The Good Doctor

July 1, 1998 By Sean Strub

Soon after AIDS hit, Dr. Joseph Sonnabend became known as an independent thinker. And from the beginning, this caused him trouble. When he invented safe sex in 1983, gay leaders said he was homophobic and just trying to get gay men to stop having sex. When he cautioned against AZT use in 1986, fellow researchers and activists alike accused him of being murderous, even crazy. He founded both the AIDS Medical Foundation (later AmFAR) and Community Research Initiative (later CRIA), and left each over a clash of principles. His idea that AIDS is caused not by a single exposure to HIV but by many infectious cofactors—his "multifactorial model"—has been alternately reviled and revisited by scientists. His early and then-lonely conviction that AIDS isn't 100 percent fatal gave hope to many PWAs when hope was scarce. As a clinician who focuses on what makes his patients sick today, Sonnabend has shown a gift for keeping people alive. Even the "lost" causes.

I'm one of the dying he has kept alive. Not through some magic combination of pills he urged me to take, but through an intangible conveyance of hope, respect, trust and—ironically—through urging me not to take certain pills. Since my diagnosis, I've outlived three of the four doctors I had before Sonnabend, each of whom, while caring and compassionate, had sought to prepare me for my eventual death from AIDS. Joe was the first to prepare me for survival.

Long before I was his patient, and even before I had met him, Joe's ideas influenced me to approach antiretroviral treatment with skepticism. And having the benefit of his care these last four years—including house calls and late night checking-in phone calls—has helped bring me back from the abyss.

This isn't to say that I've always agreed with Joe or done everything he advised. I probably started chemotherapy for Kaposi's sarcoma (KS) later than he would have preferred; I didn't prophylax against MAC and fungal infections as regularly as he would have liked. And he strongly disapproved when I suspended my PCP prophylaxis after my viral load dropped and CD4 cells rose. It wasn't his specific treatment plan that "saved my life"; his method of doctoring helped me do it myself. This is the story of how I came to Joe.

In 1979, I consciously avoided Joe Sonnabend. The most promiscuous gay men in the city went to Joe to get their shots of penicillin, antibiotics and other treatments for STDs. I didn't think of myself as promiscuous and resisted being linked with those Village clones. By the mid-'80s, my respect for his message had grown. But my fear of being associated with Joe had increased as well—I didn't want to be whispered about at cocktail parties, avoided at AIDS events or thought of as a “dissident,” that most-maligned of labels.

At that time, much of the AIDS establishment viewed Sonnabend as an outcast; his patients risked being labeled as outcasts themselves. Most people with an HIV diagnosis were feeling too cast out, thank you, to risk further marginalization for seeing a doctor who was the focus of such criticism.

Often, we want a doctor who helps us forget about our diagnosis by taking responsibility for it. A doctor who seems to be with the program that is sold to us from every corner—the pharmaceutical companies, AIDS service organizations, the media, even our families and friends. To choose an independent path requires a big leap, psychologically, for the PWA, and then a further challenge to explain and defend every time someone questions our choice of doctors. Back then, I wasn’t ready for that battle.

When my partner, Michael Misove, became ill the day after Thanksgiving in 1988, that no longer mattered. Mike had avoided doctors, hospitals or even any discussion of AIDS. But he had been treated by Joe years before and trusted him. Terrified, I called Joe, who responded as though it were the most natural thing in the world to be called at home on a holiday weekend by someone he barely knew in reference to a former patient whom he probably barely remembered. When I described Mike’s symptoms, Joe told me to take Mike to the emergency room immediately. He suspected—correctly—that Mike had cryptococcal meningitis. Even though Joe didn’t have hospital privileges at St. Vincent’s Hospital, where Mike was rushed to, he stayed in daily touch with me and visited Mike. And never sent a bill. Ten days later, shortly after I returned from the hospital, the phone rang and it was Joe. Mike had died. I believe the care Mike got at St. Vincent’s contributed to his “unexpected expiration,” as the hospital termed it; Sonnabend agreed. He not only consoled me, but raised the issue of Mike’s care with the hospital administration. Most doctors won’t risk criticism of another, at least not officially. But to Joe it’s always about the patients.

Through most of the 1980s, I was KS-terrified, obsessing over every pimple, blemish, freckle and bruise. It was a common refrain among people with HIV: “I can deal with anything but KS.” KS ripped away any mask of health or privacy of illness. KS shrieked AIDS. By 1994 I was finally over it. Until one August day when I found a tiny lesion—less than an inch long—on my torso.

Now I had KS. And I was worried. Not terrified; I knew that few died of a KS lesion that was visible. Far more frightening were internal lesions which, at that time, were virtually untreatable and inevitably led to death—usually within a year of diagnosis.

I liked the doctor I was seeing at the time—Josh Torgorvnick—but was ready for someone new. By 1994, Josh had heard all my complaints and worries a million times. We had argued about treatment issues and politics to the point where we could predict each other’s responses. He was agreeable to whatever treatment I ultimately chose, but it was the agreement of a doctor who felt the outcome was inevitable, so why not let the patient have his way? I wanted my body and my disease to be fresh and curious to my doctor, and that required someone new.

So I made the switch and took my measly KS lesion to Joe’s office on West 17th Street. That office was everything most people believe competent medical treatment isn't. It was in a small apartment, crowded from floor to ceiling with magazines, posters, medical supplies and furniture that wasn't worthy of a low-rent garage sale. Xavier Morales, my partner since 1992, thought Joe was suspicious. "How could anyone expect anything from that dump?" he says today.

The environment was such that patients in the waiting room sometimes rearranged the order of seeing Joe, based on our collective assessment of who needed to see him first, or who had other doctors' appointments to get to. Joe's patients are protective of him. Those of us with insurance remind him to send out bills; those without often helped in his office, cooked him dinner or volunteered with the organizations Joe started. Over the years, his patients have redecorated, filed, cleaned and helped in the management of his practice.

Joe biopsied the lesion and confirmed it was KS. I had my first decision to make: Whether to have it cut out, radiated, injected with chemotherapeutic agents or just leave it be. Joe showed me the research indicating that there was little data demonstrating that any of these treatments slow down the development of new lesions; they were primarily cosmetic. I decided not to treat the lesions at all (by now, I had found another one). Later, as the lesions became more prominent on my neck and face, I found a strange inner strength from having them announce my disease to the world just as they announced the fact that I didn't care who knew or what they thought of it.

Over a year later, I developed KS in my lungs. I couldn't forget my friend Mike Callen telling me when he got pulmonary KS that 90 percent of the people diagnosed with KS in their lungs died within nine months. He himself died of it. Joe recommended I undergo systemic chemotherapy and gave me background on several oncologists. Then I really began to get sick, partly from the rapidly spreading KS lesions and partly from the chemotherapy. While it shrank the tumors and enabled me to breathe and sleep better, the IV infusions made me nauseous and very irritable.

My relationships with friends and family became strained. My temper was explosive, with fists smashing into walls and objects being thrown, even as my body grew weaker. My lungs hurt, especially if I took deep breaths. I squirmed in bed, trying to find a position where my lungs would rest in my chest without pain and allow me to breathe. Several times I was incontinent. My nightsweats so thoroughly soaked the sheets that sometimes Xavier and I weren't sure if, during the night, I had wet the bed or not. Worse than the physical pain was the psychological pain, knowing that my condition was declining rapidly. The seriousness of it sunk in when I found a draft of a letter Xavier wrote (but never sent) to my parents in Iowa, asking them to come to New York City, as "this looks like it might be the end."

Through this awful time, Joe was a rock. He didn't make any decisions for me, but gave me choices, information and encouragement. Every time I faxed him an article about a study, treatment or theory, he would call me up to talk about it as if this was his most important task of the day. If something was nontoxic, but he believed useless, he would tell me that "it couldn't hurt," giving me a desperately needed whisper of hope. That hope, along with treatment and the love of Xavier and my family, carried me through that winter's toughest months and slowed the KS. Early in 1996 I began combination therapy. Within weeks, the impact was dramatic. Today, where my skin was once an angry noir-violet with lesions, only the faintest pink shadows remain.

Sean O. Strub: How did you first become involved in the epidemic?

Dr. Joseph Sonnabend: I started a private practice on West 12th Street in Greenwich Village in 1978. I'd been an associate professor for about eight years—all I had ever done was research as a virologist and microbiologist—and was suddenly out of a job. Basically, I was forty-something and I didn't know how else to make a living.

I had also moonlighted at the New York City Health Department and the Bureau of VD Control, and I volunteered on Monday nights at a screening clinic called the Gay Men's Health Project in Sheridan Square. So when I opened my door, I was immediately seeing tons of young men, all referred to me from the clinic. Of course, the rates of syphilis and gonorrhea in the mid-'70s were simply staggering.

Why do you think you were drawn to that work when others wouldn't dirty their hands?

I never had any problem treating VD. It's not a put-down for me at all. I was quite familiar with the sexual opportunities and situations here in New York City. I was in the center of all of that.

When did you first realize that something was wrong?

Looking back now, of course, I realize that I was seeing cases of AIDS-related PCP in the late '70s. But I first encountered the disease a few months before the first New York Times report in June 1981. I had a patient who had parasites and had become anemic. And in order to have him worked up for anemia I referred him to a colleague. She had him admitted to St. Vincent's Hospital. In the course of working up his anemia, they put a tube down his stomach and saw these purple lesions. The biopsy showed KS. Well, neither of us knew much about this rare a cancer, so she called the National Cancer Institute for a referral, and found out that there were 26 or 28 cases of young homosexual men in New York with KS. And this was unbelievable.

What was your next move?

The dermatologist who was seeing these KS cases was Dr. Alvin Friedman-Kien at New York University. I knew Alvin, so I called him and said, “Is it true? Is this happening?” He said, “Yes, it's absolutely true.” And as I say, it was astonishing, this number of cases—it was just quite unreal.

So I started to work on it. The first thing I thought was, How on earth do we tell people about this? There were only a handful of us seeing gay men with sexually transmitted diseases, and I immediately wondered if these doctors knew about the KS. I mean, I hadn't known. The ones I knew, I called.

But the gay-doctors network and some of the doctors seeing patients with KS didn't think it was that urgent to get the word out. Actually they viewed it as off the wall.

In an upcoming book about the early years of the AIDS epidemic based on the oral histories of about 80 doctors, you weren't included.

I was in fact interviewed. But the tape-recording was garbled. Anyhow, when you read this sort of thing, it's rather unattractive. It's sort of gooey—like telling the world, "I've got a big heart."

Here's a quote from the co-author, Dr. Gerald Oppenheimer: "One thing that strikes me about these doctors is, they are ordinary people who, in the face of an epidemic, did extraordinary things."

I can't agree. There certainly was no leadership. There's no shortage of examples, but the most glaring one is PCP. In the beginning, all we knew was that gay men were getting PCP and were dying. We couldn't know which patient was going to get PCP, but it didn't take us very long to know that if you'd had PCP once, you were going to get it again. Where were all the extraordinary doctors who pushed to get the FDA to approve prophylaxis for PCP? It just wasn't there. But who remembers that now? Who remembers that for many years people were allowed to get PCP a second time and die from it?

How did you develop your multifactorial model?

When AIDS first appeared, having witnessed this incredible surge in STDs in the late '70s, I felt that the two were connected. Saying that it was caused by some brand-new virus just didn't seem reasonable to me. I had been trained in a view of health and disease that had gone out of fashion by the time this disease hit. In my day, we were taught to look at disease not simply as something caused by a germ—there are many other factors that affect one's immunity and the ability to handle infectious diseases.

By the '80s, it was "one bug, one drug."

When something new comes along, scientists will try to make theories to explain the mystery. But one can account for things that are new by recombining old influences in new ways. So I felt there was a connection between the STDs and AIDS. The question was how? And that's when I put together what I still think is a plausible interactive model for how this disease could come about without the need to postulate anything new. And I was then attacked by gay leaders for this model because it implied there was something unhealthy about a lifestyle that exposed you to so many infections.

Do you think people just needed to believe that it was one viral scourge?

The notion that there was a sexually transmitted killer virus appealed to many different constituencies: People who like "family values," people who hate gay men, prostitutes and junkies, people who love to think that extramarital sex can kill. Some gay men liked it, too, because it deflected attention from all the sex taking place in the bathhouse scene.

Anyway, this model I wrote was published. And the next thing that made sense to me as a researcher was to recruit scientists who had expertise in different areas to work on this. I called Dr. Stuart Schlossman, who was the T-cell expert at Harvard, and I said to him, "I suppose you've been bombarded with people who would like your assistance with this." He said, "You're the first person to call me." This was late '81.

I realized then that I was in a unique situation. The other doctors who were treating AIDS didn’t have the research experience or the instincts or the colleagues. I’m not putting them down. They were just doctors with patients. And the academic researchers—the top immunologists, virologists and so on—who had the expertise, didn’t have the patients.

I had both the background and the patients. And that was an amazing discovery. I mean, it was as if I had jewels. I had something so valuable. I had patients who liked me, who were willing to give me blood, who would participate in anything. The one thing I didn’t have was a freezer. I couldn’t afford a freezer, so I kept the blood in a refrigerator that had a little freezing compartment.

I worked in the lab in the mornings, and saw patients in the afternoon. Nobody paid me. I was just sort of intrigued. And, by the way, while I was in the lab, I found out that people with AIDS have lots of interferon in their blood.

Interferon was your connection to Dr. Mathilde Krim…

We had both done interferon research in the ’70s. She also raised funds for good causes. I had a little network of scientists working on this disease, and Mathilde was tremendously supportive. Without her I couldn’t have continued. That’s how the AIDS Medical Foundation (AMF), which later became AmFAR, came into being. We needed money for research. And I have to say that although it was the idea of one of my patients, started out of my office and was incorporated by lawyers who were my patients, without Mathilde none of it would have happened. We started this thing together.

Why did you leave AMF?

I was chairman of the scientific committee, and I felt that scientific issues were being decided without my knowledge. The most glaring example is the effort in 1985 to put out the message that there would be a heterosexual epidemic for which there was absolutely no evidence at that time.

When did we lose our skepticism?

We have definitely lost it. I don’t know that we had it, but we certainly had a wish that maybe some kind of magic had come into the whole treatment issue around 1987 with the appearance of AZT. That’s probably how AZT was promoted and marketed, certainly on the part of drug manufacturers, but also by activists. I think that set the tone for our current HIV-eradication hype, where unfounded expectation really took the place of cautious skepticism.

The results presented in ’86 and ’87 about the efficacy of AZT were beyond belief. Nineteen people in the placebo group died in something like three months, whereas only one person receiving AZT died.

In looking at the AZT trial results, one had to conclude that a key factor in the high death rate might have been inadequate patient management—that is, using the latest therapies to prevent or treat opportunistic infections.

When were you first called a dissident?

I had written a report on that trial. It didn't say that AZT didn't work, but it raised some doubts about the dramatic effects of the trial. I suggested that if AZT was used, it should be used for no longer than 12 weeks because that was the observation time. I didn't intend for this to be published, I just circulated it around. It was met with total silence. I never got a comment from anyone, not a soul. Not even to say this is rubbish, I don't agree with you, nothing.

What happened in the early days when you weren't prescribing AZT?

I think the patients who came to me were people who were reluctant to take AZT, who didn't feel comfortable with the hype, for whatever reasons. Only a few doctors were supportive of such patients.

I was accused of malpractice for withholding treatment. There were two extreme responses to my position on AZT. The first group—mostly patients, advocates and community people—were very angry with me. Then there were others who shared my aversion to AZT but who represented a kind of dissident position I didn't want to be associated with.

When did you find out you were on the minority side of the issue?

I was kind of surprised to find myself on the outside. I had rather thought that I represented a kind of academic caution that I took for granted to be the norm. I always believed my criticisms were reasonable and not radical.

In light of the results of the 1993 Concorde study, it's generally accepted that AZT monotherapy hurt more people than it helped. Has the medical establishment ever admitted to PWAs that it was wrong?

There were particular categories of people that it probably did help in the short term. But I think that, in the aggregate, more people were hurt by AZT. The establishment has not and never will recognize it, certainly not in this generation.

After you became branded a dissident, how did that affect you?

In all kinds of ways. I couldn't get my research funded, I couldn't get my work published. I'll just give you two examples, one petty, the other less so.

A few years ago, Bob Gallo invited me down to his annual meeting in Bethesda to give a talk. And during lunch, I was standing in line next to an NIH epidemiologist with whom I had interactions in the early days. He turned to me and said, "Oh, I guess it's OK to talk to you now." It was a little joke. I mean, people shunned me. It was like little children, afraid to sit next to me or be seen talking to me.

The other example was when I was involved with Michael Callen and Tom Hannan in setting up the PWA Health Group in '87. We started the group to distribute the egg lipid, AL-721—not homemade but purchased. We were having trouble with the company, and we needed to get the product tested to make sure the 7-2-1 ratio was right. I found a lipid chemist at Brown University in Providence, went up and spent the day with him, and he agreed to help us. A few days later I got a call saying that he had checked with someone at the National Institutes of Health, and was told not to have anything to do with me. And he told me he wanted nothing to do with me.

It must have upset you.

Of course it did. Also, it saddened me because it's no good having good ideas if you can't get support for them.

The STD-AIDS "lifestyle" connection may have been attacked by gay leaders, but it was embraced by many PWAs.

Yes. I talked about it to my patients, and it really resonated for two of them, Michael Callen and Richard Berkowitz. So I got them together and they hit it off, and they became what my detractors called my "shock troops." We wrote a booklet, How to Have Sex in an Epidemic, to try to get out the message about using condoms. And in those days, GMHC hated us because we spoke about promiscuity and used words like sperm and rectum in public. We brought the ire of the gay community down on us for even daring to suggest that behavior spreads germs. All that's become fashionable now with people like Gabriel Rotello, but back then it wasn't the thing to say. We became hated people.

It must have been hard to lose an ally like Michael Callen [who died in 1993].

Of course I miss Michael. He was my mouthpiece as it were. You know, I'm a rather reserved person. I don't like being in the public eye, but I feel I've had things that needed to be said. And Michael was a brash person who loved fame and all of that. So, I wrote his lines on medical and scientific issues, basically.

Michael Callen called AZT "Drano."

That was one line I didn't write. I said, "AZT is incompatible with life." Michael Callen was a great guy—complicated, but great. He had enormous sexual exuberance. He did many wonderful things—he embodied a sort of confrontational activism that I understand and respect—not the collaborationist kind. It starts with the importance of self-reliance and not depending on experts. I mean, you can't do without them, but you can't trust them, either. But what you can do is, deal with them generically. That is, make them accountable to you by asking a lot of questions. I think the same notion of self-reliance led me to help start a series of do-it-yourself organizations.

AIDS Medical Foundation, Community Research Initiative, PWA Health Group.

And except for the health group, I no longer have anything to do with any of them. But they started as institutions that were meant to embody that kind of confrontational activism. Of course, that's a very romantic view. It hasn't survived as a viable thing. The community doesn't seem to want it.

You mentioned a second type of activism, a collaborationist kind.

That’s what has essentially won out. As exemplified by TAG and Project Inform and all these activists who sit on all these committees with industry and government representatives.

Do you think that the state of research and current treatments would be better off if there had been no ACT UP? Yes. I have come to think that. There’s no quick fix in terms of the basic science, and to the extent that activists lobbied for a single drug and early intervention and all that, they did an injury. But you can’t blame them really. The question to ask is, Why do the academic researchers dangle this hope in front of them?

As a clinician, how do you see the influence of pharmaceutical money in prescribing patterns?

[The drug companies] absolutely call all the shots. But unlike you and your magazine, I don’t have to deal with these things if I don’t want to. I mean, they don’t need me at all. For one, they advertise directly to patients. Their objective is presumably to get as many people with HIV as possible to take the drugs. That was true for AZT and now it’s true for the protease-based combinations. But since there’s no evidence to support the use of these drugs in asymptomatics, the industry has mounted this incredible campaign with potent imagery to get people scared enough that they demand treatment. It goes like this: New research shows that the virus is never latent, and that every day there are trillions of new bugs produced and your T-cells are blowing up. Even though you may feel fine, there’s a war raging in your blood. Now we have these wonderful tests that measure the virus and these amazing drugs that can put a stop to it. “Be smart, get tested, get treatment.” And they have these billboards all over the place. It’s terrifying.

Do you see any good effect at all in terms of public education from the direct-to-patient advertising?

What one needs is unbiased, disinterested information, and there’s precious little of that other than journalism. And for the most part, science writers have been bought out. They have a rolodex of famous names, they receive press kits from the companies or the scientists. Every learned institution has its own media-relations department, whose job it is to raise money by presenting the work of the institution in some sort of wonderful, glowing light. And this is what journalists read and who journalists interview.

What do you expect to see in the next years?

In the immediate future, I think the balloon is going to burst as more people exhaust their options. And that’s beginning to happen. It’s going to be sort of similar to AZT, which didn’t live up to its promise. There has been a series of empty promises put out there that were no more than grandstanding.

The epidemic’s demographics are shifting. I fear that AIDS is going to become the disease of the inner cities and invisible to the rest of the world and we won’t really care because it’s about the problems of black, Hispanic and poor people. Traditionally, their health concerns have not been anybody’s concern.

What have you been most wrong about in the course of the epidemic?

In the beginning, as far as gay men were concerned, I thought this disease was only affecting those with a history of multiple STDs. But now I've encountered people who apparently have never had syphilis, hepatitis or anything else—who don't fit into that model. So that was wrong.

The other thing is the role of HIV. It's not as simple as saying that HIV causes AIDS. It's rather a view that infection with almost any microorganism doesn't cause disease in every infected person. It's not clear that HIV came from monkeys who suddenly started to bite people in the last hundred years. It's probably been endemic for ages in a small percentage of humans, maybe more or less in different geographic areas. And that a small inoculum may not be followed by seroconversion, but that HIV becomes integrated into DNA, dormant and latent. It may be reactivated, but the immune system may control it and not enough virus is made to seroconvert. After all, many species have their own immunodeficiency retrovirus, which usually doesn't cause disease. Why should humans be any different? I don't think we're dealing with a simple infectious disease.

This theory might explain why men so rarely get HIV infection from women in the West. Despite frequent sexual contact with infected women, men rarely get AIDS that way. But it's hard to believe that they don't get HIV.

That's a fascinating and new idea.

Well, it's not new: I proposed this theory a long time ago. The best evidence is from studies of seronegative partners of seropositives who have not seroconverted but have immune responses to HIV measured by various techniques. One explanation could be that they were exposed to defective virus. Or that they are about to seroconvert. But HIV has also been found in people who don't seroconvert over the long term. The way to prove the theory would be to find HIV in seronegative people by taking specimens at autopsies of thousands of people and looking for HIV in tissues.

Do you think HIV can be eradicated?

The eradication hypothesis was always, for anyone who knows the most basic elements of virology, a fanciful and cruel idea. Knowing the nature of retroviral replication, to even dangle this hope was a way-out notion. It may have been a theory worth investigating, but it should have been kept quiet. It was a gimmick that says something about the lack of wisdom and maturity of some of those leading AIDS research and the naiveté of the activists who propel them forward. When the viral reservoirs were found in those deemed "undetectable," why were they surprised? Anyone could have told them this would be the case before HIV was even discovered. We've been turned into idiots because we're all pop scientists.

Where are we in terms of treatment and what do you expect in the next year?

We've made quite a significant advance. It's not as far-reaching and dramatic as has been presented, but without question, sicker people have benefited from the new therapies. Unfortunately, I think the durability of the current combinations is going to prove, for many, not as permanent as we had been led to expect. Which isn't to say other useful drugs won't become available. But we have to improvise—do on-the-job training—because we have so little experience with these drugs. That’s not the way things ought to be, but that’s how it is.

How many patients with HIV have you treated?

Oh God, thousands. The only list I ever kept was the list of my patients who died. But I’ve stopped. I was well into the 300s when I stopped. I just couldn’t bring myself to do it anymore.

Twenty years after he first began seeing immune-compromised patients, Joe Sonnabend’s life is somewhat calm and may, for the first time since the beginning of the epidemic, soon be defined more by the personal than the professional. He is excited over a budding new relationship with two sons he fathered 37 and 42 years ago. One he had never spoken to until he received a call last March. They spoke for an hour; the son knew all about Joe and his AIDS work and told Joe how proud he was of him. How glad he was to have finally found him. How anxious he was to see him and introduce him to his family.

When Joe called me with the news, he said, “Guess what! I’m a grandfather and one of my grandchildren is named Sean and one is named Megan.” My sister, who publishes POZ, is named Megan. I smiled at the coincidence, and my heart swelled with joy for the happiness and excitement in Joe’s voice. For years, his family was his patients, whose instinct to survive drove them to him. Now, at 65, he’s been found by a family who might need him for entirely different reasons. And he them.

Sonnabend’s Brief

Two decades at ground zero

1978 Opens New York City practice of mostly gay men; soon starts to see immune problems in patients

1981 Develops theory that leads to discovery of interferon in PWAs’ blood; also theorizes about auto-immunity in AIDS

1982 Develops multifactorial model of AIDS (published in JAMA in 1983)

1983 Helps found AIDS Medical Foundation (later AmFar), based on collaborations he had initiated; chairs scientific committee

Develops and promotes concept of safe sex; helps write first safe-sex publication (with Richard Berkowitz and Michael Callen)

Co-authors first publication on confidentiality issues in AIDS that wins prize for research in ethics by American Federation for Clinical Research

Files, along with five patients and New York state attorney general, nation’s first AIDS discrimination lawsuit to stop eviction by co-op board (settled, 1984)

Starts and edits first AIDS scientific journal, AIDS Research

1984 Writes first account of importance of PCP prophylaxis for PWAs

1985 Resigns from AMF, angered by what he believes are fundraisers' exaggeration of AIDS threat to heterosexuals

1986 Fired as editor of AIDS Research, which subsequently is controlled by government-affiliated scientists and industry

1987 Writes proposal to conduct AIDS clinical trials in a community setting; CRI is formed

Cofounds, with Tom Hannan and Michael Callen, PWA Health Group to distribute egg lipids; it is soon expanded to import AIDS medications not yet approved in U.S.

1989 CRI denied large grant by NIAID, some say due to Sonnabend's criticism of that agency's policies

1990 Cofounds Community Research Initiative on AIDS (CRIA), CRI's successor, and becomes medical director; champions trials of non-pharmaceutically sponsored treatments

1996 After months of bitter feuding, the CRIA board dismisses him as medical director

1997 Becomes staff doctor at Stuyvesant Polyclinic in East Village

NOT YOUR AVERAGE JOE

Richard Berkowitz, Journalist

Joe has been my doctor for 20 years. Knowing how important sex was to me, in 1982 he told me, "Don't get any more sperm inside your rectum and I think you'll be OK." In the darkest days of panic and despair, he handed me hope. Then in 1987, everywhere you turned, the unrelenting message was to run and get your AZT—but Joe convinced me to stay off the bandwagon. His eternal optimism with respect to surviving an AIDS diagnosis with quality of life, dignity and a healthy sexual appetite has a slut like me welcoming the new millennium with more CD4 cells than I had in 1983.

Dr. Robert Gallo, Virologist

Sonnabend introduced the epidemic to many scientists. While initially we sat on two opposite poles, we're now studying the same thing. We got off on the wrong foot because of his original beliefs about the virus, but he is long beyond that now—he knows HIV causes AIDS.

Spencer Cox, Treatment Action Group

Joe is an iconoclast, but unlike other less-informed rebels, he's not unsusceptible to data. The most important thing I learned from him is the scientific mindset: Look at the evidence, figure out what it means, and decide what’s missing. And he’s taught that mindset to many other AIDS advocates and doctors as well.

Dr. Peter Duesberg, Molecular biologist

Sonnabend was one of the first to question the HIV hypothesis. For that he should be commended. But he lost dearly: His lab, his influence, his editorship—he became an outcast in the AIDS community. Lately he’s become fairly critical of me. He’s found a more middle ground and developed a new, more “multifaceted” hypothesis. I’m not condemning him. There is such pressure to conform -- people give in after a while. I give him credit for raising his voice, but I’m disappointed he didn’t follow through.

Gabriel Rotello, Author

Sonnabend is one of the most important people in the history of AIDS prevention. He helped invent safe sex as we know it. Having done that, he’s saved more lives of more gay men than anyone. For that he deserves a place of honor. We followed his advice as best we could at the time, but if we had followed it earlier, I believe the outcome of the epidemic would have been less tragic.

Mathilde Krim, AmFAR cofounder

What did Sonnabend contribute? He contributed me. He was the one who alerted me to the problem. I remember the day in the early ’80s when Joe came to me and said, “I’ve lost my stature as a physician. I have patients with big lymph nodes and high fevers, and they don’t get better. What’s strange is they’re all young, gay men.” He’s the only doctor I know who goes to every funeral. From the beginning, Joe said the government was wrong to give money to academic clinical research—people who had no contact with the disease.

Marisa Cardinale, CRIA former director

Joe’s safe-sex piece with Callen and Berkowitz was one of the first times that people who were gay and affected by AIDS spoke out. It was extremely unpopular at the time, but it started the ball rolling toward early prevention. He clearly inspired me as well as some of the more dedicated activists who have focused their lives on AIDS. What was he like to work with? I don’t think I should comment on that.

Laurie Garrett, Journalist

Joe has a very strong sense of conscience. He has pushed and prodded and provoked the medical community to put the patients first. From the back of the room at esoteric virology conferences, he would get up and yell, “Hey, what about the patients?” His theories haven’t always been correct, and he’s always had a style that could be off-putting. Basically, he is what he is, and you either dig it or you don’t. But he doesn’t make it easy.

Randolph Wicker, Activist

Some years ago I had a $2 million medical policy and a lover dying of AIDS. In the hospitals, doctors would come in for five minutes and charge us $250. Joe was a completely different story.

He came all the way out to Jersey and wouldn't let me pay him anything. He's the kind of doctor who gives medicine a noble name, but he's not the kind of guy you'd notice in a crowd. But when he used to walk in AIDS marches, people would applaud when he went by. He is a living saint.

Celia Farber, Journalist

I sat next to Joe at the 1993 Berlin conference when the Concorde results were announced. And all the AIDS kings were lined up at the podium—Martin Delaney, somebody from TAG and a few hard-core AZT doctors. They kept using all the buzzwords: reassessment, confusion. And Joe was livid. "You bastards," he muttered under his breath. "There was never any confusion. You're the ones who caused the confusion. God, they're all so dishonest." "Say it," I whispered. "Stand up and say it, Joe." And he almost did, but he didn't. That's the thing about Joe. He always forgives them. Almost like a parent would. The tragedy—in the purest sense of the word—of the AIDS epidemic is recorded in him. But who can he tell it to?

Dr. Anthony Fauci, NIAID director

Joe has been there from the very beginning. He is one of the true soldiers in the war against HIV. He is a model for a real translation of care to the patient. In terms of the controversy surrounding his work, I think, in general, at the end of the day, most would agree that his contributions have been positive. He is an outstanding man.

Xavier Morales, Sean Strub's partner

Joseph Sonnabend is cuckoo—like Einstein.