Trial of the Year

The whole world watches as one man wins the right to choose his fate

April 1, 1996 By Bruce Shenitz

When Jeff Getty received a transplant of baboon bone marrow cells last December, the procedure unleashed a flood of AIDS-related reporting surpassed only when Magic Johnson rejoined the Lakers. His face popped up on *PrimeTime Live* and in *People* magazine; his name appeared in endless newspaper interviews. Television crews from all over the world descended on his Oakland, California home, while hundreds of interview requests flowed by fax and phone. But even as he handled the press with the skill of the long-time political activist that he is, Getty was settling back into his home office, getting back to what he does best: Giving hell to anyone he thinks is standing in the way of better treatment options. “I’m a real mean activist,” he acknowledges, not without pride. “I take no prisoners.”

That uncompromising attitude is one reason why he’s accomplished so much and lived for more than 10 years with HIV: He’s always willing to push the envelope. In fact, the bone-marrow infusion was not the first time he put his body on the line. He was an early user of compound Q (which didn’t work) and was the first person with HIV to receive white blood cell transfusions from a sibling (which temporarily shored up his immune system). He’s gotten used to advancing the frontiers of knowledge -- and life expectancy: “For every year that I was HIV positive, that was the same number of years the CDC said that you could expect to live,” he jokes, adding that every January he picks up the phone only to hear the caller hang up; he says it’s the CDC seeing if he’s still alive. “If I answer the phone, they add another year on to how long you can live with AIDS,” he laughs.

His willingness to try the new procedure was inspirational. “An awful lot of people have felt a sense of hope,” says Martin Delaney, Founding Director of Project Inform. “[There is] the sense that a single person can make a difference, that obstacles can be overcome. He’s inspired other people to keep on struggling.” Getty, never shy, agrees. “I’ve always been at the edge.”

As I prepared to meet Getty for the first time, I wondered whether he would prove to be as formidable as his reputation: Even friends outdo one another in enumerating the ways in which he can be difficult. “He’s abrasive, he’s rude, and he always gets what he wants. And that’s why we love him,” says Katie Krauss, a spokesperson for ACT UP/Golden Gate. Not knowing what to expect, I phoned up from the security gate of his small apartment complex in a transitional area in west Oakland. As he buzzed me into the courtyard, he opened a second floor window to wave me over.

Getty looks surprisingly boyish in person; he has an oddly plastic face that changes abruptly with his moods. When he's off and running at the latest target of his anger, it's all sharp angles and planes, and he shows no hesitation as he lays out his arguments in a strong and clear voice. Catch him in a more reflective moment, though, and his voice softens; he's likely to crack a smile or laugh at his own foibles. He also has a deeply felt spirituality that provides strength when his many battles become overwhelming.

And although he skillfully uses the media as much as the media use him, he retains a sense of humor about and separation from his public persona. We watched a bit of a home video taken after the infusion that showed him exploring the hospital hallway wearing a surgical mask; he turned to the camera and started jumping on the furniture, as if savage baboon genes had altered his personality. I started laughing and told him it would be a good counterbalance to the ogre-like public image he takes such pains to cultivate; he guffawed but good-naturedly told me to shut up. Even a medical pioneer can't take himself seriously all the time.

Despite his appearance in *People*, Jeff is not related to that other famous HIV positive Getty, Elizabeth Taylor's daughter-in-law and oil heiress Aileen. Jeff Getty was born in New London, Connecticut in 1957, one of four children, and the only son. He grew up near the Coast Guard academy, and sailing became an important part of his life from an early age. By the time he was 10, he had bought his first sailboat with his sister Kim. (Sailing remains a great passion, and friends say that to really understand Jeff, you have to see him on his boat.) When he wasn't busy sailing, he was living a Tom Sawyer boyhood. Along the docks, the young Getty nurtured his pioneer spirit. "We lived in the country and we were let loose to run anywhere we wanted," he says. "As children we were raised to be very independent." When he was as young as five, his mother would pack the kids off with a lunch and suggest they go on a hike. Getty remains close with his three sisters as well as his parents, who are now divorced. He has a videophone at home, and his father has one at his home in Connecticut; when Jeff was in the hospital for the infusion, he kept the videophone right by the bed. "Every day, my father's face would appear," he says softly. "Sometimes, I'd take my shirt off so he could see if I was losing weight. Which was good, because it kept him from flying out here."

In addition to his mother and sisters, his partner Kenneth Klueh was with him as well; Getty and Klueh have lived together since 1987. Klueh, a cabinetmaker and general contractor, has been HIV positive for about 15 years. He had a bout of non-Hodgkin's lymphoma in 1991 but has been in remission ever since. Klueh, 49, has a calmness about him that counterbalances Getty's high energy . Klueh's not interested in being in the public eye, he says, though "I think it's great that Jeff can do it. I'm very proud of him, and I support him 100 percent." In marked contrast to Getty, Klueh is not an activist. "I like to think of myself as being able to provide some perspective, and also to provide a reference point, stability at home." Also sharing their home is Tuna, a three-year old black cat who quietly glides through the house when he's not checking out the papers on Getty's desk or nibbling an olive with the pit thoughtfully removed.

For a man who was gladly injected with baboon marrow, Getty has some unconventional notions about how to stay healthy. He hasn't flown for several years, because he doesn't want to get sick

from breathing recirculated air. “I knew activists who flew all the time,” he says. “They’re called ’flying AIDS divas’ and they really flew themselves to death, I think.” Staying in one place has it’s advantages, he says. “Number one, I think I get more work done than anybody else. Number two, everybody knows where to find me.”

Where he can usually be found, when he’s not out at an ACT UP/Golden Gate meeting, on his boat or at the Center for AIDS Services in Oakland, is at the cluttered desk right by the entrance to his three-story loft. The facilities are minimal: Two file drawers filled with articles and other research materials, a phone, a fax, a photocopier and a pile of books with a Ken doll on top. “What I do is work on getting the most promising therapeutic drugs and treatments for people with AIDS,” he says. He’s explaining this to me as we sit in the upstairs bedroom; Getty is wearing a bright red bathrobe, gray sweatpants and a plain white t-shirt. I’ve stopped by on my way to the airport, and he’s squeezed in another short session as he’s getting ready to run off to do a TV interview in downtown Oakland. “It’s what I’ve been doing for years. I just sit there, and I just work at it all day. And I don’t mind doing that. I don’t mind that being my life, because it’s very rewarding work. When we know that we’ve cut a year or two off of [the drug approval process], we know we’ve saved lives.” He also makes himself available to talk about medical issues with people with AIDS. “Sometimes they just need a pep talk,” he says. “And sometimes they need for me to give them some ideas.”

The idea for the baboon bone marrow infusion experiment began about three years ago when Dr. Suzanne Ildstad, a transplant surgeon at the University of Pittsburgh, got in touch with the Immune Reconstitution Think Tank (funded by Project Inform) for help in building support for the project. Martin Delaney told Getty about the procedure, and after researching the topic himself, he wrote to Dr. Ildstad and volunteered himself as a subject. He was, as he told the *San Francisco Chronicle*, “a soldier in the front lines of AIDS,” where he was “sitting in a foxhole, watching shells landing in my friends’ foxholes and watching them die one at a time.” When it turned out that Getty matched the experimental protocol almost perfectly, he was selected to receive the transfusion. But that was really just the beginning of the battle. As Delaney says, “It took someone like him to make this happen. It had to be a patient who was willing to take an active role in the fight.”

The FDA was concerned about the possibility of a cross-species transmission of an undetected virus that might take a more virulent form in a human host -- and then spread unchecked, a new plague. Martin Delaney vigorously rejects overplaying that concern. “What’s so irritating [is the attitude] that Jeff can’t be trusted not to screw everybody,” he says. “Transmission is a far more common risk in animal handlers, veterinarians and zoo keepers. Getty’s no more likely to get [an animal disease] than someone bitten by a monkey.” According to Getty, “The CDC doesn’t want me to have any sexual contact with anybody for now, until we’re sure that I don’t have any baboon pathogens. They don’t want me exchanging saliva to be extra, double safe. It’s my assumption that at some point I’ll be able to return to having safe sex.” For the time being, he says, “The only person I can have sex with is the government. They send a little cup [for sperm samples]. I suppose it would be safe to have sex with baboons.” Getty is complying with the government regulations and provides regular specimens for CDC monitoring; so far, no baboon

pathogens have been found.

That alone is a triumph, as far as Getty and Project Inform are concerned. Although no baboon cells were detectable about 6 weeks after the infusion, Getty's health improved markedly. He's gained weight and has regained normal lymphocyte counts. His CD4 and CD8 counts have returned to levels he hasn't seen for several years. His doctors believe that the immunosuppressive radiation treatment Getty underwent before the engraftment may have also destroyed the HIV as well, bringing about the improvement in his immune markers. In any case, they intend to repeat the experiment on a new subject and make use of the knowledge they gained from Getty's procedure.

Getty almost didn't have the chance to see if the procedure would work. Dr. Ildstad was ready to perform the operation last April when the FDA informed her that federal law required government approval for an experiment that could be dangerous to the patient or the public. Last summer, when the FDA was about to hold public hearings on the safety of the procedure, Getty's family went into action. His sister Kim used a personal contact to set up an interview with an Associated Press reporter; when the story went out on the wires, it played up the fact that a "no" from the FDA would crush Kim's hopes for her brother. On July 14, which happened to be Getty's 38th birthday, the agency unanimously approved the procedure.

The operation was scheduled for the fall but had to be delayed while Getty recuperated from a bout of pneumonia. After he recovered and was getting ready for the operation, he said, "Part of me said I'd come out of it, part of me said I didn't know. It's always like that when you try something." And there was a hard moment at home, sitting on the living room sofa and saying good-bye to his cat. "That was really the only time I cried, because I didn't know if I was going to see my cat again."

Getty first came to San Francisco from Vermont in 1977, figuring that he could establish residency and continue his education at the University of California; he also liked the idea of leaving the cold weather behind. It was, he recalls, "exactly like *Tales of the City*," Armistead Maupin's portrait of a pre-AIDS San Francisco where you really could step out to the neighborhood supermarket and pick out a sex partner along with the groceries. It was a great time to be a 20-year-old bisexual in San Francisco. If life in Baghdad-by-the-Bay sometimes seemed like an endless party, "I was the party favor," he laughs. "I had a lot of fun, but I got infected, too."

Getty eventually got a job at the University of California, where he was an administrative analyst in the admissions office. He took advantage of the University's employee development program to learn about software, and became something of a computer jock. He got married to a woman in 1982; that lasted five years. He and his ex-wife, who is HIV negative, remain close.

When he was first diagnosed as HIV positive in 1985, he went to a therapist, who advised him he needed to find a reason to live if he was going to fight the disease. "At the time, I was somewhat of a yuppie, getting the house and then the cars and then the boat." Sometime later, Getty happened to run into an old friend who suggested he try doing some volunteer work. "I'd never

really done anything like that," says Getty, "and so I started working at food banks, and it became addictive. I enjoyed it. It evolved into caring about other people. And becoming more extroverted, more compassionate, and then empowering myself, by making these really good connections."

Pierre Chapman, the friend who helped launch Getty on the path to community activism, doesn't think Getty changed all that radically. "Jeff Getty a yuppie? No way," he laughs. "What happened was that the disease caused him to focus and apply his energies to something. It's his struggle. He's taken the bull by the horns and run with it." His sister Kim, a real estate broker in Concord, New Hampshire, also thinks Jeff overstates the yuppie characterization. "He was always a little more offbeat than mainstream." But, she says, "he's definitely changed [since getting AIDS]. He has gotten much more sure of himself, much more aggressive about his treatment."

Not long after becoming politically active, Getty crossed a personal Rubicon just as he was crossing the U.S.-Mexico border. He'd traveled to Mexico from a conference in San Diego in order to obtain isoprinosine, and he hid a cache of it in a piñata. As Getty opened his suitcase for inspection, the piñata fell out and burst open. The U.S. Customs officer was, laughs Getty, really angry. "What are these drugs for?" she screamed. U.S. policy permitted AIDS patients to bring a personal supply in, Getty says, but "she knew that I had to say that I had AIDS, and I knew that I had to state that I had AIDS. So I just very loudly stated to the whole room, 'Because I have AIDS.' I'd totally faced them and done it," he laughs again. "This was a major turning point in my life. When I stood up and said the words, the fear balloon popped."

As we talk about the baboon infusion, Getty takes a break by restringing his Martin D-28 acoustic guitar. He's been playing since the sixth grade and still plays the blues for emotional release. "I've been playing a lot of blues since I've been to the hospital." When we met in California in late January, he knew nothing about whether the operation would be successful. Nevertheless, he was excited when talking about the procedure, which he likes to refer to as "a 37-minute bungee jump." For Getty, the significance of the operation doesn't lie just in the fact that it was a first. "I saw the seams of AIDS research stretching," he says. "One of the most compassionate moments I've ever had in dealing with AIDS researchers and doctors was when I realized that they were willing to kill me, right there at that moment, in a one-shot attempt to learn something that would possibly save me, rather than do nothing and watch me fade." It may not fit everyone's definition of compassion, but Getty had volunteered for the operation to help advance research as well as to try out an experimental treatment for himself. He scoffs at those who want to "protect" those AIDS patients who are willing to take a risk from the potential dangers of their own actions. He compares himself to the first person to take the rabies vaccine: "I'm the same guy. It's the same damn thing. And it's the same ethical dilemma. It's just when you look at the rabies story, who do you think was right? Well, hindsight is 20/20. I can take it one step forward. Why not respect their right to try to save themselves and other and make a contribution?"

Treatment options are a recurrent theme with Getty. "Give us as many options as possible," he says. "I've always felt that to take on this disease very aggressively was probably the only way to survive. And so far it's worked out for me. All the people I know who said 'wait and see' are dead." I wonder whether that attitude can revictimize people who are already struggling with the reality

of a life-threatening illness, since it implies that the only reason people ever die is that they don't fight hard enough. "Within the community of the people that are dying, we have our own little communications to each other," Getty says. "We urge each other on and we know when it's time to give up, and we let go. We help keep each other alive. And sometimes when people die it's easy to say, 'Well, they didn't fight very hard and they gave up.' And that's probably not correct all the time. But it's naïve to say that that isn't true, either."

Aside from the fact that he's a fighter -- Getty often speaks in war metaphors -- he has a strong grounding in a spiritual practice called Eckankar, which he has studied since he was a teenager. He describes it as "an esoteric spiritual path that deals with something called soul travel, which some people would refer to as out-of-body travel." Coupled with his fierce desire to fight the disease and survive is a sort of tranquility. "I don't fear death," says Getty. "I've had three or four experiences where I was taken up and shown the world that we live in after we leave this one." He says that "I got to visit my [deceased] friends because I was pining for them and was worried about them. And then I got to see that they were okay." When Getty talks about his beliefs, he's very quiet yet firm. At one point, when he described one of his soul travel experiences, he looked up at me and smiled. I had the feeling he was waiting to see if I would scoff, but the matter-of-factness of his manner compels respect from the most skeptical of listeners. As Getty puts it, "I don't have a spiritual belief system, I have a spiritual reality. I don't believe it, I know it."

Jeff Getty has been feeling well since the transfusion; as an unexpected side effect of the irradiation treatment he underwent to suppress an immune reaction to the baboon cells, he no longer has asthma. He's resumed most of his old activities, and has even been out on his sailboat again. He's beaten the odds, so far. Ironically, he's partially a victim of his own success. His original financial plan was drawn up to take him through 1995; now, he jokes, "I may be the first late-stage AIDS patient that viatical insurance will turn down because they think he's going to live."

Jokes aside, Getty does acknowledge that "I can see myself more as late stage now than ever." But, taking a cue from a banner that hangs in his room -- *Don't give up the ship* -- he's not even close to surrendering. "Maybe I could go down fighting," he says. "I don't want to end up in the hospital. I'd rather be killed on the battlefield."

© 2026 Smart + Strong All Rights Reserved.

http://beta.docker.poz.com/article/Trial-of-the-Year-1782-2790