

Kenny Jenks: Aids Battler

Kenny Jenks is the last surviving AIDS patient in the United States to receive government medical marijuana. Now 31, Jenks was born on the Fort Walton Beach, FL airforce base, where his father, a career military man, was stationed. When he was six months old the doctors there discovered that he suffered from the rare blood disease hemophilia—which prevents clotting and causes its sufferers to bleed uncontrollably. Twenty-five years later Jenks contracted the AIDS virus from a supply of contaminated blood used to produce Factor 8, the material used by hemophiliacs to stop their bleeding. His wife, Barbra, contracted the AIDS virus from him and died on March 28, 1992. Before she died, however, both Barbra and Kenny worked with Robert Randall to establish the Marijuana Aids Research Service, MARS, which reduced the amount of paperwork involved in applying to the Food and Drug Administration for the Compassionate Investigational New Drug (IND) program which provided marijuana to patients suffering from AIDS, cancer, glaucoma and a number of other illnesses. The MARS project was so successful at reducing the amount of time it took for a doctor to apply for the program on a patient's behalf that the Federal Government shut the program down altogether in March of 1992, claiming that too many patient's doctors were applying for medical marijuana. Kenny and Barbra were the recipients of the Drug Policy Foundation's 1992 Robert Randall Award for Excellence in the Field of Citizen Action, and Kenny continues to speak publicly about marijuana as a vital medicine for AIDS patients. HT originally contacted Kenny for this interview in November, 1991, and last spoke with him during February, 1993. At that time he was feeling well, and though the strain of coping with both the loss of Barbra and his continuing battle with AIDS have robbed him of some of his strength, he remains vital, committed, good-humored and full of a rare dignity. HIGH TIMES: What was it like growing up a hemophiliac? KENNY JENKS: I was a typical military brat. I didn't have a bad childhood, but I couldn't take PE in school, couldn't participate in any sports and I spent an horrendous amount of time in the hospital. I had hundreds of bleeds growing up and I'd be in the hospital for weeks at a time strapped to an IV pole. And back when I was a kid, the treatments for hemophilia were mostly ice packs and plasma. The plasma didn't stop the bleeding, it just replaced what you were losing into the tissue. HT: How does the bleeding start? KENNY: It depends. Sometimes it's a bump but other times it's spontaneous. You just start bleeding. HT: Are the bleeds painful? KENNY: The definition of hemophilia is pain. What happens is that blood leaks into the tissue and it swells in the joint, pushing apart the bones. After a number of bleeds the joint tends to get weaker and weaker and the pain gets more severe. I've had so many bleeds in my joints and knees, that they hurt all the time. But I get around real good. A lot of hemophiliacs, by the time they're my age, they're pretty crippled up. HT: What were your dreams, what did you want to be when you were a kid? KENNY: I wanted to be a park ranger. One of the jobs I had when I went to high school was working on a 200,000 acre cattle ranch on weekends and during summers. I went to college for it for a while, in Arizona, but I couldn't afford to continue so I ended up going to work. HT: How did you manage to work outside with hemophilia? Did you carry plasma? KENNY: No. Plasma has to be kept frozen in a hospital. But by the late 1970s something called Factor 8 had been developed. Factor 8 is the blood-clotting factor that's missing, in a very concentrated form. It takes about 2,000 people to make one dose. I was able to bring that home and self-administrate with an injection. If you can get a shot of Factor 8 you can stop the bleeding pretty quick, but the pain still lasts for a few days because the swelling takes a while to go down. HT: Tell me about meeting Barbra. KENNY: Well, I've always worked on cars, and Barbra's father had a garage near where I lived in Arizona. One day a friend and I were at his place looking for some parts and she was there, so I asked my friend who she was. And when we came back a day or so later I told her I wanted to go out with her. I was drunk, to be honest, and she said I should come back and ask her out when I was sober. I thought that was pretty neat. So the next day I did. HT: And? KENNY: It was love at first sight. We knew each other six months then moved to Florida. I worked in a nursery doing landscaping at first, then went to work for a friend who owned a hot dog stand on the beach, cooking hot dogs for the tourists. Barbra worked at a motel, running the desk and doing housekeeping. HT: When did you first hear about AIDS and what was your reaction to knowing the blood supply used in making the Factor 8 was tainted? KENNY: By the middle '80s we heard rumors that the blood supply wasn't clean, so I asked my doctor about it, and he told me there was a good chance we were already infected. But since there was nothing we could do about it and we were afraid to get tested, we decided to wait and see. HT: How did you discover you had AIDS? KENNY: In early December, 1988, Barbra caught a cold that wouldn't go away. She just steadily got more and more sick, until by just after Christmas that year she could hardly breathe. So we took her to the emergency room where she was diagnosed with pneumosistis—pneumonia. Of course, since it was pneumosistis, a pneumonia associated with AIDS, they tested her and at that point they tested me too. We both had AIDS and they started us on AZT right away. HT: What were Barbra's feelings about you having gotten infected and infecting her? KENNY: I have tried to put myself in her position a hundred times. I don't know how she did it, but she never once complained. There was never any doubt as to being together. My wife and I were together for 10 years and would have been together the rest of forever, I believe. For my part, it was a terrible feeling, just a terrible, guilty, sinking feeling. HT: How long was Barbra in the hospital that first time? KENNY: About a month. She was given all kinds of drugs and she got so sick she couldn't eat. Her weight went from 155 pounds to 115. Even when I brought her home she was still sick. We kept a bucket next to the couch because she was constantly throwing up. The doctors tried her on six different nausea medicines but none of them worked. HT: Were you ill at this time? KENNY: Not from AIDS, but I had started to lose weight from the AZT. I'd probably lost eight to 10 pounds. I was nauseous all the time. It's kind of like being sea sick. It gets to the point to where you don't want to raise your head because you'll get sick. HT: Who did you go to when you first find out you were suffering from AIDS? KENNY: We didn't tell anyone. It was just too scary. But the health department here in Bay County came to see Barb in the hospital. They had an AIDS support group meeting once a week and we started going to that. HT: Did you ever have the feeling that the other AIDS patients in the group had done something—with needles or sex—which caused their sickness, while you hadn't? That

you were ripped off while they deserved it? KENNY: No, I never felt anything like that. Actually, until I went to my first AIDS meeting I never really had much contact with anyone who was gay. And it really did open my mind up to people in general. Because here we were, all stuck in this situation where we had this disease that was supposed to be terminal, and none of us knew what to expect. It was more of a feeling of us trying to fight this together than any kind of separation between us. My wife and I really enjoyed going. It was the only chance we had to talk about what was happening to us. HT: So how did you and Barbra decide to try pot? Were you already smokers? KENNY: No. I’d tried it a few times in high school, but I wasn’t a smoker. Barbra had never smoked at all. But at the support group we met an AIDS patient who, like Barbra, just had pneumosistis and was just starting to take AZT. He told us that if we smoked pot when we started to feel sick we could prevent the nausea, and then he gave us some. And at that point, after trying six different nausea medicines, we were pretty desperate, so we tried it and it worked. HT: How does marijuana help? KENNY: It takes the nausea away. The drugs and the disease itself make you lose your appetite. There’s no desire to eat. The smell or sight of food make you sick. It just doesn’t appeal to you anymore. But when you smoke, within six or eight puffs you feel better, then you get the munchies and food is delicious. HT: Did you tell your doctor you were smoking? KENNY: Not at first. After we started smoking every day we told him that we’d thrown all the nausea medicines away and were using marijuana. He just said to keep doing what we were doing if it allowed us to keep food down. I think it’s very hard for most patients to tell their doctors they’re using marijuana, because it’s illegal. I think the fear for the patient is that they’re already sick and dealing with the disease and they are afraid they’ll lose the legal drugs they’re getting. HT: How important to your therapy has marijuana been? KENNY: I don’t think I’d be here today if I didn’t have pot. I’m taking so many drugs that make me feel sick and I don’t think I could continue taking them without smoking. Plus, there are a lot of days I just wouldn’t eat if it wasn’t for marijuana. And if we couldn’t have controlled Barbra’s nausea to the point where she was able to eat she never would have gotten over the pneumosistis bout. She would have died that Spring. After she started smoking she gained 30-35 pounds back in the next year. HT: Where did you get your marijuana? I mean, since you weren’t a smoker you didn’t necessarily have people in place to supply you...? KENNY: I just got it however I could. My friend from the support group helped me out for quite a while, but then he moved. But I have friends and I knew other patients, and it just came. I also started growing two plants to get us through when we couldn’t find or afford it. HT: How much did you and Barbra smoke? KENNY: It depends. Sometimes, if you don’t have much you don’t smoke much, in order to make it last. You know, “I’ll just be a little sick today so I can be a little sick tomorrow.” So it just depended. Certainly five joints a day each. HT: That sounds like quite a lot. KENNY: When you smoke marijuana every day you don’t feel it very much. But you don’t feel nauseated and you have an appetite. HT: Have you ever tried Marinol, the pot pill? KENNY: I didn’t, but Barbra did during one of her hospital stays. At first she just threw it right up. And when they did finally keep it down she had anxiety attacks. She couldn’t eat, she couldn’t sleep, she cried. She described it as going downhill at 100 miles an hour in a car with no breaks, just an out-of-control. After that she never used it again. The problem with a pill for nausea, even if you could keep it down, is the time it takes for the effect to start. It’s just much longer than smoking, where, as I said, you feel the effects in just a few minutes. HT: How did you make the decision to come out publicly and admit you had AIDS and were smoking marijuana for it? KENNY: We got arrested. A confidential informant claimed to have seen a small amount of pot on my coffee table. Based on that, the police got a search warrant, and on March 29, 1990 they came to our house and found the pot plants I was growing. If we hadn't been arrested we probably would have just kept doing what we were doing and quietly led our lives. HT: And what pushed you out of the courtroom and into the media spotlight? KENNY: It was really strange. After we were arrested I bought a HIGH TIMES to get NORML’s number, hoping they might be able to tell me what to do. So I started reading the magazine, and there was an article by Robert Randall (a glaucoma patient and the first person to receive legal medical marijuana from the government. See HT, Oct. 91) about the first AIDS patient to gain legal access to marijuana. Randall’s phone number was at the end of the story and I called it and he helped us obtain a lawyer, a really good guy who took the case pro bono. As far as going public, I can’t say it was an easy decision. My wife and I thought long and hard over it. The first time we went public was at our court case. Our defense—medical necessity—was made public the evening before we went to court and the next day the TV cameras were there. The first actual interview we did was with CNN. So we went from telling no one we had AIDS to telling everyone on television. HT: What was it like for you to find yourself in front of the cameras talking about AIDS and marijuana? KENNY: We were scared to death. But we were more afraid of not speaking out. We knew we needed this drug, and we knew that other AIDS patients needed the information that there was a drug that could help them. A lot of AIDS patients die from not being able to eat; you fall into this pattern where you’re sick all the time and you literally waste away. It’s very important for people to know that marijuana can break that pattern. HT: What was the public’s reaction to that appearance on CNN? KENNY: Very positive. My wife and I got calls from patients all over the country. And the people here in Bay County were fantastic. HT: How about your family? When did you tell them and how did they take it? KENNY: I have three sisters, and one of my them found out when Barb was initially hospitalized because she has a hemophiliac son. He’s HIV negative, thank goodness. But she knew about pneumosistis, so she guessed it right away. And she told my father so he knew. We didn’t tell my mother or Barbra’s family until right before we went to court. But everyone’s reaction was complete compassion. They were upset but they were all very supportive. HT: What happened with your legal case? KENNY: We were charged with felony cultivation, possession with intent to distribute and possession of drug paraphenalia. Our lawyer put up a medical necessity defense. We had a one day bench trial in front of a judge and admitted the plants were ours, but explained that they were necessary for our therapy. The judge heard the case, then took things under advisement for two weeks or so before refusing to accept our defense on the grounds there was no precedent for medical necessity in Florida. So we were convicted on all the charges. We were

sentenced to 500 hours of community service, to be served loving and caring for one another, and a year's unsupervised probation. The judge was clearly compassionate even though he didn't admit our defense. HT: Did you appeal? KENNY: Yes. Our lawyer appealed to the First District Court of Appeals—a three judge court—in Tallahassee, which admitted our defense of medical necessity, and overturned the conviction. HT: Was that the end of it? KENNY: No. The State asked the Court of Appeals to rehear the case, which they agreed to do. The result was that they reissued their opinion that we did have a legitimate medical defense. The State then asked the Florida Supreme Court to hear the case but they refused, with directions that the State cease any further legal actions against us. What was significant about the case was that the appeals court ruling set precedent that marijuana can be considered a drug of medical necessity for AIDS in the state of Florida. HT: Did you ever wonder why someone wanted you convicted for the two plants so badly? KENNY: I really didn't understand it. And certainly I didn't like it. It's hard enough to be sick without having to be dragged through the judicial system. It was particularly hard on Barb because she was a lot sicker than I was. There was a lot of stress involved and stress isn't good for an AIDS patient. After we got arrested she went back into the hospital, and from then on it was one hospital stay after another until she died. HT: Did Barbra live long enough to see herself exonerated? KENNY: Yes. We were exonerated in the Fall of '91, and she died on March 28, 1992, almost two years to the day from when we got busted. HT: Tell me about applying for Compassionate IND access to marijuana from the government. KENNY: Well, we didn't even know there was such a thing as the government giving you pot for medicinal purposes until we read Robert Randall's article. But as soon as he asked us if we wanted to apply for it we agreed right away. The first step was finding a doctor who was willing to apply for us. Patients can't apply for marijuana, they need a doctor who applies on their behalf. HT: Was it hard to find one? KENNY: We approached three doctors about it before we met one who would file an application for us. The problem was that there was a nightmare of paperwork to fill out. It was very time consuming. We were dealing with three different federal agencies, Food and Drug Administration (FDA), the Drug Enforcement Agency (DEA) and the National Institute of Drug Abuse (NIDA). HT: Once you applied, did the government make it difficult to get approval? KENNY: Oh, yes. The FDA lost our application three times, so it took over six months to get approved, and then the DEA messed around for another three months. We started the application process in June, 1990, just prior to going to court, and didn't receive our first shipment of marijuana until February of 1991. The whole thing took about nine months. My wife and I were the last two AIDS patients to receive access to marijuana, and I'm the last survivor. There were four altogether. HT: How many joints a day does the government supply to you? KENNY: I get 300 a month. But since my nausea changes, one day I might smoke six joints and another day I'll smoke four. I smoke till I get relief and then I put it out, usually about six or eight puffs. But that depends on the intensity of the nausea. HT: Have you ever had any negative effects from marijuana? KENNY: No. My lungs are clear. The government's grass is harsh, but it's free, legal and it works. HT: Tell me about MARS, the Marijuana AIDS Research Service you and Barbra were instrumental in starting. KENNY: The MARS program, which was conceived by Robert Randall and funded by Richard Dennis of the Drug Policy Foundation, was launched in March, '91. It came out of Barbra and my efforts—along with the efforts of two other AIDS patients—to gain legal access to marijuana. And what the MARS project did was to simplify the application paperwork down from about 50 hours to the point where a doctor could fill it out in 20 minutes. So doctors who had been reluctant to apply for medical marijuana for their patients because of the paperwork involved were much more willing to help their patients with the simplified application. HT: What was the Government's response to the project and the increase in applications for medical marijuana? KENNY: The Bush administration clearly didn't like the fact that we were getting marijuana and they didn't want other AIDS patients getting it. So they panicked and shut the Compassionate IND program down last March ('92), saying that too many AIDS patients' doctors were applying. But before they did, several patients were approved for legal access and literally hundreds applied whose applications were simply thrown away when the program was shut down. But MARS continues to function as an information source for AIDS patients and tries to help with legal assistance for those AIDS patients who run into trouble because of their medical marijuana use. HT: Do you think the shut down was done out of meanness or ignorance or what? KENNY: I think a lot of it can be attributed to bureaucrats not wanting to backpedal on policy. For 50 years the government has been saying marijuana has no medical value and they don't want to change that. I also think some of the people involved in that decision are homophobic and others are hard line War on Drugs types. So you have a number of reasons for these people to want to maintain their policy. But the decision to shut the program down was clearly immoral and criminal. To maintain the attitude that marijuana has no benefits when hundreds of thousands of people know otherwise is crazy. Marijuana is a drug and drugs have applications. I don't understand a government that refuses to accept that. HT: Do you think things will change with Clinton in office? KENNY: Well, we finally have a president who's not afraid to say the word AIDS. And I think he and his administration realize that we're in this for the long haul. They know that AIDS will not disappear by ignoring it, or that the people with AIDS will simply die and go away. This is a problem that all of us will have to deal with and right now I have pretty good hopes that we can get the medical marijuana program restored. HT: After Barbra was gone, what gave you the strength to go on? KENNY: It was very hard to lose my wife. But while it's tragic to lose somebody you love, and you'll never stop remembering them, you also have to remember yourself and what you need to be doing. Personally, I've decided to focus as much energy as I can toward this issue. I feel that I need to do as much as I can, while I can, to try to get and keep this issue in the public view. I've lost so many friends to this disease it's hard to remember them all. HT: Do you think your message is getting through to the public? KENNY: As far as I can tell the issue is already won, the bureaucrats just haven't come around to it. The average person on the street understands trying to alleviate people's pain and suffering. Most people would agree that if this drug can help then you should have it, and the decision should be between you and your doctor, not some politician or policeman. HT: How about you? How are you personally feeling? KENNY: I'm feeling good. I've been off AZT

for a while now. My doctor came to the conclusion that it was doing me more harm than good. It was destroying my white blood cell count. Of course my T-cell count has been nonexistent forever. It's been two or less for over a year, and they've always been really bad. Normal is 700 to 1,200. Actually, I was really sick last Christmas. I had a microbacterial infection in my spleen and I was in so much pain I was taking morphine for it. That's what Barbra died from. What happens is that bacteria is constantly around you, in the air, water, everywhere. But in an AIDS patient if it gets inside you it multiplies until it gets out of hand. So I've been taking medication for it since last May, quite a bit of it. And the only way I've been able to do that was by smoking marijuana. HT: What do you want to say to America about AIDS? KENNY: If I were speaking to the government I would say when you're faced with a life threatening illness you should have some say so in your care. And if trying a new drug or a new alternative therapy or anything else might help, you've got to allow access to that. You've got to be able to try to heal yourself or reduce your suffering anyway you can. Certainly with AIDS that's the case. The end stages of the disease can be very devastating, to the point where you don't recognize the person that you once knew. Anything that can be done to make that person comfortable, to make them enjoy what time they have remaining, is a great thing. HT: You used to want to be in the Park Service but life intervened. What are your dreams today? KENNY: It's bizarre what happens in life. I guess a lot of my dreams are just being alive, trying to make it as far as I can. One of the things I'd really like to see before I go is for a doctor to be able to write a prescription for marijuana. That's one of my dreams, and I'm happy just to do my part toward it. HT: Thanks, Kenny.

About the Author

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