

Daring To Stay Alive

Project Inform Offers Hope in HIV Infection

by Paul Reed

P A R T I : T A K E T H E T E S T

Editor's Note: This is the first of a two-part feature covering the activities and message of Project Inform, the San Francisco-based organization which functions as an information clearinghouse on AIDS testing and treatment.

Amidst the widespread debate about the use of AIDS antibody testing, one national organization is articulating both the value and necessity of voluntary, anonymous testing as a frontline approach to fighting the disease. Project Inform, based in San Francisco, argues strongly that the medical realities of AIDS necessitate a medical response. The key bit of knowledge is one's antibody status as infected or not infected by the AIDS virus.

In recent months, Project Inform has been holding "town meetings" about AIDS treatment. The events have drawn standing-room-only crowds and influenced many people to discover not only their antibody

status but to take immediate action to begin treatment against HIV infection.

"The popular idea that the AIDS antibody test doesn't tell you anything—and that there's nothing you can do about it

anyway—is quite simply wrong," says Joe Brewer, a gay San Francisco psychotherapist and co-director of Project Inform. "A positive antibody test can be seen as a diagnosis of a major infec-

(Continued on page 19)

Inform

(Continued from page 1)

tion by a life-threatening agent."

This message is one that is just now coming of age throughout the nation, in large part because of Project Inform's national reach. Project Inform is the only AIDS organization that is vocal about the necessity for voluntary testing. Other established AIDS-service organizations focus on patient services and education, whereas Project Inform is focused on treatment research—providing necessary information about available treatment options—and on urging immune status monitoring.

Their's has been a controversial position, because political and psychological problems have clouded the issue of testing. But that is beginning to change, as

more and more people realize that they want to take immediate steps to avoid illness in the future by taking advantage of the treatment options that are now available (to be covered next week, in Part II of this series).

SILENT INFECTION

"Arguments against testing are either political or psychological responses to a medical problem," says Project Inform in their recent newsletter, *PI Perspective*. "These should be answered in the political and psychological realms. What's too often overlooked is the need to make a medical response to the medical problem. How many more must die or cross the line to full-blown AIDS while we argue about the politics and stress of testing?"

Project Inform directors Brewer and Martin Delaney stress that recent epidemiologic data clearly show that if left untreated, "silent" (asymptomatic) HIV infection leads to AIDS or ARC symptoms for nearly 80 percent of those infected after seven years.

There is growing evidence, then, that there is very little possibility of dormant HIV infection and that the length of time an individual has been infected is critical. This past summer, the

San Francisco Men's Hepatitis Study released the results of a years-long study of infected individuals which showed that by the seventh year after infection, 78 percent of those individuals with HIV develop symptoms of AIDS or ARC.

While many people have tried to argue with the data from every possible angle—pointing to lifestyle, fast-lane living, and so on as possible co-factors—the fact remains that all these other variables were "factored out" of the study. Yet the rate of progression toward illness remained uniform.

"The number who became ill in the first five years of infection increases slowly, but after that, the rate rises rapidly," says Project Inform in its newsletter. "The study shows that this alarming rate of disease is equally true for people classified as being in the 'fast lane' or the 'slow lane.'"

Project Inform points out this study has been presented at two international conferences, has been subjected to extensive peer review, and has been corroborated by other studies. "These are the best facts available to a gay man today on which to base his health choices," Delaney states. "To ignore this is to deny it—

(Continued on next page)

Inform

(Continued from previous page)

burying your head in the sand."

Brewer points out that although this data has been known for several months, massive denial has prevented individuals from fully realizing the implications of this data for themselves and for their potential conditions. "The reasons for getting yourself tested are now very clear—you have to know to begin to protect yourself."

For this reason, Project Inform has become emphatic in its position on the absolute necessity for voluntary antibody testing, and the sooner the better. They stress that the widespread availability of several anti-HIV treatments has rendered the argument in favor of "not knowing" as dangerously out of date.

"In light of the recent data, the AIDS antibody test now does have a prognostic value," states Brewer. "As infection continues, you progress generally towards illness."

TIME ONLY VARIABLE

"The only real variable here is time," explains Delaney. "This study let us know what happens over a long period of time. Regarding possible co-factors, sex practices, prior health—the study found no correspondence between these and the progression towards illness. Time is the only variable."

Both Brewer and Delaney point out that this study shows what *has* happened, but it need not be necessarily predictive. "People react as if the only possible responses to this alarming data are denial or despair," Brewer says, "but this study is based only on people who got *no* medical intervention or treatment therapy—not from their doctors, and not self-treatment. The recent availability of several substances to treat HIV infection may have an immediate and beneficial effect on that soaring rate of progression into AIDS or ARC."

What, then can an individual do?

"There *are* things you can do to fight infection by the AIDS virus," explains Delaney, "but before you start treatment, of course you have to know where you stand. Are you infected? If so, in what condition is your immune system?"

Project Inform suggests that individuals find out exactly where they stand in relation to this infection. "First, find out where you stand right now," advises Brewer. "The antibody test gives you and your doctor critical medical information."

"Testing opens the doors," says Delaney. "Without testing, you can't know whether or not to start the process of evaluating your immune system and choosing a treatment."

Both Brewer and Delaney are well aware of the great resistance that individuals have to taking the AIDS antibody test. But both agree that ambivalence and resistance to testing are results of fear brought about by political and psychological problems.

MEDICAL VALUE OF TEST

Delaney stresses that although the political and psychological problems surrounding testing are serious issues, they should be addressed in their own ways. "Never let a psychological barrier prevent you from doing what's necessary for your health—nor a political barrier. The political and psychological concerns are very real, but not insurmountable. AIDS is."

Brewer points out that "if you have the virus in your body, there's going to be one terrible experience sometime in your life—either being told you're antibody positive, when you can still do something about it, or when you're diagnosed with an opportunistic infection, when it may be too late to do something about it."

Project Inform advises that individuals get tested voluntarily and confidentially. Says Delaney of the political resistance to testing, "The gay community has endangered itself more by overlooking the medical value of the test. Voluntary testing obviates the need for involuntary testing. Refusal to test feeds the notion that the community is irresponsibly spreading AIDS. The way the laws are going, we ought to do it now before we can't be tested confidentially or voluntarily."

Brewer cautions, however, of the psychological resistance to testing, advising that individuals be prepared for their test results. "Do be careful about to whom you release the results of your test," he warns. "And do be prepared for the psychological impact."

For individuals who test negative, the relief from worry will provide great energy—energy that is often directed towards helping the community in its struggle.

For those who test positive, they will have to face just what that means. According to Project Inform, a positive antibody test means that it is time to take immediate action to fight the disease process in one's body. In addition to learning whether or not one is infected, then, Project Inform counsels that the clinical laboratory test for T4 helper cells is essential in determining one's health status.

"The best measure of the disorder of the immune system is the T-cell count," counsels Brewer. "There is a demonstrated correlation between decline in T4-helper cells and development of symptoms. As the T4-cells decline, your ability to fight off disease diminishes and symptoms may begin to appear."

Once an individual has learned the condition of his immune system, he faces the critical decisions about what form of treatment to adopt. There are many available treatments, and sorting one's way through both the meaning of one's T-cell count and treatment options is a decision process that Project Inform is ready to help with.

Next week: Project Inform's views on how to interpret the T-cell count, the available treatment options, and how to choose.

MORE INFORMATION

Project Inform is an organization that provides information about treatment approaches for AIDS, ARC, and HIV infection. Information packets are available for the asking. You can reach Project Inform by phoning: (415) 928-0293 (local); California toll free (800) 334-7422; and national toll free (800) 822-7422. Or write: 25 Taylor St., Suite 618, San Francisco, CA 94102.

The project functions on volunteer energy (neither of the two directors—Joe Brewer or Martin Delaney—draw salaries). The information hotline also needs daytime volunteers.

Daring To Stay Alive

HIV Treatment Options Complex, Improving

by Paul Reed

PART II: DECIDING ON TREATMENT

Editor's Note: This is the second of a two-part feature on the activities and message of Project Inform, the San Francisco-based informational clearinghouse on AIDS testing and treatment. The first part of the feature appeared in last week's issue of the Bay Area Reporter (Dec. 3)

In the world of AIDS treatment, all is no longer doom and gloom. If we were to divide the AIDS epidemic into phases, we might say that we have now left the "era of mystery" and entered the "age of treatment." For two years, Project Inform has played a vital role in this age of treatment, urging an aggressive approach to treating AIDS-virus infection. They stress that the belief that "there's nothing you can do about AIDS infection" is now out-of-date—dangerously so.

"There are things an individual can do, and there will be many more in the near future," state Project Inform directors Martin Delaney and Joe Brewer. "The repeated message in the media about the hopelessness of AIDS is completely out-of-date. In fact, it was never true," they say.

"In the field of treatment research and clinical strategy, the goal at present is clear—to turn AIDS into a manageable chronic illness," says Brewer.

The very first line of defense against AIDS, according to Project Inform, is for an individual to discover whether or not he has been infected. Testing should be confidential and voluntary, they advise. (The necessity and interpretation of AIDS antibody testing was covered in Part I of this series.)

SOME CRUCIAL NUMBERS

Once you have learned that you are antibody-positive, Project Inform advises that a full immunological workup be done by your doctor—especially the laboratory test for the absolute number of T4-helper cells. It is also the appropriate time to seek out anti-viral medications, Project Inform says. Since HIV infection is progressive, anti-viral treatment is clearly the prescription.

This test can be performed (or ordered) by any physician. The T4-helper cell is the immune system cell that the AIDS virus attacks, and over time, destroys. As infection with the AIDS virus progresses, the number of T4-cells decreases, thus crippling the immune system and opening the way for attack by the opportunistic infections that are the hallmark of AIDS and ARC.

"The most important number in all this is the absolute T4-helper cell count," says Brewer, a gay San Francisco psychotherapist. "You should immediately chart that number and continue to be re-tested for T-cell counts at regular intervals, usually every three or four months."

According to Brewer, charting one's T-cell count at regular intervals is the best means available for an individual to monitor the health of his immune system. "What you want to look for here is the overall trend," he says. "There is a strong correlation between the decline in T4-helper cells and the onset of symptoms of AIDS or ARC."

Trend monitoring, then, is the key to interpreting one's status with regard to possible development of AIDS or ARC. "It's important to monitor trends rather than going on just one test," adds Delaney, co-director of Project Inform.

"T-cell counts vary, going up and down over time, but the real

point of concern is when that trend is a downward trend," he says.

The absolute numbers, then, are crucial in planning one's health strategy, according to Project Inform. They base their observations of what is normal and what is dangerous on clinical evidence—trends noted and reported by physicians and medical researchers in practice and in medical journals.

According to the current medical interpretation, then, if the number stays below approximately 500, it should definitely be seen as a serious warning sign and as the impetus for taking action. A general trend in the area of 200 cells or below signals the greatest risk, as it is closely correlated with the onset of AIDS-defining opportunistic infections.

"Try not to set up any psychological barriers," Delaney adds. "No one number should be seen as a crucial barrier. But any consistent downward trend within these general numbers should be seen as plain, clinical evidence that the HIV virus is destroying T-cells and should be addressed by treatment."

OPTIONS IMPROVING

Once a downward trend is observed, then, what can you do? The old message of hopelessness has pervaded the gay community, driven by the seemingly mistaken belief that there was very little that a person could do. Project Inform says that this has never been true, and that options for treatment are improving rapidly.

"The T-cell test can help you decide when it's time to do something in terms of immunomodulator treatment," Brewer says. "If the helper cell number regularly falls below 500, or is declining towards 500, you should start to think about immune modulators. And if the trend of the helper cell numbers is below 200, prophylactic measures come into the picture," such as the recently developed aerosolized pentamidine treatment or other antibiotics to help in preventing pneumocystis pneumonia.

"These treatments have proven useful to prevent recurrence of pneumocystis pneumonia in those who've had the illness," states Delaney. "They are just as likely to prevent it in the first occurrence."

Deciding on treatment is a decision that is not only crucially important but that is often done in a seeming vacuum of medical and social support. Because only the drug AZT has been licensed by the Food and Drug Administration for use in treatment of HIV infection, the many other available treatments

are often maligned as useless or of minimal value.

According to both Brewer and Delaney, reaching a decision to treat one's HIV infection with substances that are as yet unapproved or unproven is sometimes difficult, but need not be so. Individuals should understand that the restrictions placed on physicians create a situation in which doctors are, more often than not, unwilling to recommend any treatment other than the federally-approved treatment with AZT.

Inform

(Continued from previous page)

With non-standard treatments available, the individual must often inform the doctor what treatments he intends to take, then ask the doctor to help with necessary prescriptions and lab tests to monitor and safeguard his treatment program.

Project Inform is not in the business of making such decisions for individuals, but rather in guiding them by providing the latest and best information about available treatments for AIDS, ARC, and asymptomatic HIV infection. They provide information on each available substance—through information packets available by phoning them and through “town meetings” held in recent months to standing-room-only crowds. (The next scheduled meeting is Dec. 14 at 7:30 p.m. at Metropolitan Community Church, 150 Eureka Street, San Francisco.)

TYPES OF TREATMENT

The substances currently available to individuals are of three types. First are anti-virals, intended to cripple or slow the activity and spread of the AIDS virus in the body. Project Inform reports that several anti-viral drugs have demonstrated the ability to slow the progression of the virus, both in the test tube and in real people. Of these, the best known is AZT, already licensed as an AIDS treatment. It provides many possible benefits, but at high risk of side effects.

AL721, a food-like substance, is another that is popular right now. Preliminary test results look promising. Because AL721 is non-toxic, it represents a good, low-risk choice for many, especially for those unwilling to compromise their existing health with more toxic chemicals.

Ribavirin, a wide-spectrum anti-viral available in Mexico and once the most widely used AIDS drug, has perhaps the largest body of research behind it and has shown promise in most trials. Project Inform reports that early in 1987, the Food and Drug Administration made charges against the drug, scaring people away from it. Eight months later, the charges were quietly withdrawn. Yet, most doctors remain

either uninformed or misinformed about it. Ribavirin is once again the subject of new research.

Acyclovir is an existing prescription drug used for herpes and as an adjunct to other antivirals. It is believed to help with symptoms such as hairy leukoplakia.

One of the most recent promising prospects is from Japan. Called dextran sulfate, laboratory studies look very promising and the drug is quickly being pushed into human trials. Many people are already importing dextran sulfate from overseas, where it is sold as a non-toxic, over-the-counter product.

The second group of substances are known as immunomodulators, medications that are thought to stimulate the immune system, leading generally to an increase in T4-cell production. At least four such drugs are currently available.

Of these, the drug DTC appears to boost T-cells and is available as a commercial chemical. The prescription drug Antabuse breaks down into DTC in the liver and it is expected to provide the same benefits as DTC itself.

DNCB is another substance in this category. It is an inexpensive chemical available through the “guerilla clinics” and by individual purchase, and Project Inform reports that DNCB has already been used by thousands to treat the lesions of Kaposi’s sarcoma, as well as to stimulate the immune system.

Isoprinosine, another immunomodulator and one of the first drugs researched for AIDS, is available in Mexico and continues to be the subject of worldwide research.

Naltrexone is another drug being used as an immune modulator. When used in very small amounts at the right time of day, it is believed to produce a general “toning up” of the immune system by way of the endorphine, a hormonal brain secretion.

The third type of treatment is prophylactic, and includes aerosolized Pentamidine, a prescription drug breathed in by the patient and thought to be useful in the prevention of pneumocystis pneumonia.

EDUCATE YOURSELF

Project Inform’s list doesn’t include every substance currently being marketed as an AIDS treatment, however. Instead, treatments make the list only when they meet the three-fold criteria

of established safety, availability, and a reasonable expectation of effectiveness, as determined by objective research.

Project Inform counsels strongly that individuals should acquaint themselves with these substances by researching them, then make a decision on a personal course of treatment. Information packets on these substances are available by calling Project Inform.

“Up until recently, most people did not know that these treatment substances were available—or were in as widespread use as they are,” Delaney points out. “It may make all the difference if the community—and if individuals—can see that there is indeed something you can do about HIV infection. It’s not a hopeless situation. It’s not a matter of waiting to see what happens next. It’s a matter of getting busy and taking action right now, before the infection progresses any further.”

Cooperation of a physician is important, according to Brewer and Delaney. Once you commence a treatment plan, you will need to have the full services of a physician and laboratory tests to monitor progress. If one’s physician is not cooperative and will not support an aggressive treatment plan against HIV infection, then work out an alternative.

“Doctors are sometimes unaware or ill-informed about these available treatment strategies,” Delaney adds, “in part, because these strategies are new and are developing as we speak, but also because the legalities and liabilities of practicing medicine these days have got doctors spooked.”

(Continued on next page)

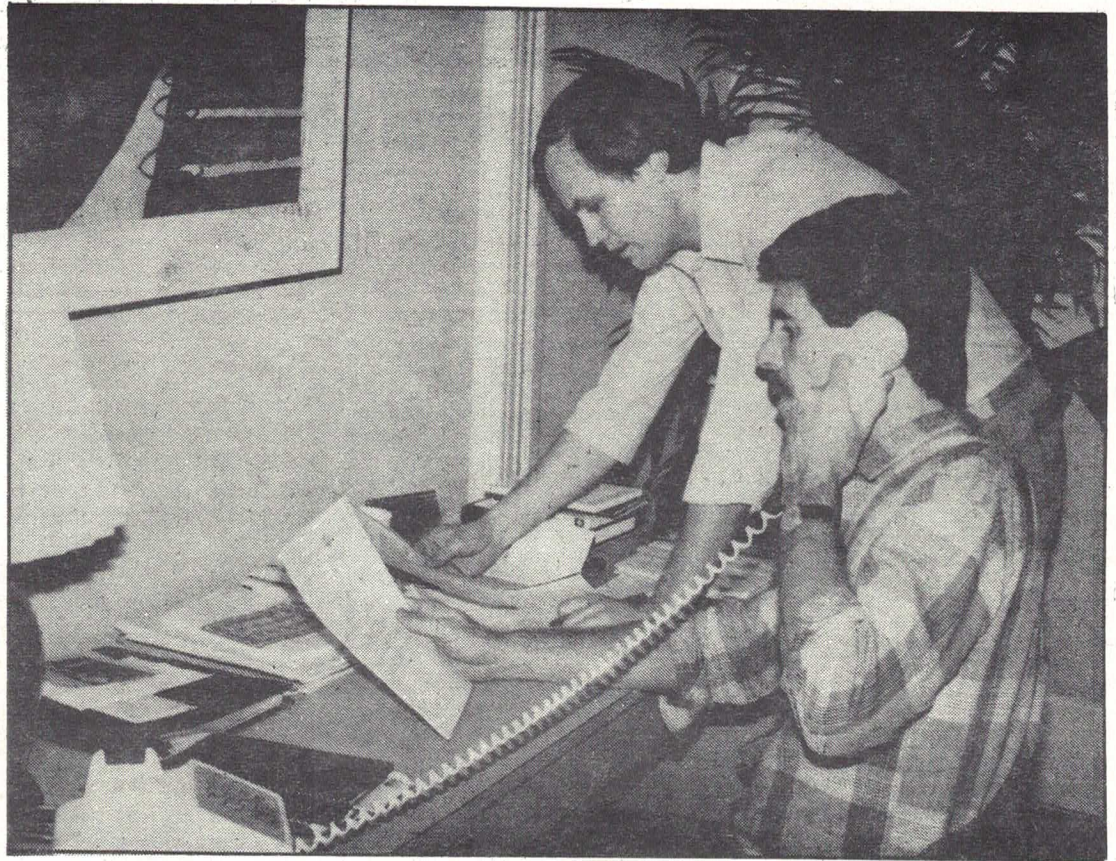
DECISION TREE

Commencing treatment is the all-important step, once an individual has determined from T-cell monitoring that it's time to take action. Brewer stresses that "the critical decision is getting yourself from a point of doing nothing to doing *something*. And remember that what you are doing can change as new treatments open up."

"There's no way anyone can tell you exactly what to do with certainty," says Delaney. "You're juggling a number of things at once and have to decide based on what fits best for your situation. Different people need different choices."

The choice of treatments is determined by several factors, including a person's financial resources, his overall condition and starting T-cell counts, past treatment experiences, and a personal risk/benefit analysis.

Reaching that decision is dif-



Martin Delaney (l.) and Joe Brewer of Project Inform

(Photo: Rink)

ficult, and individuals are often at a loss as to how to decide among the different treatment options. But the "decision tree," as Brewer and Delaney call it, can be seen as simply as process of elimination.

More serious conditions require different approaches. For example, someone whose T-cells are consistently below 200 should definitely consider the aerosolized pentamidine treatment and the most aggressive choice of available drugs. Someone who is steadily within or above the "danger zone" around 500 may seek to use "softer" approaches which are least toxic, such as AL721 and Naltrexone.

But they warn that no one is going to give a definite, clear answer with any certainty. "With

regard to certainty, everyone is frightened," says Brewer.

But, he adds, "We don't have the time to await the certainty that will come with repeated clinical trials. Since time is the only real variable in the potential progression towards serious ARC and AIDS, it's most essential to do something—anything with reasonable justification that it might work—as soon as possible."

The strategy advised by Project Inform, then, is based on the assumption that by treating HIV infection as soon as possible, individuals can delay the progress towards infection. By keeping informed and making changes as newer and better treatments become available, infected individuals may be able to literally "buy time" until a thoroughly ef-

fective treatment or cure is found.

"The goal here is simple," says Brewer. "Use existing therapies to hold your ground as new and better medications are found." ●

Project Inform

Project Inform is an organization that provides information about treatment approaches for AIDS, ARC, and HIV infection. Information packets are available for the asking, by phoning: (415) 928-0293 (local); California toll free (800) 334-7422; and National toll free (800) 822-7422. Or write Project Inform, 25 Taylor St., Suite 618, San Francisco, CA 94102. ●