The Newest AIDS Treatment Is Not a Drug

Mind/body medicine is on the brink of a major leap forward—if funding doesn't dry up first

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Jay Stinson has lived with AIDS since before it had a name. Diagnosed in 1975 with *Pneumocystis carinii* pneumonia (PCP), he stitched together a patchwork of health practices to survive a succession of serious infections in the years that followed. In 1986, after a lover died, he lost his will to live. "I became obsessed with disease and dying," he says. Within weeks, rapid-fire, he was attacked by a case of shingles, a second bout of PCP and the brain lesions of toxoplasmosis. But after starting a then-experimental drug, which his doctor said might give him two years to live, Stinson remembered Oscar Wilde's lament: "My only regrets in life were the things I didn't do."

"I had seen too many friends die bitter and angry deaths because of the things they put off, the dreams they would never realize," Stinson says. He made a few decisions: To become a master mariner and sail the world, write an autobiography and heal his relationships. He sold his possessions, bought a sailboat, and spent almost six years on the ocean. Now, after logging 40,000 nautical miles, 1,100 written pages and a dozen improved friendships, Stinson is, at 53, alive, well and land-based again.

While sailing, he learned to use a kedge, an anchor one throws off the stern when the boat has run aground. "Goals -- heartfelt, passionate goals -- are like anchors in deep water," Stinson muses. "When I get into I-don't-want-to-live thinking, I remind myself I have an anchor out there. And I use it to pull me through."

His words resonate. Ringed by a group of others not quite so far along in their self-made peace, Stinson shared this story recently in San Diego at a session of a unique psychological training program for people with HIV. Designed to boost immune competence, it is aptly called L.I.F.E., for Learning Immune Function Enhancement. Stinson is staff assistant, international liaison and inspirational role model for the L.I.F.E. Program.

L.I.F.E. is one in a growing array of programs nationwide that offer HIV positive people survival strategies ranging from overcoming denial and expressing grief to managing stress and learning basic workaday health maintenance practices. Studies are pending, but earlier research suggests that programs such as L.I.F.E. may help people gain improved quality of living and slower -- perhaps even *no* -- AIDS progression.

The 12-month L.I.F.E. Program was launched in 1992 by psychologist Jeffrey Leiphart, Ph.D., clinical director of the San Diego Lesbian and Gay Men's Community Center. L.I.F.E. is based on both Leiphart's 13 years of therapy experience with 500 HIV positive gay men and his exhaustive study of an exciting, up-and-coming field: Psychoneuroimmunology (PNI).

More than just a five-dollar word, psychoneuroimmunology is the science of how the mind, nervous system and immune system interact. For 30 years, PNI researchers have been uncovering the elaborate hormone and endocrine network by which psychology, emotions and stress influence health and disease. According to Leiphart, "PNI is a well-established branch of medical science, with both developed theoretical models and published experimental research studies that number in the thousands."

A growing body of PNI research on various diseases, including AIDS, shows that such factors as stress, depression, unresolved grief, social isolation and stigma have tremendous impact on immune function -- and thus on survival.

There have been numerous small but promising university-based PNI studies of people with HIV. All attempt to control for other factors (such as low original CD4 levels, substance use or lack of HIV treatments) that could explain the results. Among the findings:

- Men with AIDS who had negative expectations about their future health survived a significantly shorter period of time compared to their more optimistic counterparts.
- Newly diagnosed symptom-free HIV positive gay men who initially used denial to cope with the news of an HIV diagnosis had lower CD4 cell levels one year later (controlling for original CD4 levels) and greater likelihood of developing symptoms and AIDS two years later.
- Among a sample of HIV positive gay men, AIDS progressed more rapidly to the degree participants remained closeted about their homosexuality. This included shorter times to low CD4 cell levels, AIDS and death.
- Secrecy about one's HIV positive status predicted faster progression of disease.
- For HIV positive people repeatedly losing lovers and friends, grief that was contained and unresolved predicted faster AIDS progression, while expressed and resolved grief coincided with enhanced immune functioning.

But PNI findings remain controversial. Some scientists claim that controls are often inadequate. San Francisco AIDS epidemiologist George Lemp said in a 1990 interview: "Studies have shown that attitudes can affect things somewhat, but I think it's a minor part of the picture. People who live longer may have a good attitude, but that may be a false association."

Margaret Kemeny, assistant professor of psychiatry at UCLA and a leading PNI/AIDS researcher, counters that opinion. “[PNI] flies in the face of a lot of medical dogma, which does not put much credence in the psychological condition of the patient.” Kemeny, a L.I.F.E. consultant, criticizes “dogmatic” researchers and “clinicians who will not consider the findings of even the most solid research in this area because it does not fit with what they ’know’.”

Until recent years, most biologists “knew” that the central nervous system functioned autonomously from the immune system. But in 1964, psychiatrist George Solomon, then at Stanford University Medical School, become convinced, after research on rheumatoid arthritis (an autoimmune disease), that these systems were closely linked. His later experiments with rats, performed with immunologist Alfred Amkraut, demonstrated that stress can be immunosuppressive and confirmed Russian research showing that particular brain regions regulate immunity.

This groundbreaking work opened up the field of psychoneuroimmunology that today includes psychologists, immunologists, neurobiologists, endocrinologists and molecular biologists. These diverse researchers have established that the brain/immune system pathway involves the cortex, hypothalamus and pituitary and adrenal glands. “Sustained activation and arousal of this axis is intimately tied with depressed immune system functioning, especially T-cells,” Leiphart says. “Adrenaline, produced by the body during intense emotional states such as fear, panic and rage, is known to suppress T-cell functioning.”

Kemeny adds, “Research in this area has exploded in the last 10 years, showing, for example, that hormones and neurotransmitters produced under stressful conditions can alter the functioning of immune cells.”

PNI is also shedding new light on the role of natural killer (NK) cells, an often-neglected immune-system arm that can identify and destroy HIV in the blood and inside other cells. NK cells are stimulated by physical exercise, and high NK levels -- a consistent trait of many long-term survivors -- are strongly correlated with self-assertiveness [see below].

In the 1980s, PNI research on people with several illnesses (breast cancer, malignant melanoma, herpes and the common cold) as well as on healthy people showed clearly that stressful life events led to decreased immune function and that those who coped better with stress recovered more fully. An especially strong study at Stanford University Medical School found that women with metastatic breast cancer who completed an intensive group therapy program survived significantly longer than untreated women.

When the AIDS epidemic took hold, researchers were eager to test the ways PNI might apply to this disease. Long-term survivors provided key leads. The 1987 PNI study of 18 gay long-term survivors, designed with the help of 5 survivor consultants, established the field’s relevance to AIDS. That study, by Solomon, Lydia Temoshok (a widely published psychologist at the University of California in San Francisco) and others, found a number of attitudes and behaviors that distinguished long-term survivors and offered hope to PWAs. In 1994, a similar UCLA study by

Solomon and others, examining nine HIV positive, symptom-free people with under 50 CD4 cells, confirmed many findings of the earlier study.

The growing body of PNI research set the stage for clinical programs like the L.I.F.E. program. The core of L.I.F.E.'s approach is "co-factor counseling" -- assessment and remedial treatment of the 19 life issues shown to speed AIDS progression. In refining the program, Leiphart has valued the input of PWAs such as Stinson.

L.I.F.E.'s three-month group education program, during which participants learn about and measure their own co-factors, precedes another three months of individual and group counseling, where counselors and clients jointly develop strategies to reverse negative practices and maintain health-enhancing ones. The program is rounded out by six months of weekly support group sessions to help apply the new behaviors.

Stinson's spokesmodel role is a deeply personal statement of his support for the program. "Many aspects of pro-immune or immune-enhancing therapy are common sense, such as nutrition, water, sleep, exercise. However, when fear, panic, grief, depression, stress and anxiety are present, the first practices to be abandoned or forgotten are those which are common sense. The L.I.F.E. Program reminds me of my common sense. It's as simple as 'getting back on the wagon' when I fall off. Unfortunately, most people don't have a 'wagon' to begin with."

PNI-based programs elsewhere use some of the same elements. At Deaconess Hospital in Boston, for example, the HIV Behavioral Medicine Program has for eight years run a 10-week group counseling and education program that offers training in relaxation, stress management, cognitive therapy (dealing with negative thoughts), yoga, nutrition, journaling, goal-setting, communication techniques and spirituality.

Research into the therapeutic effectiveness of PNI intervention programs, often self-administered, is now underway. Psychiatrist Kemeny runs a clinical trial at UCLA Medical School, where an intensive 12-week therapy group for HIV positive people focuses on maximizing quality of life and learning stress management and relaxation techniques. Half the participants are counseled and the other half, those on the waiting list, are merely observed, with the results -- bloodwork, symptoms, quality-of-life measures -- to be compared post-program.

L.I.F.E. has several carefully designed studies underway. As in other areas of AIDS research, all previous PNI studies looked primarily at gay white men. So L.I.F.E. is taking pains to include often-excluded populations. Besides the original group for gay men, L.I.F.E. is working with other San Diego organizations to offer specialized groups for women, African-Americans, Latinos and people with hemophilia.

Leiphart notes that each group has unique traumas. "Any sustained stress from discrimination or negative social conditions can lead to immunosuppression. Good examples are African-American men who avoid HIV services because of the AIDS stigma in their community and heterosexual women isolated from their HIV positive peers." L.I.F.E.'s research may shed light on why so few women are long-term survivors and on the role of social stresses like poverty, family caretaking

and witnessing a child's death, and biological factors such as women's hormone systems.

The few completed PNI clinical investigations offer mixed results. One early study of relaxation counseling showed no changes in immune markers, whereas three later studies of stress management group therapy showed, respectively, increased CD4 cells and NK cells; decreased antibody to two viruses which can activate HIV; and reduced distress levels predictive of rate of CD4 decline over the next two years.

A two-year study at the University of Miami Medical School found that among 21 HIV positive gay men trained in stress management -- including moderate exercise, guided relaxation and positive thinking -- those who maintained the practices most, and those least in denial about their condition, had the lowest rates of disease and death.

But the research team was denied federal money for follow-up studies.

Of course, from Galileo to Gallo, the history of science has been cluttered with stories of clashing egos, monumental hubris, strong-arming, railroading and once-mocked theories avenged decades or even centuries later. Surely with this in mind, PNI researchers have -- with increasing success -- faced an uphill struggle to transform many tantalizing leads from small studies into the major funding needed for more definitive PNI investigations.

During their lives, activists Michael Callen, a founder of numerous PWA self-empowerment groups who survived AIDS 12 years until his 1993 death, and Aldyn McKean, an ACT UP/New York leader who lived with HIV-related symptoms for 14 years until his 1994 death, played key roles. They publicized early findings and generated support for modestly increased research. Callen's 1990 book, *Surviving AIDS* (HarperCollins), included a popularly written description of PNI theories and research. McKean made eloquent pleas, in both television interviews and speeches at international AIDS conferences, for more long-term survivor studies of diverse populations.

Unfortunately, the well-known views of some "think your way to health" advocates have fed some PWAs' skepticism about even the rigorous PNI approaches. Most PNI supporters hasten to dissociate themselves from that school of thought. After commenting that "it simply makes sense to try to mobilize whatever immune-enhancing effects might flow from marshaling the mind," Callen's book cautions: "On the other hand, I'm troubled by those who believe that attitude is all -- that the search for drugs isn't really necessary because if only you love yourself enough, you can will AIDS away. This seems to me to be a dangerous oversimplification of available evidence." Adds UCLA's Kemeny, "It is very upsetting to me when I see HIV positive people trying to have a positive attitude for fear that if they don't they will develop a worse illness course. I would not recommend to people that they try to force optimism. But I would suggest that people examine their perspectives on the future."

All signs suggest that PNI is on the brink of a major leap forward, in both clarifying the mind-body connection and designing effective therapies. But conservative doctors and scientists, particularly virologists focused on viral studies, control key committees at the National Institutes of Health (NIH) which review grant proposals. Their attitude is exemplified by a 1994 report of the federal

Institute of Medicine, which labeled the role of brain influences on immune defenses in AIDS progression "relatively minor in relation to the overwhelming influence of the virus and other determinants" and discouraged prioritizing such research.

While the National Institute of Mental Health (NIMH), an NIH subunit, has financed limited PNI research, the field received a setback last year. Immunologist William Paul, director of the Office of AIDS Research (OAR), which controls all HIV-related funding at NIH, halted future grants for any PNI research "not directly AIDS-related." The decision incensed PNI scientists; a delegation failed to dissuade him in a face-to-face meeting. Leiphart argues that, given the interrelated nature of PNI basic science and disease-specific research, "it makes absolutely no sense. To ignore the published scientific findings is negligent." Paul did not respond to a *POZ* request for comment. An informed source told *POZ* that this September, NIMH's director of AIDS research, Ellen Stover, stopped funding even AIDS-specific PNI research. Stover denies this, saying she has merely conformed to Paul's requirement "that all work supported with AIDS dollars is AIDS-relevant." She concedes, however, that PNI is "not among our top priorities."

Another sign of NIH's position came this past February when Paul appointed blue-ribbon panels comprising more than 100 scientists plus a few community representatives to evaluate the $1.4 billion NIH AIDS research program. (The panels will recommend a revised AIDS budget by January 1996.) No PNI expert was included among the original panelists.

Citing this and other omissions, ACT UP chapters in New York and Philadelphia began a pressure campaign seeking broader scientific and community representation. One of several concessions OAR granted was the appointment of ACT UP's nominee, Dr. Bruce Rabin, director of the Brain, Behavior and Immunity Center at the University of Pittsburgh Medical School and president of the PNI Research Society. Rabin, the author of more than 300 scientific papers, now sits on a review panel on HIV pathogenesis (disease progression). He observes, "PNI is not considered an area of priority for OAR. The NIH and OAR have to consider where we can make the most advances in how to treat PWAs. The question is viral replication versus PNI. This is simply the politics of priorities." But his own position is clear: "PNI is very important for AIDS, and AIDS money should be used."

In September, at an NIH hearing held at ACT UP's insistence, several statements called for increased PNI research. One came from Eric Sawyer, HIV positive for 10 years and living with AIDS for four. Sawyer cofounded the Michael Callen/Aldyn McKean Fund for Long-Term AIDS Survival Research, based in New York City. "We had to establish this fund because of this same attitude of resistance to financing this type of essential research," he says. "Many PWAs feel that research into PNI probably holds more potential to identify why long-term survivors live so long than endless studies of the virus. For Dr. Paul to limit NIH research to orthodox approaches shows both a lack of understanding of AIDS and an unwillingness to investigate things that might benefit people with HIV rather than drug companies. Until extensive scientific studies in PNI are done, we won't know whether psychological factors or conventional or alternative treatments are the key to long-term survival."

Indeed, long-term survivors themselves may have the most to teach clinicians about PNI. Michael

Callen wrote in 1990, “The human mind is a great, largely untapped pharmacy, and it behooves anyone facing a life-threatening illness to investigate ways to harness this tremendous resource.” Jay Stinson feels the same: “Being a long-term survivor means trying to find what works. Friends of mine who have survived are those able to commit themselves to recovery, to living.”

Stinson now devotes himself to helping form a foundation to export the L.I.F.E. Program nationally and worldwide. “What has kept me alive and gotten me through things others have died of is having a sense of purpose in life.” He recently told members of a L.I.F.E. support group, “You are my purpose. Doing whatever I can to contribute to the quality of your lives is my purpose! I know that because I feel passionately about it. That passion is my hook -- my kedge -- which pulls me through today into tomorrow.”
