

NEW YORK STATE BAR ASSOCIATION

# HIV/AIDS and the Law



## Introduction

AIDS (Acquired Immune Deficiency Syndrome) is an infectious disease caused by a virus, HIV (Human Immunodeficiency Virus). The virus damages the immune system, the part of the body that fights infections and other illnesses. HIV may be transmitted by all forms of sexual intercourse without barrier protection, by exposure to blood, blood products or certain other body fluids (such as semen, vaginal fluid and breast milk), by sharing needles (as in intravenous drug use) or when there is a traumatic injury from a source contaminated with the virus (such as a needle stick injury with a used needle from a person with HIV infection). To date, after more than 19 years of studying the transmission of HIV, casual everyday contact with a person infected with HIV has not been shown to transmit the virus.

This pamphlet is intended to advise you of your rights and to provide you with some general information and resources specifically related to issues that affect individuals with HIV or AIDS, or those who are perceived to have HIV or AIDS (or in some circumstances, those who associate with those having HIV or AIDS) who may have been discriminated against in the workplace. Although this information is current as of the date of this publication, it is subject to change as a result of court decisions, legislation and medical research. It is recommended that you seek up-to-date information from your attorney or any other resources listed at the back of this pamphlet. Please keep in mind that many of the statutes discussed require the filing of complaints with administrative agencies to preserve your rights. It is imperative that you consult with an attorney if you believe you have been discriminated against.

## Testing

There are several tests for the antibodies to HIV in the blood. A “positive” screening test may mean that the person’s blood shows evidence of antibodies to HIV, which are created by the person’s immune system reacting to the presence of HIV in the blood. A positive screening test must be confirmed by a second more specific test on the same blood sample to ensure that a false positive has not occurred. A person who tests positive for HIV is considered to be infectious and can transmit the virus to others.

In New York State, tests for HIV can normally be performed on you only if you have given written informed consent. You must be counseled before

and after testing so that you understand not only the disease, but also the potential ramifications of having the disease and/or a positive HIV test, or negative test results (such as, the window period in which positive HIV status may not be indicated), and risk reduction counseling.

Anyone, without regard to age, can consent to a test so long as the person understands the test and its consequences and has the ability to make an informed decision to consent. Sometimes consent may also be obtained from an individual who by law is permitted to give consent for you, such as a legal guardian.

A home testing kit for HIV is now available in New York State. However, for reliability, the blood sample must be sent to a reputable laboratory. You should talk with your physician to see which is the best testing method for you.

### Confidentiality

The law in New York creates substantial protection for you if you test positive for HIV, have AIDS or an HIV-related condition.

You are entitled to your own HIV-related information at any time. Your written specific consent is required before HIV-related information can be released to other persons or employers. Certain persons may obtain this information without your written consent. They are:

- (a) A person authorized by law who consented to the test for you;
- (b) A health care facility (such as a hospital, blood bank or laboratory) or a health care provider (such as a physician, nurse or mental health counselor) giving care to you or your infected child, and anyone working for such a facility or provider who reasonably needs the information to supervise, monitor or administer a health service;
- (c) Select government agencies involved in health, social services, and corrections;
- (d) Insurance companies and other third party payers, such as Medicaid, if necessary for the payment for services to you.

New York State criminal procedure law permits the court to compel HIV-related testing of persons convicted of certain sex crimes when sexual intercourse is an element of the felony charge if the victim requests such testing. Release of these test

results to the victims of the convicted individual also is required. HIV-related testing also may be compelled in certain circumstances when an individual plea bargains to a lesser felony for a sex crime. Even though intercourse was not an essential element of the felony crime to which the individual pleaded guilty, testing may be compelled when the defendant admitted to having unprotected sex with the victim and that act was an essential element of the charges that were later dropped in the plea bargaining process.

In addition, the information may be disclosed to any person to whom a court order is granted, under the procedures and the limited circumstances provided by law. Except in an emergency, advance notice and an opportunity to oppose the release of such information will be given to you.

Any HIV-related information which is sent to others must contain a statement prohibiting the receiving party from redisclosing this information to any other party without your specific written authorization.

A list of the persons or agencies to whom confidential HIV information has been released must be noted in your medical record. Upon request, you must be informed of the parties to whom the information has been disclosed.

### **Names Reporting and Contact Tracing**

Legislation enacted in 1998 requires health care providers and professionals to report the names of all individuals diagnosed with HIV, AIDS or an HIV-related illness. Each time a physician or laboratory determines that an individual has HIV infection, HIV-related illness or AIDS, the identity of the diagnosed individual must be reported. It's important to note that anonymous testing remains available within New York, and anyone about to undergo HIV testing must be advised that the HIV test can be undertaken on an anonymous basis. An individual who undergoes anonymous testing will not have his/her name reported in any fashion. This reporting is to the Department of Health and the County Health Officer. In addition, the law requires county health officers and physicians to identify contacts of any individual diagnosed with HIV infection, HIV-related illness or AIDS. Contacts must be advised that they may have been exposed to HIV. The stated purpose of the names reporting and contact tracing is to impede the spread of HIV infection by encour-

aging behavior modification by those infected with HIV and their contacts.

### Insurance Companies

A life insurer may test applicants for HIV antibodies and may reject those who are infected. In addition, under current law, your refusal to take a test may result in your not getting life insurance coverage. You must be advised about the test, its purpose, that a positive test indicates that you may develop AIDS in the future, and that you should consider further independent testing for confirmation of results. You are also entitled to be notified if an insurer rejects your application or offers to provide insurance at higher than standard rates, in whole or in part, due to results of an HIV antibody test. Providers of life, health and disability insurance may not test any specific population identified in a discriminatory manner, such as by marital status, lifestyle or zip code.

A health insurer or a health maintenance organization (HMO) may not test applicants for the presence of HIV antibodies or ask any medical questions of persons who apply for individual coverage or who are in small groups (50 or less). However, there may be a waiting period before coverage begins for pre-existing conditions. Health insurers may test applicants in larger groups. If you are currently covered by a health insurer and seek to change insurance companies, you should consider such a change with great care and consult an insurance expert if you are HIV-positive because the new policy may not cover pre-existing conditions for a period of time. If you are rejected, you may wish to contact the New York State Department of Insurance or its AIDS Hotline for information regarding possible alternatives.

Many self-insured employer health plans are governed by federal law and thus are not governed by the strict protection of this state. Therefore, state protection may not apply to you in terms of coverage, caps and premium changes.

### Housing

Persons living with HIV or AIDS may face discrimination in obtaining housing. Federal and state laws and municipal and city ordinances and regulations bar discrimination against persons with disabilities, including persons with HIV or AIDS, in the sale or rental of dwellings. An “aggrieved person” may

file a complaint with a federal, state or local administrative agency or commence a court action.

Under certain circumstances, nonmarital partners or nontraditional family members may have succession rights to apartments after the death of the prime tenant. A lawyer or legal services provider on HIV-related matters can advise you on this topic.

As a result of the burdensome cost of medical care and the loss of employment income, affording adequate and appropriate housing has become a major problem for many persons with HIV or AIDS. Depending on your income and financial resources, you may be eligible for government rent subsidies from the New York City Division of AIDS Services (for New York City residents) or the Public Assistance program administered by your county of residence. Contact these agencies for information on eligibility. In addition, if you are living on a fixed income, a number of nonprofit organizations have created supported housing programs and independent living facilities with supplementary medical and social services.

### Home Care

An overwhelming burden of AIDS or HIV-related illnesses can be the cost of home care. Without home care, many may be unable to remain in their homes, yet home care costs can be prohibitive. The Medicaid program is available to meet these needs for those without private insurance or sufficient resources. Medicaid, the public assistance program administered by county social services departments, pays the medical expenses of those eligible for its coverage and has an extensive home care component which can range from part-time help a few hours a week, to registered nurses around the clock. The Department of Social Services is required to provide Medicaid applicants with the range of services available through Medicaid. There are several levels of care for which a person may qualify, and the applicant may need to ask for a full explanation of benefits available. For those without private insurance who are not eligible for Medicaid, there are "ADAP" and "ADAP-Plus" (AIDS Drug Assistance Programs) which cover primary care to some degree.

### HIV/AIDS in the Workplace

Employees or job applicants who are infected with HIV or who are perceived as being infected with HIV are protected under federal and state law

and municipal and city ordinances and regulations from acts of employment discrimination on the basis of their actual or perceived HIV infection.

Federal Law.

### 1. Rehabilitation Act of 1973.

Section 504 of the Rehabilitation Act of 1973 (29 U.S.C. §§ 793-794) prohibits discrimination based on disability in the areas of employment and the provision of services or benefits by any program or activity of an entity receiving federal financial assistance. This section provides, in part, that no "otherwise qualified" handicapped individual shall be excluded from participation in or be denied the benefits of any such program or activity. Equal Employment Opportunity Commission (EEOC) regulations define an "otherwise qualified" person with a handicap as one who, with or without reasonable accommodation, can perform the essential functions of the job without endangering the health and safety of himself or herself, or others. A "reasonable" accommodation is one which does not place an undue hardship on the employer. The courts have held that having AIDS or being HIV-positive, as well as the perception of being HIV-positive, are all considered handicaps for the purpose of protection under this statute.

### 2. Americans with Disabilities Act.

The Americans with Disabilities Act (ADA) was signed into law by President Bush on July 26, 1990. The ADA sets a national mandate and provides uniform standards for addressing discrimination against people with disabilities in a number of areas: private employment, public services, telecommunications and public accommodations. The law has been drafted as a complement to the Rehabilitation Act and incorporates many of the same definitions and standards. Like the Rehabilitation Act, the ADA defines a disabled individual as "a person with a physical or mental impairment that substantially limits one or more major life activities, a person with a record of such impairment, or a person perceived to have such an impairment." The significance of the ADA is that, unlike the Rehabilitation Act, its coverage is not limited to federal contractors or recipients of federal financial assistance. Instead, all employers with 25 or more employees were included within the ADA's coverage as of July 26, 1992; on July 26, 1994, coverage was extended to employers with 15 or more employees. HIV-infected individuals are covered by the ADA in the same manner that they have been covered by the Rehabilitation Act. Under the

ADA, a “qualified individual with a disability” is defined as an individual who “with or without reasonable accommodation, can perform the essential functions of the employment position.” The ADA also extends protections to persons without disabilities if they have a known relationship or association with a person with a disability. A charge of discrimination must be filed with the EEOC to preserve your right to sue. The EEOC will investigate your complaint at no cost to you.

### 3. Family Medical Leave Act.

On February 5, 1993, President Clinton signed into law the Family Medical Leave Act (FMLA). Generally, the law guarantees eligible employees the right to take unpaid leave from a job for family or medical reasons. The Act took effect on August 5, 1993 and affects private employers who, within a 75-mile radius of the employer’s work site, employ 50 or more persons for each working day, for each of 20 or more calendar work weeks in the current or preceding calendar year. The Act requires covered employers to provide eligible employees with an unpaid leave of up to 12 weeks in any 12 month period for a variety of health related reasons, including the birth or adoption of a son or daughter, or the care of a son, daughter, spouse or parent of the employee with a serious health condition, or because of a serious health condition of the employee which prevents the employee from performing the functions of his or her position. There appears to be little doubt that someone with HIV will have a serious health condition as defined by the Act.

An eligible employee must have been employed by the employer for at least 12 months and for at least 1,250 hours during the prior 12 month period. The law does not require paid family or health leave. Leave may consist of paid leave, but the discretion to provide paid leave is left to the employer. Moreover, an employer can require that any leave based on a serious health condition of the employee or of the employee’s family be supported by certification by a health care provider. An eligible employee who takes leave is generally entitled to be restored to his or her old job or to an equivalent position with equivalent pay and benefits. Employment benefits which may have accrued to the employee prior to the date of leave cannot be lost or taken from the employee.

### 4. Occupational Safety and Health Act.

In 1991 the Occupational Safety and Health

Administration (OSHA) published the final rule on occupational exposure to bloodborne pathogens in order to improve “occupational safety” in the care of patients infected with bloodborne pathogens (for example, HIV, Hepatitis B and Hepatitis C). It also prohibits the discipline or discharge of an employee who refuses to work because of a reasonable fear of immediate serious injury.

Under OSHA, employees face significant health risk as a result of occupational exposure to blood and other potentially infectious body materials because those materials may contain bloodborne pathogens such as HIV or Hepatitis B. Employers are required by OSHA to develop an Exposure Control Plan specific to the workplace. The Exposure Control Plan is a guiding document to direct the specifics of the incorporation of the bloodborne pathogen standard and outlines policies and procedures related to bloodborne pathogen control within the workplace. The Exposure Control Plan delineates, but is not limited to, universal precautions, engineering and work practice controls, personal protective equipment, housekeeping and waste removal procedures, Hepatitis B vaccination, post-exposure evaluation and follow up, and employee training and record keeping requirements. All employers were required to be in full compliance with the standards by July 6, 1992. Employers failing to adhere to OSHA standards are subject to substantial fines and other sanctions.

#### 5. Employee Retirement Income Security Act.

HIV-infected patients can face staggering medical costs while combating the effects of their illness. The potential impact of these costs on insurance rates has led employers to question whether an HIV infected employee may be denied insurance coverage or simply terminated in an effort to avoid these additional costs.

The Employee Retirement Income Security Act (“ERISA”), 29 U.S.C. § 510, prohibits an employer from taking action against an employee which is designed to deprive him or her of benefits under ERISA protected plans. Inasmuch as health insurance is clearly an ERISA benefit, any attempt to deprive an individual of a health insurance benefit because of the cost associated with his or her illness is unlawful. However, difficulties can arise when a health plan decides not to cover an illness, specifically AIDS, at a stated point in time. The question of whether those with HIV can be denied health insur-

ance coverage is currently being litigated in the courts. Under current circumstances, it is unlikely that ERISA will provide protection; however, such protection may be offered by the Americans with Disabilities Act. It is recommended that you consult with an attorney if you have questions relating to retaining benefits under ERISA.

#### 6. Title VII of the Civil Rights Act of 1964.

Title VII prohibits discrimination in employment on the basis of sex, religion, national origin, race and color. Acts or practices which disproportionately affect persons in these protected categories, as well as intentional acts of discrimination directed at these protected groups, are prohibited. Title VII has not yet been interpreted so as to provide protection to employees or prospective employees suffering from, or perceived susceptible to, HIV infection. Nonetheless, a blanket policy aimed at excluding from employment those infected with HIV, while neutral on its face, could impact disproportionately on certain categories of individuals, including, for example, homosexual men, people of color and certain nationalities. Consequently, a claim under a disparate impact theory might be stated against such a policy to the extent any of these three groups constitute a protected class. Title VII extends only to race, gender and national origin discrimination and is inapplicable to sexual orientation discrimination.

#### B. State Law.

##### 1. New York Executive Law.

Similar to the Rehabilitation Act and the Americans with Disabilities Act, Section 296 of the New York Executive Law prohibits covered employers and other entities from discriminating against individuals on the basis of "disability." A disability is defined as "a physical, mental or medical impairment resulting from anatomical, physiological or neurological conditions which prevents the exercise of a normal bodily function or is demonstrable by medically accepted clinical or laboratory diagnostic techniques, provided, however, that in dealing with employment, the term shall be limited to physical, mental or medical conditions which do not prevent the complainant from performing in a reasonable manner the activities involved in the job or occupation sought." HIV infection has been judicially recognized in New York as a disability. Section 29(1)(6) of the New York Executive Law, like the Rehabilitation Act of 1973 and the Americans with Disabilities Act,

requires that the employer provide a reasonable accommodation (effective January 1, 1998).

If you believe you have been discriminated against due to HIV status, you may wish to contact the New York State Division of Human Rights. Regional phone numbers are listed in the Resource section at the back of this pamphlet. The Division of Human Rights does not charge a fee for its services.

### 2. Unprofessional Conduct and Licensure Issues - Health Care Professionals.

Under New York State law, health care professionals licensed by the State Education Department may be subject to unprofessional conduct proceedings and may have their professional licenses suspended, limited or revoked for failing to observe infection control techniques in the practice of their profession. Included among those who are subject to professional sanctions are physicians, nurses, dentists, physical therapists, respiratory therapists and physician's assistants. The State licensure provisions are intended to protect patients from infection and protect employees from exposure to infection. State licensure renewal requires documented training in the following: the responsibility to adhere to accepted principles and practices of infection control; monitoring the infection control practices of those for whom the professional is responsible; strategies for prevention and control of transmission of disease-causing organisms; use of engineering and work practice controls; selection and use of barriers and/or personal protective equipment; principles and practices for disinfection and sterilization; and prevention and control of infectious and communicable diseases in health care workers. State public policy dictates that employees who follow proper infection control procedures and adhere to universal precautions may, in most instances, continue to work virtually without regard to their own HIV status.

### C. Other Laws.

#### 1. Administrative Code of the City of New York.

Section 8-107 of the Administrative Code of the City of New York follows New York State Executive Law Section 296 and makes it unlawful to discriminate against any person with a disability, including those with HIV infection. This law also protects from retaliation those who report such discrimination, file claims to recover losses, or testify against the parties violating these laws. As is the case under the New York Executive Law, if you believe you

have been discriminated against due to HIV status, the New York City Commission on Human Rights can determine whether your rights have been violated. Refer to the Resources section of this pamphlet to obtain the phone number. The New York City Commission on Human Rights does not charge a fee for its services.

### 2. Contractual Rights.

An HIV infected worker covered by a collective bargaining agreement may also find protection from unwarranted dismissal or other adverse employment actions through the arbitration process typically found in those labor agreements. At least one arbitrator has ruled that HIV infection is not, by itself, sufficient basis for terminating an employee under a contractual “just cause” provision if the employee is otherwise physically capable of performing his job. Such a termination would also be a violation of the Americans with Disabilities Act.

## Returning To Work

Based on current medical advances many individuals with HIV-related illnesses are now able to return to work. When one returns to work after an extended absence due to illness, concerns necessarily arise regarding the potential loss of government and private disability benefits. The primary government benefits provided by the Social Security Administration (SSA) to people who have HIV or AIDS include Social Security Disability Income (SSDI) and Supplemental Security Income (SSI). SSDI is provided to people who have worked and paid Social Security taxes over a period of time, while SSI is a means-based entitlement, provided to people without a substantial work history.

The SSA has a number of special rules, called “work incentives,” that provide cash benefits and continued Medicare and Medicaid coverage. These incentives are particularly important to people with HIV disease who, because of the recurrent nature of an HIV-related illness, may be able to return to work following periods of disability.

The rules differ for SSDI and SSI. For people receiving SSDI, the benefits include a nine-month “trial work period” during which earnings, no matter how much, will not affect benefit payments, and a three-year guarantee that, if benefits have stopped because a person remains employed after the trial work period, a Social Security check will be paid for

any month's earnings below the "substantial" level (usually around \$500). Additionally, Medicare coverage extends through the three-year time frame after the trial work period, even if an individual's earnings are substantial.

SSI work incentives include continuation of Medicaid coverage even if earnings are too high for SSI payments to be made, help with setting up a "plan to achieve self-support" (PASS), and special consideration for pay received in a sheltered workshop so that SSI benefits may continue even though the earnings might normally prevent payment.

Many individuals also may be covered by long-term disability (LTD) insurance plans. Whether one receives benefits under a group or individual LTD plan, it is important to carefully read the summary plan description in order to understand the effects of returning to work. Many plans no longer pay any benefits when one returns to work, while some plans offer a partial or residual benefit.

Since individual financial circumstances, covered disability and insurance plans, prior work history, and benefit eligibility may radically differ, it is strongly encouraged that you speak with the Social Security Administration regarding the impact of government-sponsored benefits and healthcare upon your return to work, and consult an attorney regarding the effect that your return to work will have on your private disability insurance.

In December, 1999, the Ticket to Work and Work Incentives Improvement Act of 1999 was enacted into Federal law, and is intended to provide Social Security Disability recipients who want to return to work with greater access to rehabilitation services and public health care benefits (including extensions of Medicare coverage). Most of the provisions of the new law will not take effect until late 2000 or 2001. The Social Security Administration has prepared several summaries and a question and answer document concerning the new law, which are available on its Web site, <http://www.ssa.gov>.

### Other Discrimination

New York State law and New York City regulations make it illegal to discriminate against any disabled person, including individuals with HIV infection. You may not be discriminated against in your job, housing, places of public accommodation such as restaurants and theaters, applications for loans or credit, medical, legal and dental services, and other

personal services available to the general public.

If you believe you have been the victim of discrimination due to HIV status, you may wish to contact the Equal Employment Opportunity Commission, the New York State Division of Human Rights, the New York City Commission on Human Rights, or a private attorney to determine whether your rights have been violated. Please be advised that the statute of limitations for filing this type of claim is extremely short. It commences from when you know or should have known that you have been discriminated against. Accordingly, it is imperative that you contact one of the above-referenced agencies or a private attorney immediately. Neither the Equal Employment Opportunity Commission, Division of Human Rights, nor the Commission on Human Rights charges a fee for its services, and all of these agencies can investigate your complaint.

### Childbearing

A fetus may become infected with HIV during pregnancy or childbirth if his or her mother is HIV-positive. All infants born to HIV-positive mothers test positive at birth, yet only about 20 percent of those infants are actually HIV-infected. This is because the initial test only indicates the mother's HIV status, not that of the newborn. Most infants will revert to HIV-negative status once their own immune systems develop. It is also possible for an infant to become infected with HIV after birth if no intervention prevents an HIV-infected mother from breast feeding her child.

In order to help infants who are, or may become actually HIV-infected, either prenatally or postnatally, the New York Legislature in June 1996, added HIV to the list of conditions for which newborns are automatically screened. Thus, mandatory HIV testing of all newborns was instituted. When a newborn tests HIV-positive it means the mother is definitely HIV-positive. It is hoped that when mothers are informed of HIV-positive results, they will take positive steps to prevent transmission of infection through breast feeding and seek medical care for themselves. Mandatory testing of newborns, however, does not address the issue of preventing HIV infection prenatally. Study results show that treating HIV-positive pregnant women with anti-retroviral medication (such as AZT or nevirapine) during pregnancy substantially reduces the risk that their infants will be born infected. Thus, it is extremely important

that women who are pregnant or considering pregnancy receive counseling concerning the benefits of voluntary HIV testing, and they should request HIV testing as early as possible.

### **Vertical (Mother-Baby) Transmission of HIV**

More recently, the use of combination anti-retroviral therapy has become the standard care for people with HIV/AIDS. It is now accepted that pregnant women should take this combination therapy during pregnancy, rather than AZT alone.

Other advances in prevention of mother-baby transmission include studies that show the benefits of nevirapine, an anti-retroviral drug from the class of non-nucleoside reverse transcriptase inhibitor drugs. A single dose of nevirapine administered to a mother and her infant is at least as effective or better at preventing vertical transmission of HIV. In one study, the estimated risks of HIV-1 transmission were: 10.4 percent and 8.2 percent, in the zidovudine (AZT) and nevirapine groups, respectively, at birth. When breast-feeding is done, 13.1 percent of the infants given nevirapine had HIV at 14 to 16 weeks, versus 25 percent of the infants who received AZT.

Nevirapine is administered to mothers at the start of labor and to infants within three days of birth, while zidovudine is administered every three hours during labor and over the first week of the infant's life.

Moreover, nevirapine is significantly cheaper—at \$4 per dose for both mother and infant—than the multiple-dose regimen of zidovudine (AZT), making this regimen more widely applicable in developing or other resource-poor countries.

Elective cesarian section at 36 weeks has also been shown to reduce the risk of HIV transmission from mother to baby by 50% compared to spontaneous vaginal delivery. This option is now recommended by the American College of Obstetrics and Gynecology.

Earlier diagnosis of HIV-infection in children born to HIV-positive mothers is now possible. The HIV-DNA assay uses the polymerase chain reaction (PCR) method. This test can determine the HIV status of the infant and distinguish it from the mother's HIV antibody, allowing the diagnosis of HIV infection in the infant to be made at birth.

Another promising area of research investigation involves sperm washing techniques for males who

are HIV-infected. Sperm washing separates sperm from the surrounding fluid, in which most of the virus is believed to reside, and the sperm is then used to fertilize the egg, using in vitro fertilization techniques.

### Parenting

HIV-infected parents of minor children and single parents in particular may want to make advance arrangements for the care of their children. Section 1726 of the Surrogate's Court Procedure Act (SCPA) allows a person who is at risk of becoming incapacitated or of dying to petition the court for a "standby guardian" whose authority commences upon the parent's death or incapacity. This section allows the parent to name the guardian of his or her choice through either a court proceeding or a witnessed, written designation method. The guardianship does not terminate parental rights or custody. If a parent changes his or her mind about the choice of a guardian, he or she can revoke the designation. It is hoped that this law will permit improved stability for the children facing the loss of their parents while it enables parents to feel secure that their children will be cared for by the individual(s) they choose. The law was written to be "user friendly" and takes into consideration the limitations imposed on a parent by an incapacitating illness. Legal assistance is needed to establish the standby guardianship.

### Matrimonial

In New York State, no court has held that a divorce may be granted merely because one of the parties is HIV-positive or has AIDS. In addition, except for extreme or "shocking" conduct, marital misconduct is generally not relevant to property division in divorce. Fault, however, may have some limited bearing on the issues of maintenance and support. There are no court decisions that have directly addressed the issues of HIV/AIDS status in determining fault. Concerning custody and visitation, the traditional custody standard of "best interest of the child" governs. There are no court decisions denying custody, specifically because of HIV/AIDS status. The courts have specifically permitted visitation by parents with AIDS. State law permits the disclosure of HIV-related information to a law guardian appointed by the court to represent a minor.

### Planning for Your Future - Health Care Proxies

If you have AIDS or are HIV-positive, it is also important that, if such a person is available and willing to serve, you designate as your health care agent a trusted friend or family member with whom you have discussed your health care wishes. Your health care agent can make health care decisions for you in the event that you become unable to make such decisions for yourself. Forms, called health care proxies used to appoint a health care agent, are available at health care facilities and elsewhere, but there is no requirement that you use a specific form. All that is required is that you do the following things in writing:

- (1) Name the person (at least 18 years of age) whom you want to act as your agent.
- (2) State that you want your agent to make your health care decisions in the event that you become unable to make them for yourself.
- (3) Sign this writing.
- (4) Write the date of this writing, and
- (5) Have two people who are not the agent and are at least 18-years old sign as witnesses to your signature.

Your proxy also may incorporate your directives concerning the type of health care you want or the type of health care you want to decline. Such a statement can then be used as evidence of your wishes. However, it is imperative that you thoroughly discuss with your health care agent your wishes and in particular, those related to nutrition and hydration, and that your proxy include a statement that your agent knows your wishes with respect to nutrition and hydration, if you wish your health care agent to make any decisions concerning your nutrition or hydration. Your Health Care Proxy will be recognized in most states, but will have no legal effect outside the United States.

### Living Wills

If you cannot find a trusted friend or family member to act as your health care agent you can still create a document that states your wishes concerning the health care you want and the care you choose to decline. That document is a Living Will. Although the document can provide clear evidence of your health care wishes within the specific instances stated in the document, the Living Will does not author-

ize any particular person to act on those wishes. If you execute a Living Will, consider executing one every few years even if your views do not change. This avoids a challenge that you may have changed your views since you executed the document. In New York State, it is preferable to appoint a health care agent, if one is available, because such an agent can act on your behalf in making all health care decisions, not just those specifically discussed by you and because you can decide who that agent will be instead of leaving that decision up to the court. If you need medical care overseas, your Living Will will have no legal effect, but it may have a persuasive effect upon the medical staff that attends to you.

Thoroughly discuss your directives with your life partner, family, friends, medical providers, and clergy. Let them know your firm views. Engage them to be your advocates when you cannot express your own wishes.

### **Nomination of Guardian**

You have the right to name a person to be chosen as your guardian in the event that anyone starts a guardianship proceeding concerning you and you are determined to be in need of protection. A guardianship lasts only so long as the court determines that you need the protection. The court favors the selection of someone identified by the alleged incompetent. Having a durable power of attorney (described in the segment below) should avoid the need for a guardian, but having nominated someone in a witnessed document may prevent an estranged family member from seeking powers over your person and property.

### **Power of Attorney**

A power of attorney is a document to delegate authority to someone else - an agent - to act for the individual, as in times of disability or illness. The authority can be broad or limited, as appropriate. You can provide for the management of your financial affairs through a power of attorney given to a trusted friend or family member. You grant your agent authority only for those activities you designate by your initials. You can elect to use a durable power of attorney which is the kind that continues even should you become mentally incompetent or physically not able to make decisions.

For more information on Health Care Proxies, Living Wills, Powers of Attorney, and similar docu-

ments, refer to the New York State Bar Association pamphlets entitled “Planning Issues for Older New Yorkers,” “Living Wills and Health Care Proxies” and “Why You Need a Will.”

### Funeral Plans

Discuss your wishes for funeral arrangements with your trusted friend(s) and family member(s). You have the right to direct the disposition of your remains. In the absence of expressed wishes, your next-of-kin, even if estranged or if you have not had contact, control the funeral and burial. For an unmarried person without adult children, this is usually your parents or brothers and sisters. A close friend will not be recognized to make funeral arrangements unless that person can prove the wishes of the person who has died. It is therefore desirable to have a writing or direction to someone to make the arrangements. Some funeral homes will recognize the executor of the will when given the power in the will or similar document. To assure control over your funeral, you may want to consider prepaid arrangements for your funeral and burial.

### Estate Plans

It is wise to have a will, which needs to be drafted by a lawyer. You also may make use of such means as a joint bank account, living trusts or life insurance, particularly to benefit nonrelated persons. These are methods of leaving property or money in ways that avoid your “probate estate,” effecting transfer directly upon your death, to the beneficiaries you designate.

To make a will, you must have the legal mental capacity to understand what your estate consists of, who your loved ones are, and the effect of making a will at the time that you sign the document. Even though you might suffer bouts of dementia related to your illness or the medications that you take, you may still make a will if your mind is sufficiently clear at the time that you make the will.

Avoid using hospital personnel to witness your will. Many hospitals prohibit staff from witnessing wills or impose onerous conditions on their use. Witnesses may be called by the court to be questioned. In fact, do not postpone making your will until the end is near. If you are single, your need for a will is greater than that of married people. You should have a will long before you face a medical crisis.

For more information on developing estate plans, refer to the New York State Bar Association pamphlet entitled “Why You Need a Will.”

### **Making a Plan for Your Children**

If you have children, it is critical that you create a custody plan for your children after your death, especially if your children’s other parent is not living in the household, is HIV-positive, or is already deceased. If you do not do this, your children may be placed in foster care with strangers. It is important that in making your plan, you consult with a lawyer who is knowledgeable about permanency planning.

Once you have chosen a proposed custodian, a first step is making a will in which you name that person your minor children’s guardian. It is often advisable to take other steps as well to ensure that your children go to the person whom you have chosen.

If you are ready to give up care and custody of your children now, you and your proposed caregiver can pursue custody, guardianship or adoption.

If you do not want to lose custody of your children now but wish to put a plan in place for the future, you can appoint a standby guardian. You may name a standby guardian now whose authority will not begin until your death, mental incompetency, or physical debilitation. You can provide for a standby guardianship by going to court or by signing a written designation. Going to court is time consuming but far more effectual than the signing of an out-of-court form, which is merely testamentary in effect. By choosing a standby guardian through the judicial process, virtually all of the legal work will have been completed prior to the need for a commencement of guardianship. If you live within the five boroughs of New York City and money might become a problem for the person whom you have chosen as your children’s custodian, another permanency planning option is Early Permanency Planning Program (EPP) of the Administration for Children’s Services. In EPP, you place your children in voluntary foster care with a caregiver whom you have chosen and the caregiver receives resulting foster care subsidies and allowances for the care of your children. At this time, EPP is only available in New York City.

## Living Benefits

To fund health care expenses, living expenses or sometimes just a dream, people with a relatively short life expectancy may be able to cash in on their life insurance. Some issuers of life insurance include an accelerated benefits rider that allows the owner with an estimated life expectancy of about a year or less to apply to the issuer for payments of a percentage of the policy as if they had died. Currently, few issuers offer the benefit and those that do often limit the percentage that can be accelerated to one half the face value of the policy.

If a life insurance policy can be assigned for value, the owner of a policy on his/her own life can sell all or part of the policy to a third party for a payment that reflects the buyer's estimate of the seller's life expectancy, the face value assigned and interest rate assumptions. A sale to an unrelated third person is called viatication.

New York regulates viatication. Only companies that have applied for registration in New York can legally serve as agents or buyers of such policies. Those companies must comply with regulations requiring disclosure to you of certain information, including whether your broker is receiving a fee for the service. Delivery of documents and payment of the purchase price must be through an escrow agent.

Despite regulation, New York residents still get offers from viatical settlement companies that have failed to comply with New York regulation. It is wise to have an attorney review your viatical settlement arrangements. Federal tax law recently made such payments tax free in limited circumstances if received after December 31, 1996. Amounts received by New York residents from viatical settlement companies not registered in New York are subject to federal income tax.

No one, not even your creditors, can force you to viaticate insurance policies on your life. If you choose to viaticate a life insurance policy, your dealings with a regulated viatical settlement company are confidential. Working with a registered viatical settlement company does not require public disclosure of your HIV status.

## RESOURCES AND REFERRALS

The following information is intended to be used

## AIDS AND THE LAW

as a reference guide in the event you require additional information about the provisions contained in this pamphlet, or if you require the assistance of an attorney or other professional. The organizations listed are not intended as a complete list of available resources. We recommend that you contact your local bar association or attorney referral service if you have a legal question pertaining to any of the information provided in this pamphlet. As well, please refer to the following AIDS-related organizations who provide services to persons with HIV/AIDS.

### NYS and NYC Human Rights Offices

Albany .....	(518) 474-2705
Binghamton.....	(607) 721-8467
Brooklyn .....	(718) 722-2856
Buffalo.....	(716) 847-7632
Manhattan (Lower).....	(212) 417-5014
Manhattan (Upper).....	(212) 961-4425
Nassau .....	(516) 538-1360
New York City Commission on Human Rights.....	(212) 306-7500
Office of Sexual Harrassment Issues .....	1-(800) 427-2773 - (718) 722-2060
Office of AIDS Discrimination Issues .....	1-(800) 523-2437 - (212) 417-5043
Rochester .....	(716) 238-8250
Suffolk-Hauppauge .....	(631) 952-6434
Syracuse.....	(315) 428-4633
White Plains.....	(914) 949-4394

### Lawyer Referral Services

Albany .....	(518) 445-7691
Broome.....	(607) 723-6331
Cattaraugus.....	(716) 373-9994
Chemung.....	(607) 734-9687
Dutchess .....	(845) 473-7941
Erie .....	(716) 852-3100
Jefferson.....	(315) 785-6191
Monroe.....	(716) 546-2134
Nassau .....	(516) 747-4832
National Employment Lawyers Association Referral Service.....	(212) 603-6491 (NELARS)
NYS Bar Association Lawyer Referral and Information Service.....	(800) 342-3661
New York City Lawyer Referral Services:	
• Bronx .....	(718) 293-5600
• Brooklyn .....	(718) 624-0843
• New York.....	(212) 626-7373

## AIDS AND THE LAW

• Queens .....	(718) 291-4500
Niagara Falls .....	(716) 284-4101
Onondaga .....	(315) 471-2690
Orange .....	(845) 294-8222
Putnam .....	(845) 225-4904
Rensselaer .....	(518) 272-7220
Richmond County Referral Service ...	(718) 442-4500
Rockland .....	(845) 634-2149
Suffolk .....	(631) 234-5577
Sullivan.....	(845) 794-2426
Warren .....	(518) 792-9239
Westchester .....	(914) 761-5151
Women's Bar Association Referral Service .....	(518) 438-5511

### AIDS ORGANIZATIONS

AIDS Center of Queens County.....	(718) 896-2500
AIDS Counsel of Northeastern New York .....	(518) 434-4686
AIDS Law Clinic.....	(518) 445-2328
AIDS Related Community Service ....	(914) 345-8888
Brooklyn AIDS Community Service Program .....	(718) 596-4781
Gay Men's Health Crisis (Hotline) ....	(212) 807-6655
Gay Men's Health Crisis (Legal Services).....	(212) 367-1040
Long Island Association for AIDS Care.....	(516) 385-2451
NYC Division of AIDS Services .....	(212) 645-7070
Rochester Community Health Network .....	(716) 244-9000
Staten Island AIDS Task Force .....	(718) 981-3366
Upper Manhattan Task Force on AIDS .....	(212) 870-3352

*This pamphlet, which is based on New York law, is intended to inform, not to advise. No one should attempt to interpret or apply any law without the aid of an attorney. Produced by the New York State Bar Association Committee on Public Relations in cooperation with the Special Committee on AIDS and the Law.*



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