HIV TRANSMITTED BY BLOOD PRODUCTS

Margaret W. Hilgartner, M.D.

The extent to which the national blood supply has been contaminated by the Human Immunodeficiency Virus is unknown. With a basis of epidemiologic data, however, one can say that the virus probably came into the blood supply in 1977. Retrospective study of stored samples of hemophiliac plasma showed the appearance of anti-HIV antibodies in 1979 in a few patients (i.e., became seropositive) and in the majority of hemophiliacs during the years 1980–1983. The first hemophiliac was reported with the disease in 1981. When widespread testing of the donor population became available in March 1985, 0.4%–0.9% of donors were found seropositive nationwide, with the highest figures in those cities (New York, Miami, Los Angeles, and San Francisco) with the greatest reported number of AIDS patients.

Incidence

The CDC has recorded a total of 939 cases of AIDS related to transfusions of HIV-contaminated blood products as of 2 March 1987. This figure is 2.9% of the total persons reported with AIDS and includes all adults, adolescents, and children. Of this total, 287 individuals have had hemophilia or other coagulation disorders and have been transfused with fresh frozen plasma, cryoprecipitates for factor concentrate, while 652 individuals have been transfused with red blood cells or components of blood.

When the figures for the children are separated from the total, we find that 78 children or 18% of the total 453 children reported with AIDS have had the virus transmitted via blood and blood products. Of those, 24 (5%) have had hemophilia and 54 (or 12%) have been transfused for other reasons. Although these numbers are increasing with time, the percentages of the total have remained stable. The higher percentage in babies transfused with blood or components is probably related to the shorter incubation period seen in infants, while the percentage in young hemophiliacs is only slightly higher than the figures seen in the adult hemophiliac.

Natural History

Information about the natural history of the disease in the transfused patient is evolving slowly, but with some accuracy, because the date of transmission of the infected blood can be ascertained in many cases. A wide spectrum of disease seems to exist, with variables related to age, underlying diseases for which the transfusion was given, and the product used for transfusion. The Red Cross "Look Back" study currently going on in all Blood Banks is tracing recipients of blood from donors known to have been HIV-negative on subsequent testing. The Transfusion Safety Study (TSS) is enrolling all donors and recipients of HIV-positive blood donated in the six months prior to universal screening of all donors for seropositivity in four high risk cities in the United States. With these two studies, one hopes that complete epidemiological information will be obtained concerning the natural history of AIDS as transmitted through blood products. At present, data from the TSS show that 90% of those patients who received a

unit of blood found retrospectively to be HIV seropositive have themselves become seropositive. Although 75% of recipients died within one year after the transfusion of causes not related to AIDS, there is a potential reservoir of unsuspecting anti-HIV positive individuals deserving close follow-up and counseling.

Children tranfused in the newborn period who subsequently developed AIDS were first reported in 1983 by Ammann et al., who found that symptoms appeared six months to three years post transfusion. Others have shown that the incubation period from transfusion to the appearance of symptoms seems shorter in those children who were transfused as very small premature babies, when compared to the older child where the incubation period may be the same as in the transfused adult. In the adult, Curran has shown that the incubation period may be 15 months to 57 months (mean 27 months), and current CDC data suggest a span of seven years. In addition, Curran showed that blood components other than those used by hemophiliacs could transmit AIDS.

The product used for transfusion has marked influence on the transmission of disease. Those products containing white cells appear to have transmitted disease more readily than red cell products. For example a set of twins seen at The New York Hospital were transfused with components from the same donor. The twin receiving the red cells did not become HIV positive, while the twin receiving the platelets developed signs and symptoms of AIDS within 16 months.

Those who received a greater number of transfusions in the period 1980–1985 are more likely to be seropositive than those receiving a smaller number of transfusions or single donor units. For example: only 12% of the 84 transfusion-dependent thalassemia patients at The New York Hospital-Cornell Medical Center in New York City are seropositive. The figures for hemophiliacs, however, are as follows:

Table 1. *HIV Status of Hemophiliacs–NYH/CUMC*

Total Anti-HIV Positive		119/163	73%
Adults	≥ 18 years	83/94	88%
Children	< 13 years	19/43	44%
	< 18 years	36/69	52%

The thalassemia patients have a donor exposure of 12–24 per year, while the hemophiliac may have a donor exposure of 800,000 to 1 million per year. The single donor unit is less likely to be contaminated than the pooled donor product from which the factor concentrates for the hemophiliac are manufactured.

The hemophilia patient population, however, appears to be different from the homosexual or IV-drug-using population in relation to progression of HIV disease and infectivity of sexual partners. For example: only 20%–30% of the seropositive hemophiliacs have the syndrome of AIDS related complex (ARC), and only 2% have developed symptoms of AIDS. This figure appears substantially lower than for the homosexual population, where 30%–35% of those followed longitudinally have developed AIDS.

Measures Taken to Prevent Transmission of HIV in Blood Products:

Although HIV transmission via blood transfusions was recognized before a test was available to define the HIV antibody status, decisive measures could not be designed to insure the purity of the national blood supply. In the spring of 1984, the New York Blood Center developed a confidential intake questionnaire allowing

the center to determine whether the donor was at risk and thereby to designate whether the blood donation should be used for transfusion or discarded. This process of self-exclusion allowed the donor to preserve his confidentiality and contribute to improving the quality of the blood supply. Self-exclusion has now been adopted by all other blood collection agencies.

Table 2. *Measures Taken to Prevent Transmission of HIV in Blood and Blood Products*

1. Self-elimination of at risk donors
2. Screening of Donor – March 1985
   HIV antibody testing (ELISA)
3. Treatment of pooled products:
   Heat-wet or dry state
   Solvent/Detergent
   B-Propriolactone, U-V Light
   Monoclonal antibody derived
   Recombinant DNA derived
4. HIV – Antigen tests

Treatment of the pooled plasma concentrates of clotting factors was begun in 1984 to decrease the amount of hepatitis virus contamination. Subsequently all of the methods used were found effective in the elimination of HIV: Beta propriolactone, ultra-violet light, solvent-detergent treatment, and heat have been used to treat the concentrates in the wet or dried state. The Dry Heat method is the current choice. Monoclonal antibody separation and recombinant manufacture of factors are being tested and appear promising.

In 1985 the ELISA screening tests were introduced to identify blood or plasmaphoresis products containing HIV-positive antibodies. These tests are 99.2% specific for antibody and 93.4%–99.6% sensitive. The Western blot test performed on all positive donations is 75% sensitive for HIV antibodies. Newer ELISA tests currently being tested are even more specific than those in use. With all of these tests, the blood supply has been rendered virtually free of donations contaminated with HIV.

The problem remains for the donation given in that period between infection and development of antibody. A few recipients of red blood cells from units which tested seronegative at time of donation have become antibody positive; the blood donor has also subsequently become antibody positive. Many more are being identified with the "Look Back" program. We look forward therefore to the licensure and marketing of a test for HIV antigen which will close the time span between infection and antibody development, so that we may have a national blood supply completely free of HIV.

SUPPORTIVE CARE AND TREATMENT OF PEDIATRIC AIDS

Arye Rubinstein, M.D.

This summary addresses some specific issues which may alter the course of the disease.

Supportive Care

Failure to thrive due to a variety of etiologies is one of the major features of pediatric AIDS. In some cases, malabsorption and protein-losing enteropathy are identified. In others, it may be related to factors such as chronic infection. Proper nutritional support (adequate caloric and protein intake) in many instances may be crucial for the care of the child with AIDS. Where this goal cannot be achieved by oral feedings, one has to consider nasogastric feeding or intravenous hyperalimentation. In our experience nasogastric feeding is of limited value. Generally, weight gain could be achieved through intravenous hyperalimentation using venous (broviac) access, but this may be compromised by the development of infections in the access lines.

Infection Control and Prophylaxis

Probably the most frequent problems in children with HIV infection, especially under the age of 2 years, are recurrent bacterial infections which may progress to sepsis and meningitis. The optimal strategies to prevent these infections have not yet been established: I) Antibiotics (trimethoprim-sulfa, ampicillin). Several groups have suggested that the use of prophylactic antibiotics may avert the catastrophic outcome of acute infections, especially in those patients who have a severe underlying B cell deficiency. The drawbacks for the use of prophylactic antibiotics are the development of side effects, resistant bacterial strains, and poor compliance. II) Intravenous gamma globulin. Intravenous gamma globulin has been applied in pediatric AIDS since 1981. The rationale for the use of this therapy was the documentation of an underlying B cell defect. In our experience this approach has significantly reduced bacterial infections, especially in the younger age group. Many unresolved issues exist with regard to this treatment: 1) what dose is to be used; 2) is the higher dose currently used by us (300mg/kg) advantageous over the low dose used in some agammaglobulinemic patients (100–200mg/kg) with regard to a) the delay of immunological attrition, b) prevention of infections, and c) removal of circulating immune complexes; 3) although no risks have been involved with intravenous gamma globulin, it is a costly treatment and requires a twice monthly 2–3 hour hospital short-stay admission; 4) should the European double-blind control study on IV gamma globulin be duplicated in the U.S.; and 5) should gamma globulin be used in any HIV infected child who has a B-cell defect or should it be restricted to those who present clinically with infections.

Treatment of Specific Infections

Certain infections in AIDS are extremely difficult to manage.

Our experience demonstrates that salmonellosis is extremely hard to eradicate. Trimethoprim-sulfa, ampicillin, or ceftriaxone have failed in many cases to elim-

inate the carrier state. While in immunocompetent hosts the carrier state is of no risk, children with AIDS who are carriers of salmonella often suffer recurrent septic episodes. New strategies should be designed, therefore, to treat this condition. One of the promising medications is Fluroquinolone used at 400mg twice a day.

Pneumocystis carinii pneumonia (PCP). The most frequently utilized treatment includes trimethoprim-sulfamethoxazol. In cases of failure, pentamidine is introduced. Other medications such as dapsone in combination with other treatments or as an alternate treatment have not shown great promise.

Disseminated cytomegalovirus (CMV) infection with/without retinitis. No treatment has achieved permanent improvement. Trisodium phosphonoformate (Foscarnet) may have a role.

Varicella. A benign disease in immunocompetent children, varicella may be life-threatening for immunocompromised patients. Children with apparently normal in vitro lymphocyte mitogenic responses to specific and non-specific mitogens and with normal T4 cell numbers and percentages have developed fatal varicella. We, therefore, have adopted the policy of administering acyclovir in any case where an extensive vesiculation occurs or where new vesicles develop after the fourth day of the disease.

Treatment Modalities for the Direct or Indirect Control of HIV Infection

1) Immuno-reconstitution or immuno-potentiation. A whole host of such modalities has been attempted in adults, including: bone-marrow transplantation, thymic transplantation, thymic hormones, alpha and beta interferon, interleukin-2, intravenous gamma globulin, isoprinosine, imuthiol, and enkephalins. The results have been disappointing. They do not appear to control the virus, and some of these immunopotentiating agents may activate virus replication. Experience with these agents in children is limited. Several thymic transplants have been performed but did not result in permanent objective benefit. The use of thymic transplants and thymic hormones in children is of special interest, since children with HIV infection demonstrate early in the disease course low levels of thymulin (FTS). Our trials with thymic hormone – fraction V – have not yielded encouraging results. Thymic hormones seem to temporarily improve T cell functions, but subsequently a phase of rapid immunological attrition and disappearance of T4 cells was detected.

2) Antiviral agents. A number of antiviral agents have been used in adults. These include reverse transcriptase inhibitors such as ansamycin, suramin, Foscarnet, AZT, dCT, AL-721, a lipid component that promotes the extraction of cholesterol from the viral membrane, and ribavirin (Virazole) which inhibits guanyl transferase in the capping of the 5′ end of HIV mRNA. Currently the two most promising drugs are AZT and dCT. Phase I trials with AZT in children with AIDS are in progress. In adults it has major side effects. dCT seems to have less side effects in adults, but has the disadvantage of limited penetration of the blood-brain barrier. The frequent and devastating CNS disease in children with HIV infection has to be taken into consideration when an antiviral agent is selected. Infection of fetal brain could be documented in the first trimester of pregnancy. Brain atrophy can also be documented in neonates by CT scans. Consequently, early treatment of CNS disease is imperative. Any antiviral drug that does not penetrate the blood-brain barrier, therefore, may be of little benefit for the treatment of HIV infection in the pediatric age group.

3) Hyperimmune Serum. We have used hyperimmune serum intravenously since May 1984. Its benefit for the control of HIV infection has not yet been established. Hyperimmune serum, however, may have a major role in the prevention of infection. It should be considered for use in HIV-infected women during early pregnancy to prevent fetal infection.

4) Combination treatments. Two forms of combination treatments are to be considered: a) the combination of various antiviral agents. Some in vitro studies suggest, however, that the combination of two or more antiviral agents may result in antagonism. For example, in vitro AZT and ribavirin seem to antagonize each other's effect on the AIDS virus; and b) the combination of antiviral agents and immunopotentiation. Antiviral agents may avert the activation of HIV by immunopotentiating agents.

INTRAVENOUS DRUG ABUSE AND WOMEN'S MEDICAL ISSUES

Constance B. Wofsy, M.D.

Epidemiology

Women constitute 7% of all reported AIDS cases in the United States, in striking contrast to the ratios elsewhere. Of women with AIDS, 28% are white, 51% are black, 20% are Hispanic/Latino.

Table 1. *Women with AIDS*
Percent of Total AIDS Cases

International	
Central Africa	40%-50%
Haiti	20%-25%
Canada, France	12%
U.S.*	7%

*If male homosexuals/bisexuals and hemophiliacs are excluded, women make up 30%

Fifty-two percent of women with AIDS are intravenous drug users (IVDUs), but 27% are non-IVDUs who were infected by a male sexual partner, usually an IVDU male. Of importance, 78% of women with AIDS are between the ages of 13 and 39, the peak childbearing ages. In pediatric AIDS, 45% of white and 88% of non-white children acquired the disease from an IVDU parent.

It is estimated that there are more than a half million regular or casual IVDU women in the United States. As many as 75,000 women IVDUs and 20,000 non-IVDU female partners of male IVDUs may already be infected with the virus. With an estimated 1-2 million Americans infected, there may be 200,000 women who carry the virus. Many haven't a clue that they are infected. The most highly represented populations of infected women, IVDUs and nonwhites, are already highly stigmatized, but we must not let fear of stigma immobilize educational efforts.

Transmission

HIV has been isolated from blood, semen, and cervical secretions. Transmission can occur by vaginal intercourse from man to woman and from woman to man. Long-term sexual partners having unprotected sex with an infected person for several years have a 15%–45% chance of becoming infected. An interesting study done in Miami examined the percent of seroconversion in 32 couples after they learned that one was seropositive. Eight chose abstinence and none seroconverted. Ten chose to use condoms and only one seroconverted. Fourteen did nothing in the way of protection and 12 became seropositive.

Table 2. *Relationship Between Condom Use and Seroconversion*

	N	SEROCONV	%
Abstinence	8	0	0
Condom	10	1	10
No Condom	14	12	86

Fischl, et al. *JAMA* 1987; 257:640.

Sexual partners who also share needles are at even greater risk.

Women Who Use IV Drugs

IVDUs are hard to reach. Only an estimated 15% are in treatment programs. To reach others, we must rely on community networks, health clinics, jails, schools, churches, and the media. For those with little education and short attention span, the message must be simple and direct, and the language culturally specific. Many who use drugs do not perceive of themselves as users. Those who do not understand the health risks and the need to clean needles may continue to share because they erroneously consider their partner to be nonrisk. Sharing is socially expected; the urgency of the fix exceeds the risk; carrying drug paraphernalia like a clean needle or bleach bottle may make one subject to arrest. The sexual and needle risks for the woman often come from a man who is also a user, and even more recalcitrant in acknowledging his own risk and in taking responsibility for his female partner.

Our research group in San Francisco studied 289 sexually active women, none of them prostitutes, and found that 5% were seropositive. These were self-referred, so they do not represent a cross-section of the city. All of the seropositives have a personal history of intravenous drug use or have a sustained relationship with a specific high-risk partner. For over a year and a half, we followed 200 women with no such personal history and found only one seroconversion in a city rampant with HIV.

Women IVDUs have few resources. They often have responsibility for children, multiple health problems, lack of family support, lack of money, depression, and low self-esteem. Prostitution may be a means of support for the drug habit and family.

HIV Infection and Pregnancy

IV drug use does not inhibit fertility; some of these women have several children and may desire more. Birth control is often limited because of perceived lack of risk of pregnancy, irregular periods, decreased sexual frequency as a result of drug use, and lack of power to control the sexual expectations and preferences of male partners.

Few programs are targeted at pregnant addicts. Existing programs may be costly and too understaffed to deal with family patterns of abusive treatment, implementation of childbearing skills, and birth control education.

An infected woman has a 20%–60% chance of passing infection to her child. An infected child is very likely to die, or be severely ill by two years of age. Pregnancy may accelerate HIV expression in the woman and thus should be avoided for the sake of mother and child. In one study, however, it was found that 25% of infected babies were born to mothers who hadn't a clue they were infected or that their partners were in a risk group. The infected infant established the mother's diagnosis.

Many women who have had an infected child nevertheless have proceeded to have additional children despite intensive culturally specific counseling. Childbirth may provide self-esteem or be culturally expected.

Clinical Expression of HIV Infection in Women

The spectrum of HIV-related infections and malignancies is similar in men and women, except that women rarely get Kaposi's sarcoma. Gynecologic problems do not seem to be significantly increased.

Symptoms of HIV infection in women may be overlooked by physicians for

many reasons. Non-IVDU women are perceived to be a low risk group and HIV symptoms are nonspecific. IV drug users have medical problems whose symptoms mimic HIV related disorders (e.g., bacterial endocarditis, cotton lung, skin infections). Physicians may feel inadequate to the task of AIDS care, may wrongly assume that all infected women are IV drug users or prostitutes, or may not have overcome their own fears. It is known that strong stigma and profound repercussions may result from the identification of an infected individual. Availability for HIV testing or adequacy of the medical staff and community to deal with the consequences are lacking. Thus, strong clues to infection may be overlooked and women may proceed under the illusion that there are no risks.

Societal Issues for Women Infected with HIV

HIV infected women come from all walks of life. Forty-eight percent don't use IV drugs. Many issues cross all class, race, and cultural boundaries – for example: 1) extreme isolation – infection is often kept rigorously secret, depriving women of the desperately needed support of family, friends, community, and particularly other infected women; 2) profound grief for the loss of health, body image, sexuality, and childbearing potential; 3) unavailability of medical care, counseling, child care, housing, and related services; 4) lack of informed primary care, OB/GYN, sex counselors, and abortion counselors; 5) the burden of making decisions about initiation, continuation, and termination of pregnancy; 6) the lack of natural "community," such as shared by gay men; 7) the abruptness of the diagnosis, which may be disclosed at the birth of an infected baby or death of a spouse; 8) loss of self-esteem – feeling dirty, useless, unwanted, and unlovable; 9) the feeling of responsibility from watching a child die; 10) the stigma that "women with AIDS are prostitutes who infect their children"; and 11) lack of male responsibility, and the societal assumption that women have the responsibility for control of sex and conception.

Importance of all Women to the AIDS Epidemic

Women still constitute the large bulk of the country's educators and caregivers through roles of teachers, nurses, social workers, counselors, girlfriends, wives, and mothers. All persons in these positions shoulder a great responsibility. They are expected to overcome their own fears, become comfortable with sexual, drug, and lifestyle issues, acquire wisdom, nurture and teach the young, comfort the fearful, and care for the sick. It's a tall order.

EDUCATION TO PREVENT HIV INFECTION

Karolynn Siegel, Ph.D.

Education regarding modes of transmission of HIV infection remains the most important public health strategy for controlling the spread of AIDS. Education must mean more than just imparting information about practices that place one at risk of becoming infected or of infecting others. It must also aim: to motivate or persuade people to adopt certain behaviors and relinquish others, to eliminate irrational fears about transmission through casual contact, to debunk myths and stereotypes about the "kind of people" who get sexually transmitted diseases, to dispute notions of culpability or blame for the epidemic, to instruct all levels of society in safe sexual practices, and to insure cooperation in anti-drug programs.

While there is widespread agreement on the central role that education must play in stemming the epidemic, there is somewhat less agreement on who should be educated and at what ages, what messages should be communicated, and who should assume responsibility for this education. These issues are currently the focus of much public discussion and debate.

I want to emphasize the need to create a collective sense of national purpose in combatting this disease. AIDS is still viewed by the majority of people as the problem of a few select and socially isolated groups. We must strive to overcome a "we/they" mentality. We must promote a feeling that as a society we all have a shared interest in controlling this epidemic, which must take precedence over more narrow self or special group interests. Everyone needs to feel a personal investment in bringing about a solution to the problems the epidemic has posed.

The establishment of a national office of AIDS education, or a national director of AIDS education, as recommended in the Institute of Medicine report, would constitute a very important first step. The public must receive a clear and unequivocal message that this problem merits a national plan of action and concerns all Americans.

In England, Prime Minister Thatcher recently distributed a flyer under her name to every household in the country, informing people of the seriousness of the AIDS problem and telling them what they could do to protect themselves. This action sends a clear and powerful message to the populace. It says that this matter has the attention of the highest leaders of the country; every citizen should be informed about it and concerned with helping control it.

I would like to move on to the question of "who should be educated?" Clearly, we must continue to focus heavily on the established risk groups—gay and bisexual men and intravenous drug users and their partners.

We must target extensive educational activities to blacks and Hispanics, groups greatly over-represented among those with AIDS. We must enlist ongoing cooperation of support groups, community leaders and community-based organizations and must always consider cultural norms. We must find a way to tie the hoped-for behavior change into their own value and belief system. The importance of bearing a healthy child may be used to help persuade women to use condoms as protection against AIDS and other sexually transmitted diseases (STDs).

We know that adolescence is a time of experimentation that often involves drug use and sexual experimentation. The AIDS epidemic has increased the urgency to reach a goal of having "every junior and senior high school student receive timely STD education."

A principal concern is how we should communicate. Here, we can draw some lessons from our efforts over the past few years to educate risk groups members—especially gay men. Our own research indicates that some of the messages contained in risk-reduction guidelines, which have been used as a principal educational tool among gay men, have sometimes had unintended negative consequences. Recommendations like "know your partner" and "reduce your number of partners" have often created a false sense of security. One can rarely take the kind of exhaustive sexual history from a prospective partner that would be necessary even to begin to evaluate the degree of risk inherent in sexual encounter. We have found that men who continue to engage in risky sex, but with fewer partners or nonanonymous partners, believe that they have adequately reduced their risk of infection because they are in compliance with safe-sexual-practices guidelines. Similar messages are being used now in educational materials directed to the heterosexual public.

While multiple messages about different prophylactic behaviors may not seem to be competing with each other, they are. The message we communicate should be unambiguous, confrontational, and consistent. There are only two acceptable adaptations to the threat of the infection—abstinence, or using a condom in every sexual encounter where a risk of transmission may exist. If you offer people several alternative ways to adapt, they will usually choose the course of action that involves least personal change. There would be no problem if the alternatives were all equally efficacious, but they rarely are.

Who should do the educating? The source of any message is an important determinant of the attention it will receive. Therefore, I would recommend that we make greater use of opinion leaders in trying to alter the public's attitudes toward the epidemic and modify sexual norms among sexually active individuals. Opinion leaders are widely esteemed public figures who have the confidence and trust of much of the public. Because they are respected and trusted, their positions on matters are sought and afforded a special consideration. They can perform an especially valuable role in shaping public attitudes around such controversial issues as AIDS.

There is the need to develop strategies for changing social attitudes and norms to support the adoption of behavior that will slow or halt the spread of infection. Social norms can be a powerful force in constraining certain practices. The need for the acceptance and approval of others is an important motive in shaping behavior. Peer social pressure is the most compelling force for modification of life style of adolescents in particular.

Sex has always been considered a private act. Now, however, we are compelled to recognize that it can sometimes have public consequences. We can no longer afford to assert the position that what someone else does sexually is solely his own business. We must acknowledge that we have a vested interest in employing positive social sanctions to encourage people to conduct themselves in a way that will contribute to the control of the epidemic. We have to create a social environment in which abstinence is a positively sanctioned option. For those individuals who choose to engage in intimate sexual relations, we must confer social approval

on those who behave in a sexually responsible way. People must come to regard the use of condoms as a normative expectation.

At this time, we must depend on the schools to educate children about AIDS, STDs, and drug use. To pretend that we can rely on parents is really to abrogate our responsibility and to know this may leave many children unprepared to protect themselves against these threats.

There are no easy answers to the problem of educating the public about AIDS. While there is some base of knowledge and experience to guide us, the difficulties that confront us are formidable. For example, the popular perception that AIDS remains a "medical mystery" and that there is disagreement even among the supposed experts on some matters greatly complicates the educational task. When available scientific evidence is regarded as indeterminant or provisional, its power to influence behavior is likely to be significantly diminished.

LEGAL ISSUES SURROUNDING MEDICAL CARE, TREATMENT, AND RESEARCH OF CHILDREN

Harold Ginzburg, M.D., J.D., M.P.H.

Introduction

The ethical and legal issues surrounding informed consent and the individual right of privacy in the care and treatment of minors and in their participation in research protocols thus far are not unique to those infected with HIV. We can apply precedents derived from previous decisions. These form a base from which to build ethical and legal criteria to manage issues created by the AIDS epidemic, some of which may now be unforeseeable.

The Right to Knowledge: Informed Consent

Informed consent is a merger of the sharing of knowledge and the receipt of permission to proceed with the therapeutic or research intervention; informed consent is educated consent. Obtaining such consent from a competent adult is significantly different from obtaining consent for a minor or incompetent adult. A clinician or clinical investigator should seek informed consent only under circumstances that provide the prospective patient or research subject or their respective legal representatives with sufficient opportunity to consider whether or not to participate in the treatment or research. The decision-making process should be free of the possibility of coercion or undue influence. The information provided by the health care professional must be in language that the patient or research subject can be expected to understand. No informed consent, either oral or written, may include any exculpatory language through which the subject or representative is made to waive or appear to waive any of the subject's legal rights, or releases or appears to release the investigator, the sponsor, the institution, or its agents from liability or negligence.

Informed consent has become a structured and formal process; a written document is prepared by the medical institution which explains the proposed medical treatment or medical research. The basic legal tenet of modern informed consent is over 70 years old. Justice Cardozo stated that:

> "Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault and battery for which he is liable in damages... [A person] is considered to be master of his own body, and he may, if he be of sound mind, expressly prohibit the performance of life-saving surgery or other medical treatment.... The law does not promote [a physician] to substitute his own judgement for that of the patient."

The American Hospital Association (AHA) has promulgated "A Patient's Bill of Rights" which states in part: "The patient has the right to receive from his physician information necessary to give informed consent prior to the start of any procedure and/or treatment" and "The patient has the right to be advised if the hospital proposes to engage in or perform human experimentation affecting his care or treatment. The patient has the right to refuse to participate in such research projects." Another policy statement of the AHA deals with collaborative (physi-

cian and patient or research subject) decision-making as the basis for informed consent. The need for essential information to be present in the language familiar to the *patient* (or his parent or guardian) and the need for formal documentation of the presentation of such information have resulted in lengthy informed consent forms that are specific to the condition being treated. Gone are the "blanket" informed consent forms hospitals have used in the past.

The medical and legal (professional) communities have long held that neonates and young children are not able to give meaningful consent for medical care and treatment. Parents are presumed to be in the best position to speak the mind of the child under the substituted judgment theory. Thus, parents or court-appointed legal guardians may give legally binding permission for children to receive medical treatments and also to become participants in research protocols. Few would argue about the appropriateness of the parent or guardian being the responsible person for authorizing medical treatment for their child or ward. Enrolling a child in a medical research protocol, however, is a more complex issue. Although the potential benefits of participation in research protocols (extended life or an improved quality of life) may often be substantial, many of these research protocols also may present substantial risks to the child. What are the decision-making processes that will maximize the potential benefits of medical science to the non-consenting child while protecting his or her fundamental rights?

The Right to Privacy

The right to privacy is a fundamental constitutional right; this right may be overridden only by the demonstration of a compelling State interest. While minors are legally presumed not to be able to give informed consent or withhold consent for their medical care and treatment [in most jurisdictions this is an "irrebuttable" presumption (i.e., it cannot be successfully challenged in a court of law)], the *parens patriae* doctrine, the doctrine of informed consent in emergencies, the "Infant Doe" regulations of the United States Department of Health and Human Services, and numerous cases where a court-appointed guardianship is created to permit the treatment of a minor over the objections of the parent(s) (e.g., Jehovah's Witness' blood transfusion cases)—all support the general presumption that medical care and treatment should be provided to minors. Adults do have a right to refuse treatment, even if it will lead to their demise; they do not have the right to extend their personal beliefs to their children when the outcome of such an imposition is irreversible.

The minor's personal right of privacy has been invoked when the guardians or parents, after determining that the minor is terminally ill and medical care offers no real hope of restoring health, have declined treatment. Historically, refusing necessary and life-saving treatment has constituted child abuse. In such circumstances the court may intervene, in *parens patriae*, to act as the general guardian, granting consent for the initiation of medical treatment. The court generally will not intervene in this role to grant consent for the initiation of an experimental medical treatment.

The final regulations of the Department of Health and Human Services to implement the Child Abuse Amendments of 1984 to the Child Abuse Prevention and Treatment Act, 42 USC section 5101(a), enacted October 9, 1984, indicate that medical neglect (failure to provide adequate medical care) and withholding of medically indicated treatment, in the medical care of infants, are to be based on "reasonable medical judgment" and not on "quality of life standards." The final

rule requires that procedures be developed consistent with State law to obtain access to medical records and/or other pertinent information when such access is necessary to assure an appropriate investigation or a report of medical neglect.

The Judicial Council of the American Medical Association states that the decision whether to exert maximal efforts to sustain life should be the choice of the parents in consultation with the treating physician. Parental authority should be respected unless there is convincing evidence to the contrary. There is a substantive consensus on the deliberate withholding of life-saving treatment:

1) The law will support a decision not to provide treatment that would be futile or inhumane; no available treatment or surgical procedure offers any hope of survival; heroic efforts would be invasive, traumatic, and painful; medical opinion on diagnosis and prognosis is clear and unanimous.
2) The law will support terminating life-support for a patient whose brain has irreversibly ceased to function.
3) The law will defer, in matters of honest professional disagreement, to well-reasoned medical-ethical decisions which are the result of free and open communication among all concerned parties.

The tension develops when, as in HIV infections, there is no acute decision to be made; the clinical course, though predictable, is not rapid; and the quantity of pain and suffering cannot be estimated, with any degree of medical certainty, before it occurs.

The Duty to Warn

Individuals with HIV antibodies have a right to medical confidentiality, but is it the physician's duty to warn those in foreseeable danger of contracting HIV from an infected individual? When, and under what circumstances should individual liberties, such as medical confidentiality, be abridged for the good of the community? If the female partner has not been notified that her male consort is seropositive or infected, becomes pregnant and delivers an infected child, is there liability? And for whom? The physician? The male consort? Both? These and other questions, basic to the medical care of children with a variety of health conditions, become all the more difficult when the condition is HIV infection.

MANAGEMENT OF THE CHILD WITH HIV INFECTION: IMPLICATIONS FOR SERVICE DELIVERY

Mary G. Boland, R.N., M.S.N., C.P.N.P.

Management of the Child with HIV Infection: Impact on Health Care Services

In areas where HIV infection is epidemic, children with HIV infection and their families are straining the resources of health care delivery systems and human services agencies. The child and family have multiple medical, social, and emotional needs. The need for children to receive day care and attend school is forcing communities to deal with AIDS-related issues at the local level.

While a small number of children acquire the disease as a result of transfusion of infected blood and blood products, the majority of infected children acquire AIDS perinatally. Mothers of these children are infected, and it is not unusual for both parents and one or more siblings to be infected and ill. Thus, the parents are confronted by issues regarding their own health status as well as that of the child. For the most part, children who get this disease and their parents are disenfranchised. They are not like the gay community, which is able to mobilize itself. They need health care providers who are not only sensitive to their needs but knowledgeable regarding the disease, and willing to advocate for the children and their families.

About 80% of the children come from a home where one or both parents have a history of drug abuse. Because of problems related to drug use, many families are already receiving assistance from multiple health and human service agencies. The majority of the families are headed by a single parent, usually the mother, who is eligible for or receiving public assistance and Medicaid. After the diagnosis, many of the children are eligible for and do receive Supplemental Security Income (SSI) and Medicaid. Prior to the diagnosis, 25% of the families in our program were known to the child protective services agency (Division of Youth and Family Services), and many were already in foster care. For most children, placement occurred because of unwillingness or inability of the mother to care for the child, rather than as a result of illness in the child. Active intravenous drug use resulted in inability of the mother to provide food and shelter for the child. In two families, acute encephalopathic symptoms in the mother required legal action and placement of the infant with other family members. We have no boarder babies in our institution and have a good record in terms of identifying foster homes for our children when we have needed them.

Initially, many of the mothers appeared well. However, as length of follow-up has increased, more mothers are becoming symptomatic, and several have died. Progressive physical illness in the mother decreases the energy available for care of the child. Impending death of a caretaking parent prompts discussions regarding long term care of the child. While grandparents and other extended family members frequently accept care of the child, they are dealing with grief due to loss of the parent and justified fears regarding the death of the child whose care they assume. In one family where both parents and one of two infected children have died, the maternal grandmother gave home care for the mother and child, and is now caring for the surviving infected child and his well siblings.

The existence of both progressive and static encephalopathy has been described in children with HIV infection. Of the 61 children in our program who underwent comprehensive developmental evaluations, only 5% tested at an appropriate age level in all areas. Delays occurred predominantly in speech and language development and acquisition of motor skills. A few children actually lost achieved milestones. Parents, however, rarely identified developmental delays as an area of concern. It is not a population of people who come in saying, "I think my child is behind; he is not walking; he is not talking." We often find it difficult to get the message across that there are developmental delays to address in terms of their child's later education. For instance, we have no child in a handicapped preschool program at this point. Parents are afraid to enroll their children because they hope things will get better and because they are afraid of what will happen to the older sibling when the diagnosis becomes known in the community.

In the infant and child, HIV infection can produce dysfunction of various organ systems requiring care by multiple pediatric subspecialists. Institutions such as children's hospitals that provide tertiary level care are best suited to provide the range of services these children require. To date, the New Jersey Children's Hospital AIDS Program (CHAP) has provided on-going care for 89 children from 81 families. In most families, the child is the index case and identification of other infected family members occurs after diagnosis of the child. While the goal of treatment programs is to maintain the child within the home and community, there are occasions when hospitalization is necessary.

We have an outpatient visit about once or twice a month per child, the majority for intravenous gamma globulin therapy. Our average of hospitalizations is between 2 and 3 a year per child, with a range of 0–7. The majority of admissions are for pulmonary disease, either Pneumocystis or complications related to lymphoid interstitial pneumonitis. After that, septic-like episodes and otitis predominate.

The morbidity and mortality resulting from HIV infection demands an approach to care that is comprehensive and coordinates care between the hospital, home, and community. The ill child must be viewed as a member of a family system that, however weakened or malfunctioning, has its own tasks and stages that are disrupted by illness in the family members. HIV infection is a life threatening but chronic process that has the potential to destroy an entire family.

We have developed a child-centered, but family-focussed, program to treat the illness and its symptoms while attempting to prevent further disruption of the family unit. We have adopted many of the concepts related to the chronic childhood illness model, because much of it applies to children with AIDS. Despite the pessimistic statistics, they are living longer. We have several children in our program who were infected from birth, sick as infants, and are now school age and in school. Our oldest perinatally infected child is eight.

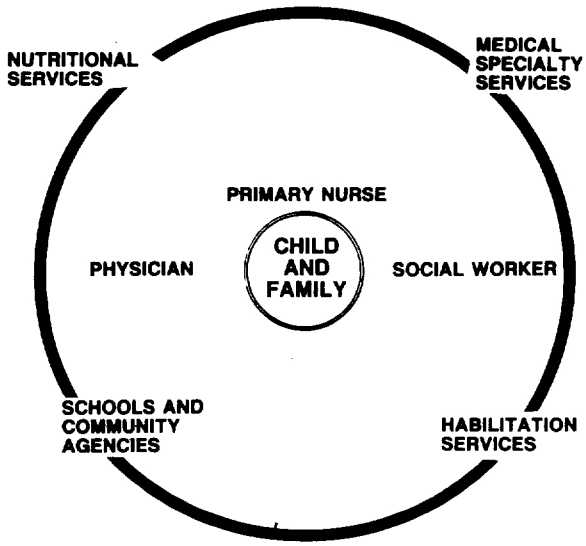


Figure 1.

The need to collect epidemiological data, the multiple health and developmental problems resulting from infection, and the implementation of drug treatment trials as more antiviral agents become available—all require that programs regionalize services to cover a contiguous but wide geographical area. These programs must be multidisciplinary and utilize physicians, nurses, nutritionists, social workers, and developmental specialists.

Health care providers in the acute setting must be willing to reach out and form innovative partnerships with the various agencies providing service to these children and their families. These types of model programs can provide direct services, including collaborative case management with agencies in the child's community.

Table 1. *Children's Hospital AIDS Program*

Nursing Services
- Coordination of Care and Service
- Ongoing Assessment of Parental Health and Coping Ability
- Identification of Resources
- Collaboration with Other Disciplines
- Advocacy in the Health Care Setting and Community

Social Services
- Assessment of Family System
- Ongoing Counseling for Child and Family
- Support Groups for Families
- Assistance to Families in Navigating the Bureaucracy of Social Agencies
- Collaboration with Other Disciplines

In addition, the expertise of program staff can be utilized to provide outreach education to health care providers, as well as to advocate for the child and family within the community.

CURRENT DEVELOPMENTS AND FUTURE PROSPECTS FOR AIDS VACCINES

Gerald V. Quinnan, Jr., M.D.

Prevention of infection from human immunodeficiency virus (HIV) is dependent on avoidance of exposure and the successful application of measures which prevent transmission. The availability of a safe and effective vaccine would be an extremely valuable adjunct to existing preventive measures. Once HIV infection occurs, it persists for life. And even with effective antiviral therapy, there may be a lifelong risk of developing AIDS. Primary prevention is, therefore, an essential objective.

Technological advances occurring over the past decade make many approaches to vaccine development potentially feasible. Recombinant DNA techniques have been used to produce viral proteins in E. coli, yeast, insect cells, and mammalian cells. Recombinant live viruses, including vaccinia and adenoviruses, have been constructed that express HIV genes in cell culture and, in the former case, in animals. Synthetic peptides homologous to amino acid sequences of proteins of HIV have been prepared and shown to induce antibodies. Antiidiotype monoclonal antibodies offer another approach under study. HIV-specific immune globulin is under development for use in passive immunization. It is indeed fortunate that the technology exists to make these products so quickly. However, many substantial difficulties remain, including definition of appropriate antigens for use in vaccines and development of methods for demonstrating efficacy.

Most efforts at vaccine development have focused on HIV envelope antigen as the principal immunogen. Both the external gp 120 and transmembrane gp 41, as well as the complete gp160 envelope proteins, have been included in candidate vaccines. Envelope antigen is capable of inducing neutralizing antibodies and can serve as a target antigen for antibody-dependent cell-mediated cytotoxicity and cytotoxic T cells. These immune responses may be crucial for protective immunity. Envelope antigen appears to be important in animal retrovirus immunity. Genetic variation of envelope antigen is a concern, but human neutralizing antibodies are often broadly reactive. The use of HIV core antigen as vaccine is also under study.

Table 1. *Candidate AIDS Vaccines*

Type	Antigen	Source
Subunit Recombinant DNA-Derived	Envelope Envelope	Virus E. Coli Yeast Mammalian Cells Insect Cells
Live Virus Vectors	Envelope	Vaccinia Adenovirus Herpes Simplex Virus
Synthetic Peptides	Envelope Core Antigen	Solid Phase Synthesis
Antiidiotype Antibodies	Envelope	Monoclonal Antibodies
HIV Immune Globulin	All	Plasma
Inactivated	All	Virus

Preclinical evaluation of candidate vaccines has involved immunization of a variety of animal species. Neutralizing antibodies have been induced to variable degrees depending on the product and the species. Studies in primates have been considered essential. Chimpanzees are the only animal species which can be infected consistently with HIV. The possibility of using chimpanzees as a model for demonstrating effectiveness of candidate vaccines is still under study. It does not appear that chimpanzees develop AIDS when infected, and the relevance of high-dose intravenous challenge to prevention of human infection is unclear. Promising preclinical data indicate that—even though immunity in animals hasn't been established—clinical studies will likely begin soon.

Clinical studies of AIDS vaccines will occur in phases. The first studies, referred to as phases 1 and 2, will consist of initial evaluations of safety and immunogenicity and definition of optimum immunizing regimens. The complexity of these studies may vary, depending on the product. Evaluation of safety may be more difficult for recombinant vaccinia viruses than for purified proteins. Single doses of some vaccines may be fully immunogenic, while multiple doses administered at intervals over several months may be required for others. The results obtained from animal models and phase 1 and 2 clinical trials will have to provide a basis for decisions regarding which candidate vaccines should be entered into expanded trials.

Definitive clinical trials of safety and efficacy are referred to as phase 3 studies. The size, duration, and complexity of these studies depend on a number of factors. A particularly difficult issue is the question of what the principle objectives of efficacy studies will be. If vaccines prevent infection, the phase 3 studies will be relatively straightforward. On the other hand, if transient or even persistent infection occurs after vaccination, without progression of infection to AIDS, the phase 3 studies will require large numbers of volunteers, will take a relatively long time, and will be complex. Feline leukemia virus vaccine is an example of one that prevents disease without preventing persistent infection. The goal, after all, is disease prevention.

Regardless of what level of efficacy is observed, there are many variables that must be addressed during phase 3 studies. Vaccine efficacy must be addressed in relation to each mechanism of transmission, geographic location, and strain variability. Efficacy for gay men, drug addicts, heterosexual partners, and newborns may differ. It is desirable that multiple safe and effective vaccines become available. Phase 3 of vaccine development is likely to be a multiyear endeavor involving many candidate vaccines, people of all ages in all continents, and people in all risk groups.

Table 2. *Concerns to be Addressed in Phase 3 Trials of AIDS Vaccines*

Safety
Efficacy
Transmissability
Strain Variation
Geographic Variability
Modes of Transmission
Multiple Vaccines

Children represent important and varied target populations for study of vaccine efficacy. Several approaches might be used to prevent infection in newborns.

Table 3. *Potential Methods of Interruption of HIV Transmission to Neonates by Vaccination*

Immunization of at-risk males
Immunization of at-risk females
Infected Spouse
Other
Immunization of Newborn
Ig ± Vaccine

Vaccination of women at risk of infection, such as prostitutes, intravenous drug abusers, and other women partners of infected men may reduce the rate of transmission to newborns. It is not known how often neonatal infections result from transmission of virus at or soon after birth. Those infections which do not occur in utero may be preventable by intervention at birth, perhaps through a combination of vaccine and immune globulin. An important feature of vaccine efficacy trials in newborns is the relatively short incubation period compared to adults. It may be possible to demonstrate disease prevention in newborns more quickly than in older target populations. Fortunately, HIV transmission to children does not occur readily in the family setting. It must be remembered, however, that sexual activity, including homosexual activity, often begins in childhood.

The process of demonstrating vaccine safety and efficacy will be further complicated by related concerns. Target populations for efficacy studies will be people at high risk of infection. It will be necessary to continue to develop methods for prevention in these groups in parallel with clinical trials.

Table 4. *Potential Impact of AIDS Vaccines*

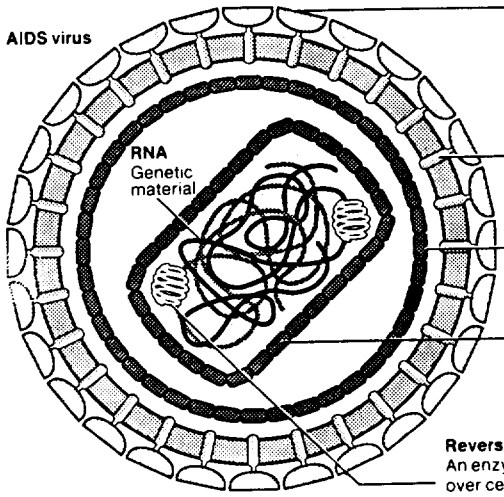
Coverage	Efficacy	Infections Prevented
80%	80%	64%
90%	90%	81%
95%	95%	90%

Practical aspects, such as health care and legal concerns, are also at issue. These related problems will have an effect on the time required to complete efficacy studies. Furthermore, it cannot be assumed that the first generation of candidate AIDS vaccines will be found to be safe and effective. Already, potential approaches to second generation products are being considered and evaluated.

It is impossible to predict exactly when an AIDS vaccine will become generally available. It is certain that the development of an AIDS vaccine will be the best planned and coordinated national and international effort at vaccine development that has ever occurred.

The AIDS Virus: Developing a Vaccine

Once in the body, the AIDS virus provokes production of a range of antibodies that battle it. These do not necessarily protect infected people from developing AIDS. But scientists hope that if a vaccine can induce production of certain antibodies in advance, invasion by the AIDS virus could be warded off. Scientists are trying to locate subunits of the virus that, when injected in the body, will stimulate production of protective antibodies.



GP-110 Also called **GP-120**. A glycoprotein, or sugar-containing protein, that helps the virus attach to and invade cells. Number refers to molecular weight, which scientists label differently.

GP-41 A glycoprotein, also along the outer coat, that plays a role in cell invasion.

P-17 A protein in the inner shell that is suspected to protrude to the viral surface; function is unknown.

P-24 A core protein; function is unknown.

The Current Search

Some experimental vaccines use only GP-120, others use combinations of GP-120 and GP-41 while another uses a synthetic version of part of P-17. Some experts propose using the entire killed virus, but others fear the possibility that some particles could remain alive and cause disease.

The Next Steps

Experimental vaccines are being injected into animals to see which types of antibodies are produced. Since each animal species responds differently and animals do not develop AIDS, these studies cannot reveal whether a vaccine would prevent disease.

The next step is to inject promising vaccines into small numbers of humans to determine safety and the range of antibodies that are produced. At least one French scientist has already done this and American teams plan to soon.

If tests indicate that a vaccine is safe and stimulates production of desired antibodies, complex, large-scale human trials will be started to determine whether it actually protects against AIDS, a process that will take many years.

Once safety and efficacy are determined, a vaccine can be widely distributed.

A MOTHER'S VIEWPOINT

Mrs. Helen Kushnick

On 13 October 1983, my three-year-old son, Samuel Jared Kushnick, died as a result of Acquired Immune Deficiency Syndrome. After birth, he received twenty blood transfusions from thirteen separate donors in the neonatal unit of a hospital in Los Angeles, California.

Sam's death devastated our family, including his twin sister, Sara. Sam was not the first, but the fourth, premature male to die in Los Angeles during a six-month period, as a result of blood-transfusion-related AIDS. The first was in February 1983, the second in April, the third in June.

When my son died, pediatric AIDS was not considered a disease. I was told that our son's death would not be counted as an AIDS fatality because he hadn't reached the age of five. My husband fought with the hospital administrators, including the head of the blood bank, for 45 minutes after Sam died to have AIDS listed on his death certificate as the cause of his death. What we didn't know was that once the mortuary saw AIDS as the cause of death, they refused to dress his body for burial. The insurance company that provided our medical coverage tried to claim a "pre-existing" condition so that they wouldn't have to pay the $94,000 in medical costs for Sam's 19-day final hospital stay. For six months after he died, I received bills addressed to him on an almost daily basis. They lost. They paid. Then they cancelled our policy.

The first official statistics out of the Centers for Disease Control were published in November 1984. Seventy-two pediatric cases had been recorded. There are now 456 recorded cases of pediatric AIDS, and the pediatric ARC cases are not counted in these statistics.

During Sam's illness, our daughter was ostracized and rejected by a segment of our well-educated, affluent Beverly Hills community. Lack of public awareness of the correct facts concerning the transmission of AIDS caused these people to panic and to force nursery school administrators to expel Sara for fear she could contaminate the other children.

Even after the school and parents had been assured by leading pediatric immunologists and the Los Angeles County Health Department that Sara was perfectly healthy and that AIDS was not communicable by casual contact, the public hysteria persisted, and we were forced to place Sara in another school.

Sara then started kindergarten in a public school. Our applications for private schools had been rejected. Although she had had the required medical examination and inoculations prior to her admission, I was called by the principal and asked for an additional letter from her doctor stating that she was healthy. The school had received a number of calls from concerned parents, even though my daughter was exceptionally healthy and more than two years had passed since her brother's death.

In 1983, my family's decision to go public with our story seemed courageous. To us, it was simply a question of not having a choice. It was clear to us then that AIDS was not a homosexual disease, but a virus.

In my conversations with officials at the Centers for Disease Control in 1984, it was obvious that the number of young victims of AIDS would be growing each

year. Yet the cities have not come very far in the care and education of these children.

Let me tell you about my friend whom I'm going to call "Mrs. Smith." She is black and a single parent. Her three-year-old son also contracted AIDS through a blood transfusion. She has a daughter six years of age. She works as a teacher's aide. She tells no one that her son has AIDS because she doesn't feel she could fight the discrimination and isolation of herself and her daughter were the facts known.

The most horrendous part of this disease is fear and rejection. It is hard enough for an adult to cope with and impossible to explain to a child. This is the end result of our lack of education through proper channels. Until we find a vaccine or cure, the only way to stop the spread of AIDS is through education. We need effective educational programs, designed under the auspices of the Surgeon General, in every city and State in this nation—regardless of how few AIDS cases are statistically counted. As we know, the statistics have been wrong, and ARC cases aren't even being counted. The public must become comfortable with the knowledge that quarantine is not the answer to preventing the spread of AIDS. *Education is.* And not *after* a child with AIDS is admitted to school, but *before.*

The citizens and physicians, practicing and academic, are still not being correctly informed about AIDS. It is not appropriate that both the public and physicians receive most of their medical information through the news media, which has been the case with the AIDS crisis. The majority of the general public does not understand the difference between a specific test for a virus and an antibody test.

While there are now only a handful of post-March, 1985, blood-transfusion AIDS cases, these will surely grow. The same system existing when my son was infected is still in place. Any physician will tell you that blood is a dangerous drug and there is still no standard of care across this nation for blood-transfusion procedures in neonatal units. Yet the population at greatest risk for blood-transfusion AIDS continues to be the children, as the increased cases are showing us.

Most of the local school boards haven't even addressed the issue yet. They wait for crisis situations and then throw the child out of school while they figure out what to do. Shouldn't our citizens be able to go to their government for facts? Aren't the parents of school-age children entitled to receive their facts from the Board of Education?

Government agencies have not effectively utilized educational media, such as television and radio. As a result, the news media has reported its own version of events, which in some instances has been sensational, inaccurate, and has provided little public health information.

And what of the mothers like "Mrs. Smith"? Isn't she entitled to an effective support group? Having a critically ill child is a nightmare, one I hope none of you will ever have to face. The one thing you need most is support.

Statistics show that the highest percentage of pediatric AIDS cases in the years to come will be from IV-drug-user mothers. These children will, in all likelihood, be abandoned in our hospitals. Who will pay for their care? Must these children be abandoned to live in hospitals because there is no residence facility to send them to while a foster home is found? Must the families of children cared for in their own homes be forced underground?

Any facility that receives government funding should not be allowed to discriminate against these AIDS victims.

Response on a Federal and city level to the magnitude of pediatric AIDS has been extremely slow. Please, let us stop dragging our feet, and let us act responsibly now.

During World War II the Federal government with our allies was able to bring together the best scientific minds in the world to develop the atomic bomb. Well, we are at war now and our allies are the world health community. We need to bring together the best scientific minds in the world—not just in our country—to fight this killer. We need the best researchers, clinicians, and scientists under the same roof on a daily basis. We cannot continue to ask these people to spend months filling out grant applications to fund their work.

Three years ago I made a promise to my daughter. She became frightened one evening that she couldn't remember Sam's voice—afraid that she was beginning to forget him. I promised her then that her father and I would not let Sam be forgotten. You see, we hear his voice all the time.