term disability programs because your health at times may make it difficult or impossible for you to continue working even with reasonable accommodation. However, you may have the option to maintain your employer sponsored insurance in the event your employment is voluntarily or involuntarily terminated.

a. COBRA

The Consolidated Omnibus Budget Reconciliation Act (COBRA) requires most employers to offer their employees and other beneficiaries (i.e., spouse and children) the opportunity to elect to continue insurance at their own cost upon termination of employment. The federal law does not apply to federal government or religious organization employers. Additionally, group health plans of employers having fewer than 20 employees are not covered by this law; however, you may have continuation coverage under state law for nine months in Missouri, six months in Kansas. You may also have conversion rights under state law. Most federal government employees have similar protection available under other federal laws. State law provides more limited coverage for some employees who are not covered by federal law.

Generally, if you are terminated from or quit your employment, you are entitled to COBRA benefits. However, if you are terminated for gross misconduct, you may not be eligible. Benefits under COBRA are

required to be identical to your former group health plan and/or identical to coverage provided to similarly situated employees who have not been terminated or quit. COBRA provides different lengths of coverage for different events. The length of time you are eligible for COBRA will depend on the reason your employment was terminated. If you quit your job or are terminated for other than gross misconduct, you will be eligible for 18 months of COBRA coverage. If you are “disabled” under Social Security guidelines at the time your employment terminates or any time during the first 60 days of continued coverage, the continuation period increases to 29 months. Consult with your employer or insurance administrator on the criteria for being judged disabled, however, these criteria are usually established by the Social Security Administration.

If the Social Security Administration determines that under their regulations you were disabled at the time you left your employment, you must notify your employer within 60 days of the Administration’s decision and within 18 months of your employment being terminated to be eligible for 29 months of COBRA coverage. The 29 months of coverage eliminates the 11 month gap between coverage by the employer’s insurance and Medicare coverage. Your spouse and dependents would be eligible for an additional 36 months after you become eligible for Medicare.

Under COBRA, employers may require that the terminated employee pay the entire premium (both employee and employer portions), plus 2%. In other words, you cannot be charged more than what the

employer pays to insure current employees other than the 2% administration fee. After the initial 18 month period, if you qualify for the additional 11 month disability period, the premium may be increased to the total premium plus 50%.

When you enroll in a group health plan you should receive information regarding your COBRA rights. Employers are also required to notify an employee of his COBRA rights within 30 days of the termination of his employment. In most cases, you need to decide whether to elect coverage under COBRA within 60 days of the end of your employment or within 60 days of the date that the COBRA notice is sent to you, whichever is later. There are some exceptions to the election period and notice requirements if you are mentally incapacitated.

You may be able to convert to an individual policy at the end of the continuation period, but usually at higher premiums and lower coverage. Again, if you want to convert the policy you must do so within a short period of time after the continuation period ends. Medicare coverage is not available until after 24 months of your entitlement to Social Security disability or 29 months from the onset of your disability. Medicaid coverage is available any time you are otherwise eligible.

Assistance with Medicare or private insurance premiums may be available, depending on where you live, your income and assets. Check with Division of Family Services in Missouri and Social & Rehabilitation Services in Kansas. Resources may also be accessed through a Ryan White case manager.

The most important factor in maintaining insurance is keeping up the premiums. Some policies may have waivers of premiums if the insured is disabled. Check your policy carefully for this benefit and submit proof of disability in a timely manner.

b. HIPAA

The importance of COBRA becomes even more clear when considered in light of the Health Insurance Portability and Accountability Act of 1996 (HIPAA). If at all possible, you do not want to break the chain of health insurance coverage. Even Medicaid and Medicare coverage will prevent you from losing your coverage under pre-existing condition clauses if you maintain insurance. When you return to work, this law provides that so long as you were insured by a group plan at least 18 months without a significant break in coverage, you must be accepted and usually no pre-existing condition exclusions will apply. This law is complex and you should discuss your coverage with the human resources person at your employment or consult an attorney if coverage is denied.

3. Coverage for AIDS

HIPAA provides that covered group plans may not deny you insurance or terminate your insurance because of your health status. Missouri law requires that most new or renewed insurance policies in effect since January 13, 1989 must cover HIV infection and AIDS in the same manner as any other serious medical condition. Kansas law provides that an insurer must not discriminate in the manner they underwrite and classify risks on the basis of disability but provides no specific protection for persons with AIDS or who are HIV positive.

One problem that some people are facing is capped benefits for AIDS treatment. For example, although the lifetime benefits an insurance company will pay for cancer treatment or other catastrophic illness may be \$1,000,000, that same insurance company may cap lifetime benefits for AIDS treatment at \$10,000. Although this practice was legal a few years ago, with the adoption of the Americans with Disabilities Act (ADA), the Equal Employment Opportunity Commission (EEOC) has been challenging caps as violations of the ADA. Although the EEOC's success has been limited, this is a quickly changing area of the law. If you find out your employer or insurance administrator caps AIDS benefits at a limit lower than other illnesses or catastrophic injuries consult with an attorney or notify the EEOC.

■ B. Legal Instruments

1. Health Care Declarations: Formerly Known as Living Wills

All people have the right to make decisions about their health care and medical treatment. Whether you take medication or not, have surgery or not, who provides your treatment and all other decisions about your health care are yours to make. Problems can arise, however, if you become unable to make or communicate these decisions. Your family and health care provider will not know what your end of life health care decisions would be — unless you tell them. The best way to make sure your wishes are followed is to discuss them with your family and friends and then put them in a written, legally enforceable document.

Although it is not necessary to have an attorney assist you with your health care

declaration, LAWMO's AIDS Legal Assistance Program can assist you.

You have the right to make decisions about your medical treatment. A *Health Care Declaration* (HCD) is a document in which you may advise health care professionals, family and friends about your wishes with regard to medical treatment or withholding medical treatment if you become unable to communicate your choices because of your physical or mental incapacity. These declarations become effective only if your condition is terminal (you are not expected to live much longer) and you are unable to give direction about your care. You may use this instrument to direct your physician to withhold life-prolonging procedures, which are defined as those which serve only to prolong artificially the dying process. Such procedures that you can request be withheld include, but are not limited to, surgery, heart-lung resuscitation (CPR), antibiotics, mechanical ventilation (respirator) or tube feedings (food and water delivered through a tube). Unless there is a serious reason, a physician must follow your wishes or refer your case to another physician if he or she is unwilling to follow your directions.

Think carefully before signing a Health Care Declaration and discuss it with your physician, family or friends so that your wishes are clear to those who may assist in treatment decisions if you become incapacitated.

Make sure a copy of your Health Care Declaration is placed in your medical file, with your physician and your hospital. You must sign the Health Care Declaration while you are of sound mind, so don't put

off making the declaration until you are seriously ill. The declaration might then be subject to challenge because of pain, suffering, or mental incompetency. You may make amendments at any time as long as you are mentally competent. A declaration may be revoked at any time after signing and only controls the decisions regarding your treatment if you are unable to express them.

The written declaration must be signed in the presence of two witnesses over the age of 18. To make the declaration stronger, it is recommended that the witnesses not be your health care providers, relatives, or beneficiaries under your will.

2. Durable Power of Attorney for Health Care

A health care declaration can be created in two separate parts: a *Health Care Treatment Declaration* (living will) and a *Durable Power of Attorney for Health Care Decisions*. These documents together allow you to communicate your health care treatment preferences when your decision making capacity is lost, and will provide complete legal protection of your wishes. All persons have a constitutional right to refuse medical treatment, including life-prolonging procedures, whether their condition is terminal or not (i.e., they are in a persistent vegetative state). An advance directive can be made effective even though you do not have a terminal illness by adding the Durable Power of Attorney for Health Care.

A Durable Power of Attorney for Health Care is similar to a regular Durable Power of Attorney in that you appoint someone now to make decisions for you after you have lost the capacity to make or

communicate your decisions. The one major difference is that the Durable Power of Attorney for Health Care Decisions is specifically limited to health care decisions. The person you appoint can make treatment decisions for you that are not covered in your Health Care Treatment Declaration — such as what to do if your condition is not terminal. The person may also be given authority to make decisions regarding the disposition of your body after your death, autopsy and organ donation. Organ donation by a person with an HIV positive status can only be made for purposes of medical research. If you elect to give someone Power of Attorney, your Health Care Declaration must be witnessed and notarized.

The Health Care Treatment Declaration and Durable Power of Attorney are effective even if you do not have a terminal illness so long as you appoint an attorney in fact to make decisions for you. It also permits you to direct the withholding of nutrition and hydration. You may state when to continue or discontinue life-prolonging treatment. In your directive you should describe what a “minimally acceptable quality of life” is for you. A short example would be “I do not want life support if I can no longer communicate, recognize people and make decisions for myself.”

For additional information regarding advance directives, call the Midwest Bioethics Center, (816)221-1100, or visit their web site at www.midbio.org, or consult with an attorney.

3. Durable Power of Attorney

Like the living will, a Durable Power of Attorney permits you to make decisions

while you are still of sound mind and body. Specifically, you may designate one or more persons to become your “attorney in fact.” You may direct that the person(s) become your “attorney in fact” at the time the document is signed, or only if you become incapacitated, or upon the occurrence of some other condition or event.

The “attorney in fact” is authorized to act as your agent in almost any matter except to change testamentary instruments such as wills, trusts, health care directives, etc. Most commonly, an attorney in fact would be given the power to take care of your financial affairs, health care, government benefits, insurance, etc. The powers granted may be very specific or very broad. For example, you may simply want to insure that a close friend has access to you in the hospital and can get medical information about you since hospitals typically release information only to close relatives. In other instances you may need someone who is able to take care of all your financial affairs, such as cashing checks and paying bills.

A Durable Power of Attorney must specifically state that it is not affected by your disability or incapacity or uncertainty as to whether you are alive or dead. Both Kansas and Missouri require that it be signed before a notary. At least one additional witness should sign. In Missouri, the document must be recorded with the Recorder of Deeds office in the county where the real estate is located, in cases where real estate may be affected. In Kansas the document may be recorded but doesn’t have to be. There is a filing fee which varies depending on the length of the document. The power of attorney may

only be revoked or modified by another legal document which in Missouri must be recorded, usually with the Recorder of Deeds office in the county where your principal residence is located. In Kansas, the revocation need not be filed at the Recorder of Deeds office but filing operates to put all others on notice of the revocation. In both Kansas and Missouri the attorney in fact and all others who have conducted business pursuant to the Durable Power of Attorney should be notified of its revocation in writing. The Durable Power of Attorney is automatically terminated at the time of the principal's death, but the attorney in fact may continue to act in good faith on the principal's behalf until notified of the death.

The attorney in fact must keep your property separate from his or hers, clearly indicate to each person he transacts business with that he or she is acting on your behalf, and must in good faith act in your best interest. Choose your "attorney in fact" very carefully as this person has great power over you and your property. This is a document which should not be signed without the advice of an attorney at law.

4. Last Will and Testament

A will is a legal document by which you can direct what happens to your property after your death. Depending upon the type and value of your assets it can be very simple or very complex, or you may decide a will is unnecessary if your assets are very limited.

Most people wonder whether or not they need a will. The following gives an abbreviated example of where your property will go in Missouri if you do not have a will:

- If you are survived by a spouse only, your spouse takes everything;
- If you are survived by a spouse, no children and one or both parents, \$20,000 plus 1/2 of your remaining property goes to your spouse, the other remaining half goes to your parents and siblings in equal parts;
- If you are survived by a spouse and children, \$20,000 plus one half of the remainder goes to your spouse and the remaining half goes to your children to share equally;
- If you are survived by children and no spouse, your children take everything to share equally; and
- If you are survived by parents and siblings only, parents and siblings take everything to share equally;

In Kansas, if you don't have a will your property will be generally distributed as follows:

- If you are survived by spouse only, your spouse takes everything;
- If you are survived by spouse and children, your spouse takes one-half and your children take one-half to share equally;
- If you are survived by children but no spouse, your children take everything to share equally;
- If you are survived only by parents and no spouse, children or grandchildren, parents take everything to share equally; and

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- If you are survived by siblings only, siblings take everything to share equally.

It is a good idea to have a will or some other plan of transferring your property to another upon your death. This is of particular importance if you do not want your property to go to an individual who would normally receive your property under the laws of Missouri or Kansas. If you are in a same gender relationship, neither Kansas nor Missouri law recognizes your partner as your spouse.

Another consideration is the fact that the cost of probating your estate through the courts may cost more than the value of your property. Although the will would be good evidence of who you want to receive your property and would be legally controlling, you should also take the time to communicate with your family, friends and loved ones. Let them know, in writing if necessary, who you want to have your possessions. This might smooth the way for an amicable settlement of your property. Also, be sure to read the “Self Help” section which follows.

Once you have decided that you need an estate plan or will you should consult with an attorney to make sure your plan is effective and binding. When you visit an attorney there are a few questions you should consider prior to that meeting:

- You must designate a personal representative and possibly an alternate personal representative. This is the person who will be in charge of administering your estate and making sure things are carried out to your

wishes. Although this person doesn't have to be a resident of the state where you live, it is preferred.

- Develop a list of your individual personal property (excluding money, securities, bank accounts and real estate) that you may want to give to friends, loved ones or family members. Missouri and Kansas allow for a list to be attached to a will that transfers individual personal items to specific individuals. An example would be giving a piece of jewelry to a friend. This list does not need to be prepared by an attorney and can be changed and updated at any time. However, consult with your attorney for the original form.
- Develop a list of your other personal property such as money, bank accounts, securities and real estate and decide whether you want to leave individual assets to individual persons or whether all beneficiaries are to “share and share alike.”
- Consider whether a specific person should have custody of your body.
- Consider whether there are persons that may need your monetary support in the future, such as a life partner, spouse or children, or someone such as a niece, nephew or friend.

After these considerations, make an appointment with an attorney to draft your Last Will and Testament and sign other documents to make your estate plan effective. To become effective, the will must be signed in the presence of a notary and at

least two witnesses, none of whom may be a beneficiary under the will.

Don't attempt to create your own will. Handwritten, unwitnessed wills or oral wills are not effective in Missouri and if your will is not properly executed, your property will be distributed under the intestate laws of your state, regardless of your intentions. Oral wills in Kansas are recognized, but only in very limited circumstances, so do not rely on this method.

5. Suggestions for Self Help

There are many things you can do on your own to make sure your affairs are in order. Some things to consider are:

- Put all your personal papers, including insurance papers, employee benefit handbook, bank, savings and credit records, real estate documents and car title in a safe place, and tell a trusted friend or relative where they are.
- You may want to add another person's name to your safe deposit box.
- You may also want to consider *Payable on Death* (POD) designations for bank and savings accounts. This means that upon your death, the bank will turn over all money in that account to the designated individual. This designation operates independently of a will. Consult your bank or an attorney before attempting such designation.
- A *Beneficiary Deed* or time of death transfer is an instrument which will transfer ownership of your home or other real property to another individual upon your death. Beneficiary Deeds are effective in Missouri and in Kansas. Their chief benefit is that ownership directions may be changed at any time prior to your death, but the property usually will pass automatically without probate. Consult with an attorney and your mortgage company for more information.
- You can also consider having your home or other real estate held jointly with the person whom you wish to receive this property upon your death. This option's drawbacks are that you need the other person's permission to change your mind or sell the property before your death.
- Consider a *Transfer on Death* (TOD) designation for your automobiles in Missouri. This document will transfer, upon your death, the title to your car to a designated individual. Again, consult an attorney before attempting such designation.
- Make sure your insurance policies list the beneficiary of your choice. An insurance beneficiary clause, if a beneficiary is effectively designated, operates to confer insurance benefits independently of a will. You can request change of beneficiary forms directly from your insurance company.
- If you have special possessions, a journal or private papers, make sure your wishes regarding them are well known.
- Make sure your physician knows who

to call in case of emergency, and give that person the names of others you want to notify.

- Give keys to your residence and automobile to a trusted friend or relative.

Planning ahead also makes it easier for friends and family to help out in emergency situations.

■ C. Viatical Insurance Settlements — Cashing in your Life Insurance

Persons living with HIV/AIDS may want to consider converting the proceeds from their life insurance policy into cash now in order to allow use of these funds for medical treatment and living expenses, or because the cost of the life insurance may be too expensive to maintain, or you wish to give cash to your heirs or a charity. Converting a life insurance policy to cash prior to death is accomplished by entering into a viatical settlement agreement with a company that will purchase the life insurance policy, and in return, give the policyholder a portion of the policy value in cash. Sometimes conversion occurs by contracting with a broker who will find a buyer for the life insurance policy. Since this process allows for use of the life insurance policy proceeds now, the policyholder would not be able to leave the proceeds of the policy to a family member, partner or friend at death. Thus, for those who provide financial support for other people (such as a child), the decision to enter into a viatical settlement agreement is one that should be carefully considered. For many others, however, a viatical

settlement can be a useful tool.

The watchword for anyone entering into a viatical settlement is “buyer beware.” Some viatical companies are reputable; others are not. Unfortunately, viatical companies are not regulated in most states. Kansas residents are afforded some protection under Kansas law. Here are some questions to ask when considering the use of viaticals.

First, ask how much a policyholder can expect to receive when entering into a viatical settlement. The National Association of Insurance Commissioners (NAIC) has standards for evaluation of cash payments. These standards are based on the policyholder’s life expectancy and suggest a minimum percentage of the life insurance policy value to be paid.

Policy Holder’s Life Expectancy	Minimum Suggested Percentage of Policy Value to be Paid
Less than 6 months	80%
Between 6 and 12 months	70%
Between 12 and 18 months	65%
Between 18 and 24 months	60%
Greater than 24 months	50%

Second, ask if the policyholder can rescind a viatical settlement within a reasonable period of time after entering into the contract. In Kansas, the law allows a policyholder to rescind a contract within 30 days of its execution. In Missouri, general contract law applies and rescission will be more difficult.

Third, ask how the payment will be disbursed. Ideally, the proceeds should be paid to an escrow or trust account at a bank

which is required to transfer those funds immediately to the policyholder when the life insurance policy is transferred. This is very important since some companies have delayed payment of the proceeds to the policyholder. An escrow account prevents this from happening.

Fourth, the NAIC suggests and Kansas law requires that the following be disclosed to potential policyholders entering into viatical settlements:

- possible alternatives including accelerated benefits offered by the issuer of the life insurance policy;
- possible tax consequences of entering into a viatical settlement; and
- possible adverse effect on the policyholder's eligibility to receive Medicaid or other public assistance.

Last, the policyholder should ask how and

to what extent he will be contacted by the purchaser for the purpose of determining health status after the agreement takes effect. The NAIC suggests that contacts by the viatical settlement company or broker be limited to once every three months for those with a life expectancy of more than one year and no more than monthly for those with a life expectancy of one year or less. The company or broker should explain the procedure for these contacts before the agreement is signed.

The consumer must be very careful when entering into a viatical settlement. Generally, it is a good idea to get at least five bids from prospective viatical companies and to have an attorney or an insurance expert review any proposed viatical settlement before entering into the contract. If the policyholder takes the time to ensure that the viatical settlement contains reasonable provisions affording some consumer protection, the viatical settlement can help make life much easier.

Immigrants

Most persons who apply for lawful immigrant status in the United States will be required to take an HIV antibody test by the Immigration and Naturalization Service (INS). If your test results are positive, in most situations your application will be denied. Waiver is available for HIV positive persons in some limited situations. You will need an attorney to apply for a waiver of your HIV positive status. It is strongly recommended that any potential applicant for immigrant status arrange to be tested anonymously prior to initiating any contact with INS. Take the test where both pre- and post- test counseling are available. Anonymous testing is available in Kansas City at the Free Health Clinic **(816) 753-5144**. Finally, see an attorney prior to initiating any contact with INS to find out whether or not you must be tested for the HIV antibody or to determine your eligibility for waiver if you have tested positive.

Some public benefit programs will not be available to immigrants depending on your immigrant status or the date you lawfully entered the United States. If you are denied assistance for SSI, general relief or general assistance, Medicaid, food stamps, housing assistance or temporary assistance to families or other benefits because of your immigrant status, contact an attorney immediately so the decision can be reviewed for accuracy.

If you are an undocumented immigrant, the only program you might be eligible for is temporary Medicaid. Do not apply for other kinds of public benefits, including food stamps, as you may be reported to Immigration and Naturalization Service (INS).

You may contact the Legal Aid office in your area to apply for assistance with immigration questions, or contact a private attorney.

Permanency Planning for Children

■ A. Introduction

Every parent wants to insure that their children are cared for in a safe and loving environment whether it be for a few hours, a day, a week or in the event of a parent's death or inability to care for the child, a permanent arrangement. If you are HIV positive and also a parent one of your responsibilities is to decide who is going to care for your children if you become unable to do so yourself. Careful planning and preparation will make the transition to a new or joint caregiver smoother for you and your children. This may be the most difficult decision you ever have to make. Counseling for you and your children may be available from a number of sources, so do not hesitate to ask for help. In Kansas City, the Permanency Planning Project is available as a source of information and referrals. Call (913) 722-2105 for assistance.

There are a number of different ways to give the caregiver you choose legal rights and responsibilities with regard to your children. These are listed below in order from the least binding (and least secure) to the most final - adoption. This information may help you make this difficult decision.

■ B. Choosing an Alternate Caregiver

Your first consideration must be the child's other biological parent. If that parent is available as a caregiver, then he or she is considered by law to be the child's "natural

guardian" and is entitled to custody unless abandonment, neglect, or unfitness can be shown; or unless his or her parental rights have been terminated or some other legal basis to deny custody can be proven.

If the biological parent is available and willing to care for the child, then usually little needs to be done to transfer custody upon your death. In some circumstances a will would help clarify your custody wishes and avoid conflict. If you are a single mother, were not married to the child's father and his name is not on the birth certificate, you should have the father's name added to the birth certificate.

You may do this for children born in Kansas City, Missouri at City Hall, Vital Statistics, 21st Floor, 414 E. 12th, Kansas City, Missouri, 64106. Both parents will need to go to City Hall and have identification with them. The child's birth certificate would also be helpful. Other cities will have their own vital statistics office and Jefferson City serves the State of Missouri.

In Kansas, amending a birth certificate requires that you first obtain a copy of the certified birth certificate from the Department of Vital Statistics in Topeka, (913) 236-1400, then call the clerk of the district court where you live, and tell the clerk what you would like to do. The clerk will schedule an appointment for the father and mother to appear in front of a district judge where form BS-211 will be completed. If all requirements are met, the judge would then order an amendment of the birth certificate.

If you do not want the other parent to have custody of the child or if the other parent is deceased or unable to care for the child, you need to choose someone to take the responsibility. Make sure the person you choose is willing to care for the child and is eligible to be a guardian. Also, if your child is 14 or older, the child's consent is an important element to consider in the choice.

If you have chosen a relative or friend who may already be caring for your children, you will need to legally formalize the arrangement at some point. Otherwise, the caregiver may be unable to get the child enrolled in a new school, give consent for medical treatment, or receive needed public benefits.

The Permanency Planning Project can assist you in locating a "second" family who is willing to adopt children of parents with terminal illness. If you are unable to choose a suitable guardian for your children and are interested in this option, call them for more information at (913) 722-2105. The Project is also available to assist you with social counseling, as well as advice regarding the legal aspects of a will, power of attorney, guardianship or adoption, if you have already chosen an alternative caregiver.

There are five (5) options for conferring custody of your children, with attendant rights and responsibilities, on an alternate caregiver:

1. Power of Attorney
2. Appointing a Guardian in a Will
3. Foster Care
4. Guardianship
5. Adoption

■ C. Your Options

1. Power of Attorney

If you anticipate periods of time when you will be hospitalized or too ill to care for your children for short periods of time, you may wish to give an alternate caregiver power of attorney over your children. This gives the caregiver custody of the children under conditions that you choose. The caregiver would also be legally authorized to consent to medical care for the children, provide for their education, and manage other responsibilities usually carried out by a parent.

This document is a good, quick temporary solution as it does not require you to go to court for approval to make it effective. You may also revoke it without court approval if the caregiver doesn't work out. It does nothing to change your public benefits as long as the children remain in your care the majority of the time. In order for this document to be valid in the event of your incapacity, it must state "This is a Durable Power of Attorney and its validity shall not terminate if I become disabled or incapacitated." You should be sure it restricts the caregiver's ability to make decisions you do not want the caregiver to make — for example, consent to the marriage or placement in foster care of your child.

In Missouri, the document granting power of attorney must be signed by you before a notary public and two (2) witnesses. It has to be renewed yearly in order to remain effective. In Kansas, the document must be signed before a notary or two witnesses and remains effective until your death, you revoke it, the child reaches 18 years of age,

or a court terminates the order. A Missouri Power of Attorney would also be ineffective if any of these events occurred. The chief disadvantage of the Power of Attorney is its temporary nature in Missouri and the fact that it does not provide for your children after your death. It also does not prevent your children's other natural parent from taking custody. A third problem is that some school districts will not recognize these documents as adequate to allow the child to enter school where the caregiver lives.

2. Appointing a Guardian in a Will

A will should be made only with the assistance of an attorney. A will is usually thought of as a legal document that allows you to direct who you want to have your property after your death. It can also be used to select the person you want the courts to name as the guardian of your children under the age of 18 after your death.

If you are not naming the other parent as guardian, you should be aware that the other parent has the right to be notified before the court can legally appoint anyone else as guardian. However, if you have the other parent's consent to appoint the chosen guardian and agreement to waive notice of the hearing, the guardianship may be approved without notice to the other parent.

The appointment of a guardian in a will does not give you a guarantee that your wishes will be followed by the court. After your death, your proposed guardian must petition the Probate Court to name him or her as guardian. The procedure is then very similar to the procedure for appointing a guardian during your lifetime (*see Section IV, page 43*). The court will usually try to follow your wishes but the overriding concern is

the children's best interest. In Kansas, the person nominated by the "natural guardian" has priority unless the child is 14 or older, then the child's nomination has priority. The interest of the other parent (if he or she appears in court) will also be considered unless it can be shown he or she abandoned or neglected the child or is an otherwise unfit guardian.

In order to assist the court in making its decision to name the guardian you have named in your will, you may prepare a written statement of the reasons you chose the guardian and the reasons you didn't choose the other parent or other interested caregiver. The statement should be signed and notarized and placed with the will. In some instances, you may wish to make the statement in the will.

This is a relatively quick way of expressing your choice of guardian and does not require a court appearance by you. You retain custody of your children, your public benefits remain the same, and you do not give another person any rights or responsibilities with respect to your children until after your death. Even if you aren't particularly ill and don't feel a guardian will be necessary, your children will be afforded some protection if something happens to you unexpectedly.

You should update your will periodically, at least every five years.

There are some problems with this choice. Probate proceedings can sometimes take several months. Your chosen caregiver may be unable to receive benefits for your children, enroll them in school or get medical care for them until the proceeding

is complete or temporary orders issued. Also, the other parent or another interested family member may seek custody of your child. If this is not what you want, you won't be there to argue for your choice.

3. Foster Care

This is an option that should be a last resort. If you ask to place your children in foster care you are admitting that you have lost the ability to take care of them to a state agency. This is rarely a desirable option and in most counties is not commonly done. Usually children are placed in foster care because they have been abandoned, neglected or abused, and the state agency takes the children from your home. To get them back, you have to prove to the state agency and a Court that you have regained the ability to care for the children, which may be difficult or impossible to do if you are very ill or have been unable to stay in contact with the children. You do not usually get to choose where your children will be placed. You will lose your children's public benefits.

In Missouri the Division of Family Services (DFS) administers the foster care system. The Kansas Department of Social and Rehabilitation Services (SRS) is the state agency in charge of administering the foster care system for children living in Kansas. The children may be placed by these agencies in either a group home or with a foster family. Foster families are often in short supply. The children may be separated. If a relative is willing to care for the children, DFS or SRS should give preference to an arrangement allowing the family to be the caregivers. A foster family or an approved relative foster family may be eligible for foster care payments. If you

have a family member who would care for your children and they are already in the custody of the state agency, you should let the agency know immediately.

If your children are placed in foster care, DFS or SRS has a good deal of control over your relationship with your children. DFS or SRS with court approval decides when and how often you can visit. Even if your children are placed with a relative, DFS or SRS may supervise the relative and the way the children are cared for. DFS or SRS decides where the children will live and may remove them from the relative's home if the agency decides another placement would be better and the court approves their decisions.

If possible, try to avoid foster care as first choice for the care of your children. DFS, SRS or other agencies may be able to provide you with in-home services that allow you to keep the children with you until an alternate caregiver is chosen and the arrangements for placement can be completed.

4. Guardianship During Your Lifetime

Once you have chosen a guardian for your children it may be an advantage to go ahead and transfer rights and responsibility for your child to the guardian you have chosen. You would still retain the ability to be with your children and direct their care so long as the guardian consents. The children may stay in your home as long as the guardian approves.

To start this process, the proposed guardian files a petition in probate court. If the other parent is alive and has not consented to the guardianship or has not waived notice of the guardianship hearing, he or she must be

given legal notice of the proceedings or the guardianship may not be permitted or may later be invalidated. If it is unknown where the other parent lives, notice may be given by publication in a newspaper.

Later, a court hearing will be held where the court will determine if the proposed guardian is qualified and will hear objections, if any, from other persons notified of the hearing —grandparents, aunts, uncles, brothers and sisters, nieces and nephews or whomever the court in its discretion may require. If possible, you should be present even if you have previously consented to the guardianship, particularly if someone is challenging the person you have selected. Your children should also be present. If they are over the age of 14, they will be asked to consent to the appointment of the guardian. **THE COURT HAS FINAL AUTHORITY TO DETERMINE THAT THE PROPOSED GUARDIANSHIP IS APPROPRIATE AND THE BEST INTEREST OF THE CHILD IS THE CONTROLLING FACTOR.** A guardian ad-litem may be appointed to insure that the child's interests are protected.

Once the guardian is appointed, the court will continue to informally oversee the guardian. Usually this means the guardian must file an annual report on how the children are doing. If the children have significant property or income, the guardian may also be appointed conservator of the children's property and an annual financial accounting will be required as well. In Kansas, the need for a guardianship and the effectiveness of the guardian are reviewed every three years. A guardianship automatically ends on the child's 18th birthday.

The only way to change the court appointed guardian without the guardian's consent is to go back into court and try to convince the judge that the guardian is unfit and failing to perform the obligations of a guardian appropriately. In Kansas, the court may decide that a guardian is no longer needed and remove the guardian. In very limited circumstances a parent may be able to regain custody if he or she can show that the circumstances which led to the consent to the guardianship have changed. Again, the best interest of the child will be the primary concern. This is a fairly permanent option, so be sure you choose a guardian whom you trust and who will continue to allow you to retain as much contact with and control of your children as is possible under the circumstances.

A guardian may receive public benefits such as Temporary Assistance (T.A.) for the child even if he or she is not a relative. The guardian's income and resources do not disqualify the child for benefits. Medicaid benefits are also available regardless of the income and resources of the guardian. The child will remain eligible to inherit from his or her parents and to receive Social Security benefits on the parent's account in the event of their death or disability. Only if the child's income (from Social Security, life insurance, etc.) is over guidelines for the receipt of these benefits, will the Medicaid, SSI and T.A. benefits be unavailable.

You will have the peace of mind of knowing that your children are in the hands of a person that you and your family choose. The guardianship will continue even in the event of your death. The legal guardian has full responsibility for making sure that your children are well cared for

until they reach the age of 18.

The disadvantage of guardianship is that if you are very ill and the court does not approve your choice of guardian, the court may appoint someone else guardian in order to protect the children. Also, although it is difficult, guardianships are subject to challenge and do not permanently terminate the rights of the other parent.

5. Adoption

Adoption means that someone other than the natural or biological parent of a child becomes its legal parent with all legal rights and responsibility for the child. The natural parents give up or lose all rights. This is a permanent arrangement and is not supervised by the court nor can the adoptive parents' relationship to the children be terminated except in the same manner as the rights of a natural parent are terminated.

The children are treated by the law as if they were born to the adoptive parents. Their birth certificates may be altered to show the adoptive parents as their parents. They can inherit from the adoptive parents and receive Social Security benefits on their account. In Kansas, the child may continue to inherit from the birth parent as well.

In order for an adoption to occur, the court will require a home study of the adoptive parent by a court appointed social worker. If the home study concludes the adoptive parent(s) are suitable, the court will usually approve, too. In Missouri, the law requires that the adoptive parents have actual legal custody of the children for at least six (6) months before the adoption can be

finalized. In Kansas, the time is much shorter.

Again, both biological parents' notification and consent will be necessary unless there is proof of abandonment or neglect, or other specific criteria are met. The child's consent is also an important factor in the approval of an adoption if the child is old enough, and is necessary if the child is 14 or older.

Adoption proceedings take place in court and you, your children and the adoptive parents will need to appear for a hearing. You will lose all rights to your children, their custody and their benefits as well. If your child is HIV positive or has other special needs and the adoption takes place through a state licensed child placement agency, the second family may be eligible for an adoption subsidy and the child may remain eligible for Medicaid regardless of the adoptive parents income and resources. These adoption subsidies must be negotiated with the state agency. This is very important because private insurers usually will not insure children who are HIV positive and their medical expenses may be very high.

Traditionally, adoption has meant that the birth parents were excluded from the children's lives. In recent years an arrangement called Open Adoption has evolved. The birth parents in this arrangement can continue seeing the children on a regular basis after the adoption. However, this arrangement is not well recognized in Missouri. Special counseling, both legal and social, are necessary for both families before this arrangement can be successful. The time and effort are worth it as the children and

all parents involved can be very sure that there is a new family in place to care for the children permanently.

Every legal issue has not been covered, most notably the issues facing those who become involved in the criminal justice system, but an attempt has been made to

address common civil legal problems.

The information provided is very general in nature and is not intended to address specific legal problems of an individual. Consult with an attorney, if at all possible when particular problems arise. The law is complex and changes in the law frequently occur.

SECTION VII

Conclusion

It is hoped that this information is helpful and provides some guidance about the legal issues and rights of persons who have AIDS or who are HIV positive.

Many of the laws discussed in this handbook provide for attorney fees to be

awarded in addition to other remedies. Private attorneys may be willing to represent you if this is the case. The Lawyer Referral number is **(816) 221-9472** for Missouri and you may also call your local Legal Aid office to see if you qualify for free legal assistance.

Appendix: *Resources*

The following resources are available to assist you with your legal needs:

American Civil Liberties Union

3601 Main Street

Kansas City, Missouri 64111

Tel: (816) 756-3113

- *Violations of Civil Liberties and/or constitutional rights*
- *No general legal services*
- *Services not contingent on income parameters*

Department of Health and Human Services Office of Civil Rights

601 East 12th Street, Room 248

Kansas City, Missouri 64106

Tel: (816) 426-7278

- *Accepts complaints of discrimination by health care providers to Medicaid and Medicare recipients who are residents of Missouri, Kansas, Nebraska and Iowa.*

Douglas County Legal Aid Society

University of Kansas · Green Hall

1535 West 15th Street

Lawrence, Kansas 66045

Tel: (785) 864-5564

- *Douglas County residents only*
- *Domestic, juvenile and municipal matters in Douglas County court*
- *Individuals must meet income requirements*

Equal Employment Opportunity Commission

Gateway Tower II

400 State Avenue, Suite 905

Kansas City, Kansas 66101

Tel: (913) 551-5655

- *Discrimination complaints - disability*

Johnson County Health Department

Mission Clinic

6000 Lamar

Mission, Kansas 66202

Tel: (913) 826-1200

- *Confidential and anonymous HIV testing*

Johnson County Health Department

Olathe Clinic

11875 South Sunset, Suite 300

Olathe, Kansas 66061

Tel: (913) 894-2525

Kansas City Free Health Clinic

2 East 39th Street

Kansas City, Missouri 64111

Tel: (816) 753-5144

- *Confidential and Anonymous HIV testing*
- *Legal services offered to HIV challenged persons and loved ones at the clinic the 2nd and 4th Mondays of each month*
- *Call for appointment.*
- *At present, no limit to types of questions*
- *Initial consultation is free. If additional legal consultation or services are needed and client is indigent and qualifies for legal aid, this attorney will follow through with the client. If client does not qualify for Legal Aid, he/she will be referred to an attorney who will charge on a sliding scale for further consultations.*

Kansas City, Missouri Health Department

2400 Troost

Kansas City, Missouri 64108

Tel: (816) 513-6008

- *Coordinates Ryan White Case Management for the Greater Kansas City area*

Kansas City Human Relations Department

City Hall · 4th Floor
414 East 12th Street
Kansas City, Missouri 64106
Tel: (816) 513-1836

- *Handles discrimination complaints due to disability and sexual orientation*

Kansas Human Rights Commission

Landon State Office Building
900 Jackson, Room 851 South
Topeka, Kansas 66612
Tel: (785) 296-3206

- *Accepts and investigates complaints about discrimination in Kansas on the basis of race, religion, sex, disability, national origin or ancestry in employment, housing and public accommodation.*
- *No general legal services*

Kansas Insurance Department

Toll Free Tel: 1-800-432-2484

Kansas Legal Services

707 Minnesota Avenue, Suite 600
Kansas City, Kansas 66101
Tel: (913) 621-0200

- *Serves residents of Johnson, Wyandotte, Miami, Franklin and Linn counties*
- *Civil matters*
- *Spanish speaking personnel*
- *Must meet federal poverty guidelines*

Legal Aid of Western Missouri

1125 Grand Avenue, Suite 1900
Kansas City, Missouri 64106
Tel: (816) 474-6750

- *Missouri residents of Clay, Platte and Jackson Counties only. Residents of other western Missouri counties will be referred to the appropriate office.*
- *Spanish speaking personnel - West Office (816) 474-9868*
- *General legal services*
- *Individual must be indigent and/or meet income requirements*

Missouri Commission on Human Rights

4049 Pennsylvania Avenue, Suite 150
Kansas City, Missouri 64111
Tel: (816) 889-5100

- *Accepts and investigates complaints of discrimination on the basis of race, religion, sex, disability and national origin in employment, housing and public accommodation.*
- *No general legal services*

Missouri Division of Employment Security

Regional Telephone Claims Center
P.O. Box 149122
Kansas City, Missouri 64141-6122
Tel: (816) 889-3101
Fax: (816) 889-3060

- *Accepts applications for unemployment benefits*

Missouri Division of Insurance

615 East 13th Street, Suite 510
Kansas City, Missouri 64106
Tel: (816) 889-2381

- *Handles only complaints of Missouri residents and non-residents who are insured in Missouri*
- *No income guidelines*
- *Legal aspects of insurance, denial of insurance and how to read a policy.*

SAVE, Inc.

P.O. Box 45301
Kansas City, Missouri 64171-8301
Tel: (816) 531-8340

- *Provides housing assistance for persons with HIV/AIDS*

U.S. Department of Housing and Urban Development (HUD)

Toll Free Tel: 1-800-347-3735

Wyandotte County Health Department

619 Ann Avenue, Room 104
Kansas City, Kansas 66101
Tel: (913) 321-4803

- *Confidential and anonymous HIV testing.*

Handbook made possible by:

