



EDWARD M. KENNEDY ORAL HISTORY PROJECT

FINAL EDITED TRANSCRIPT

INTERVIEW WITH MATHILDE KRIM

December 12, 2007
New York City

Participant:

University of Virginia

Janet Heininger

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Janet Heininger: This is an interview with Mathilde Krim on December 12, 2007. Tell me how you first met Ted Kennedy.

Mathilde Krim: I don't remember exactly when I first met him, but it must have been in the early '60s. I met him through my husband's activity in the national Democratic Party. We would attend events and dinners and so forth, and I met him through one of those. At the time, of course, one of his brothers was the prominent Jack [Kennedy], and then Bobby Kennedy also. For me, he emerged, really, out of the background of the mid-'70s. I didn't see much of him before that. I had no idea of his personality; I knew virtually nothing about him. But when he started emerging, it was very meaningful, because he dealt with the realities of politics, the problems of this country, the problems in his family in a very concrete way. So it was not just knowing somebody; it was working with somebody or for somebody.

In a more restricted field, where I was involved, starting in the early 1980s, he became our major supporter, particularly in this country, a major activist. He has been very precious to us, still is. I got to know him as a working colleague. He had not seen me too much on my side of the story. I like him very much. Even in character, he is regularly available, positive, interested, knowledgeable, and he has a wonderful staff. He always has very competent people on his staff, and he makes them available. When you work with Teddy Kennedy, you deal with substance. This is my impression overall.

Heininger: How did you first become involved with the AIDS [Acquired Immune Deficiency Syndrome] issue?

Krim: I used to work at Memorial Sloan-Kettering, in a lab. I am not an MD; I have a PhD. I was interested there, in the late '70s, in the field of interferon research. Interferons are a family of proteins that have antiviral properties. I was interested in viruses because of interferon, and I was doing essays and so forth on viruses. A colleague of mine—His name is Dr. Joseph Sonnabend—was interested in interferon research. He was there in it from the early days. Interferon was first discovered in 1957. He had been in this field through the '50s and '60s, but there was very little, if any, support from the federal government for interferon research. The only money that was really there was in the cancer field, thanks to an initiative of Mary Lasker and a few friends of hers, who convinced Senator [Andrew] Schoeppel to nominate a commission to investigate cancer research. I am digressing a little bit, but I became interested in that, and I knew that the National Cancer Institute had some money.

I tried different ways to have the Cancer Institute put some research money into interferon research. The argument was that interferons have an effect on the rate at which cells multiply, and they suppress some multiplication and therefore have anticancer properties. So with that big argument, I went to the Cancer Institute and said, "You should fund interferon research." They said, "It's an antiviral." I said, "No, it's also an anticancer substance." Finally, we won the day, in a limited sense, in that they twice gave me money to organize an international workshop on interferon research.

My friend Sonnabend was involved in interferon research. Sonnabend was one of the victims of a lack of money for interferon research, and he had to give up working in the lab. He had established a medical practice in downtown New York, and he was working there. A good portion of his clientele was gay men, because he was in Chelsea. One day he came to visit me. He used to come regularly to pay me a little visit. I remember one dark winter afternoon, as we have these days. He came to the lab, and I was doing something. I was busy.

He stood next to me and was just looking at me. I said, "Joe, what's the matter? How are you?" He said, "I'm depressed. I am losing my touch as a physician." I asked, "Why do you say that?" because he was an excellent physician, in fact. He said, "Because I have several young men in my practice, and they are all gay men. They have these inflamed lymph nodes, and they seem to have some sort of infection, and I can't make them better. I've tried every antibiotic I can think of, and there is something going on." But that went from one year to the next, and then all was forgotten about it.

Very shortly thereafter, within days—I was chief dermatologist—I was looking for human cancers that could have skin manifestations that one could see, because my idea was to develop antitumor units of interferon. One could prescribe interferon with antitumor agents. It would have been useful to have had a human tumor that I could have injected to see if it would shrink, and a dermatologist would have, in his care, all the skin diseases. The name of the guy was Bijan Safai. I think he's still there.

Bijan listened to my request and he said, "Yes, we have two tumors that one can see through the skin very clearly. One is a kind of T-cell lymphoma or leukemia." I don't know what he called it. "The other one is one called 'Kaposi sarcoma.' Kaposi is the best, because it makes big blotches that you can see very well. Unfortunately, it's a rare disease, but you are really lucky because Sloan-Kettering has seen only nine cases in 25 years, and now I have 12 just in my ward upstairs." I said, "Really? May I see them?" He took me upstairs, and to my surprise, several of them were there. I don't remember if they were all there, but several were.

They were all young men who looked very well, except that each one had those blotches on his face and chest and back, and that was uncharacteristic of Kaposi sarcoma, which is usually a disease of the lower limbs. These guys seemed to have nothing else wrong, and in fact they looked pretty healthy, apart from the blotches. He said, "The funny thing is that all of these men are gay." Then I remembered what Sonnabend had said, so I ran to the telephone to call Sonnabend, and I said, "You must come over. There is something going on, and you'd better compare notes with Bijan."

So we did. The three of us looked at the patients and talked. Then the first thing we decided to do was to call other physicians and research centers to see if others had seen things like that. The first one we saw, who we identified here in New York, was Dr. [Alvin] Friedman-Kien. He had seen cases, because he was a dermatologist also, because people, when they have something wrong with their skin, go to a dermatologist, of course. Then in San Francisco, we found Dr. [Marcus] Conant, who had seen cases of lymphadenopathy, large lymph nodes. Then we found one in Los Angeles, and then one in Atlanta, and so we realized that there was something very mysterious, very big, going on.

Heininger: Was this before the CDC [Centers for Disease Control] report was issued?

Krim: Oh, yes.

Heininger: This was very early.

Krim: Oh, yes. I'm talking January 1981. The CDC report came out in June. This was before that. So we formed an informal discussion group on this subject. The funny thing was that at first, we thought that the first thing to do was to let the CDC know about this. We called the CDC, and they said, "OK, we're going to send one of our experts." So they sent an expert. It was Dr. [James] Curran, and Dr. Curran was young and jovial, a nice guy. We met in my lab because I was the only one who had a large table for meetings. We sat around the table, and Dr. Curran pulled out something from his pocket, a little notebook, and a pencil, and he said, "So what do you want to talk about?" I looked at him and I thought, *Well, the poor kid, he doesn't know what he's in for with the little notebook.* It was really comical.

Then there was my friend Sonnabend, who was an investigator by profession. He immediately understood how serious the situation was. He and I talked often, and we activated each other. He pushed me to do things, and I admired his foresight and his dedication, so we worked quite effectively together. Joseph is an original guy, to say the least. For example, he is very principled. He was seeing as many of these young men as possible in order to get an idea of the frequency of the incidents. But he never charged these patients for the visits because, as he said, "I am an investigator. They are research subjects. I don't have the right to charge them."

Heininger: Expensive.

Krim: Yes. Then I had to help him with finances, and so I did. Also, I had worked on the ground floor of the co-op building. All the co-op members there came up infuriated, because the word started spreading that there was a dangerous disease around, and it was a gay men's disease. You remember those days. They decided, the other co-op members, to fire, to throw Dr. Sonnabend out. Even before that happened, when we started feeling the antagonism grow, of course we were afraid that he would lose his medical practice completely and then he wouldn't be able to work with us anymore.

Second, we felt that his patients needed somebody to take care of them. So the first thing we did was arrange for Sonnabend to see people in his own apartment. This is why when people ask, "How did you start?" I say, "We started by throwing out the cat," which is true, because Dr. Sonnabend had a cat. He was a messy, forgetful scientist. The cat did not have a well-designed

litter box, and the apartment stank. Joe reads a lot but never throws away anything, so there were piles of medical journals all over, and that cat was on top of them.

Joe had introduced me to Michael Callen. Do you remember the name? He was a singer, a musician. Michael had a friend called [Richard] Berkowitz. The three of us, those two young guys and me, cleaned Joe's apartment to make it a possible reception area. That's the way we started, and Joe learned to be a medical investigator. Then I became more and more concerned and interested myself. Joe was an awful public speaker. He didn't speak clearly; he didn't speak loudly enough. We couldn't use him as a spokesperson. So I suddenly became a spokesperson too, but I was working with him and with these two or three other people.

Right away, we did important things. One of the first things—I don't remember the year. It must have been maybe '84 or '85 or maybe earlier. Do you remember when the first cases of AIDS were discovered among Haitians here in Brooklyn and Queens? There were groups, communities of Haitians living in these areas of New York, and there were many cases among them. The rumor was that "the Haitians brought this here. God knows how these people live. Most of them are drug addicts." The worst things were said about these poor Haitians, and they were losing their jobs. Their kids were thrown out of school or were harassed, assaulted by others. It was really sad and so unwarranted, so stupid.

One of the first good things we said was to get AIDS off the Haitians' back. The CDC had already started using a method, which is an epidemiologist's technique, to investigate the level of risk of a certain disease in different groups of the population. When you find a group that has a higher risk than another, then you can determine whether there is something that's part of the life of these people that makes them more vulnerable. It's a way of inquiring into how a condition occurs and spreads. They had already started identifying groups at risk. The first was gay men, and the second was Haitians. That justified the hatred and fear of the Haitians. We decided, "This is not right," so we pleaded with the Department of Health here in New York not to go along with this stereotyping and to take the Haitians off the list of groups at risk. I thought we should know more at least. Finally, they removed the Haitians from the groups at risk, and this was our first successful intervention. Almost overnight, the Haitians were forgotten. It's funny. The CDC agreed also to change its designation.

Heininger: All of this was taking place before the virus was identified?

Krim: Yes. We did not yet know that it was a virus. We suspected it, but we did not know. Another thing we did, thinking that it might be a virus, was to start giving small amounts of money to biologists to see whether they could isolate some viruses. They did isolate a lot of viruses, but never the right one, because they also saw infections and other viruses that benefit from the broken immunities, so they might multiply and create problems, but they are not the basic cause.

We started giving some money to some of the researchers, but it was never enough, and it was very little. It was what you could put together, and mostly me probably, and a few thousand dollars here and there. But that was not the way to go in the future. We decided to form a not-for-profit organization, because that would allow us to solicit monies, to never pay out of pocket, and also to make the gifts tax-deductible. We created what we called the AIDS Medical

Foundation. The situation there was that either the members or the people working with us in the research field did not want to be part of the foundation, because that would exclude them from receiving foundation money. Joe was not the type to be the head of an organization. He would not know how to administer anything. He couldn't even administer his apartment here.

We had two lawyers who volunteered their services and who also gave us some space in their basement in Chelsea, on 13th or 14th Street. That's where we were working from. They also gave us their legal services for free, and they incorporated the AIDS Medical Foundation in Albany, so then we were in business seriously. We formed the board, and we formed the scientific advisory committee and even an IRB, an institutional review board, to be able to do experiments on human beings.

Heininger: Were you still working in the lab at this time while you were doing this?

Krim: Yes, I was. It became a bit much, and in '85, '86, I realized that this was ridiculous, because the situation with AIDS was worse. We had it clear in our minds that this was going to be a world-wide problem, that the gay men were almost a smokescreen, that the victims, the people who were most vulnerable to the disease would be women and their children. In our world, people move back and forth all the time. So that gave a great value to our existence, to the AIDS Medical Foundation.

In 1984, we had our first big fundraiser on Broadway, which was an event that we called Comic Relief. Terry [Beirn] was already in the picture.

Heininger: You had already known Terry Beirn at this point?

Krim: Yes. I cut corners here. I was trying to think of things of importance that we did very early on at the AIDS Medical Foundation. There were several. The Haitians issue was one. In fact, two or three days ago, there was a dinner here that was given by an organization called the Nation Institute. Hamilton Fish is the head of it.

Heininger: Yes.

Krim: He's a good friend, and he's surrounded by interesting characters. The Nation is a typical liberal, left-wing group of people, but interesting people. Most of them look like retired professors. Most of them come from academia, and they publish a magazine called *The Nation*, which is very serious and very good. In any case, I met there the other day, for the first time in 20 years, a fellow named—I have his name here—This fellow was already there then, in that organization, because we enlisted his help to go on visitations.

When we started getting involved in the situation with the Haitians, it needed to be verified. We couldn't work just on what we heard. We needed somebody serious and believable to go to, I guess, Florida, where they had camps where they were putting Haitians already. He went and he was instrumental in working through the administrative problems that we were facing and also through the political questions and strategy. He did it very competently, and I think he did the whole thing for \$10,000.

Heininger: That amount was worth a little more then than it is now. That's nothing.

Krim: But still, exactly. When you think of the impact this had on the life of so many people, it was very valuable. So this fellow, I met him two days ago at this Nation dinner, and we fell in each other's arms because we hadn't seen each other in 20 years. It's terrible right now. You work so closely with somebody for a while in a very concentrated fashion, and then life takes you apart and you lose people. It was nice to see him.

Heininger: Were you at the point where you were able to hire staff for the AIDS Medical Foundation?

Krim: Yes, and we did. In '84, I started saying that we made \$400,000 at this benefit, which was extraordinary for us. That same year, we gave out eight or sixteen or something grants to different groups. On this, the details, I have the information. So, so far so good. Then there was a fellow called Michael Gottlieb, who was a physician working in immunology at UCLA, the University of California, Los Angeles. Like here, the first people to see cases and report them were physicians. Gottlieb was, in fact, my equivalent for the physician in Los Angeles—the physician who had seen some of the first cases and who brought them to Gottlieb and got them in the lab, where they did the immunological analysis. The two of them published this first paper, also in June of '81, describing the condition, without being able to give it a name yet, but describing the symptoms. I remember that Gottlieb had received money from the famous actor who died early on of AIDS.

Heininger: Rock Hudson?

Krim: Rock Hudson had given a quarter of a million dollars to Mike Gottlieb, and to us that sounded like a large amount. So Terry and I—and Terry was already there with us—we decided, “We have to get hold of this quarter of a million dollars,” and we're going to propose to merge. We felt so confident, because we had been first, because we already had a functioning organization, and because legally, we were a not-for-profit and so on. They had nothing. They had just the—

Heininger: Money.

Krim: —money and the wish to do something with it. So we proposed that we merge, and it took a while. They were also different. Here we were, mostly basic researchers, trying to identify the virus, while they were treating physicians. They were clinicians, and they had simplistic ideas, like so very often clinicians do, and we were more fundamentalists. For that reason, it was difficult to merge, because there were different types of characters. It also took several months because we needed a full set of people. They were not organized. They had no strategy, but still they had the money of people who had said, “We would help. We would like to work with you.”

We had to unload, on both sides, a number of people in order to not start with an extravagantly big organization. We decided who to drop, set aside, and with whom we would continue. Still it was not enough. We decided to have people from New York and Los Angeles. We wanted to have people from middle America. Florida and Chicago also had a number of cases. All of these things required a lot of meetings, a lot of thought. But we were getting there, and in '84, '85, and '86, we were able already to give out a number of grants and to start doing serious work.

In 1985, the virus had been described. People had seen it in the electron microscope, photograph, but that doesn't mean that what you see causes the disease. The situation needed to be checked out more, secured scientifically. Also, by then we knew that everybody was dying, with no exceptions. It has never actually been described in so many words, but it's unique to AIDS. With all other diseases, you have a few survivors. Here, no. Even to date, we haven't saved one life through treatment, only through prevention, and the prevention is ineffective and not good enough.

In any case, Sam Broder, who was the head of the National Cancer Institute, had decided—in cancer they do that—“We're going to check all the drugs that are on the shelves already to see whether any one of these can do something against the virus clinically, not in the lab. We'll give it to people who have AIDS.” They'll die anyhow, you know? So he did that. He checked thousands of drugs, including AZT [azidothymidine]. AZT had been developed as an anticancer drug. Lo and behold, it prolonged life. It seems to make people better. Of course, we knew nothing about whether the dose was right, and it was at first too big, and it was making people sick. But it did something.

So this was the launch of belief, because people would not even believe that it was worth looking for a treatment. The people go from one extreme to the other, and they had decided, “Yes, everybody with AIDS is going to die,” and without believing that we might find something to treat it. You have to look, and this is done through research, and that costs a lot of money, but it justified our existence, that's for sure. Dr. Broder must have published information on these tests that he did. They were phase-one clinical-trial results, and he could say, “The thing is activity. There's some toxicity, but it's worth trying and developing.”

I had met a man, a gay man, by the name of Mr. [Richmond] Crinkley. I cannot remember his first name, but Crinkley was an adorable fellow. He was not a scientist and not a physician, but he had heard about Broder's work, and he came to see me to say, “That's a great idea. We should develop drugs. We'll start with AZT and then prove it. We need to do clinical research, and we need to ask the NCI [National Cancer Institute] or the NIH [National Institutes of Health] to grant us the money that it takes to do it.”

I remember then calling Dr. [Anthony] Fauci, whom I knew from the interferon discussion, and asking him to please institute a program of clinical research. Everybody felt that it was time to go with it. He said, “I can't. I don't have the desks.” I said, “What?” He said, “No, I don't have the desks.” He meant positions, but he also meant literally desks. He took me around his AIDS department at NIH to show me that there was no room, so he could not start a new program. It was inane.

In any case, Crinkley and I—That's when I must have met Teddy Kennedy on this subject—we decided to ignore Fauci. Fauci would find desks if he got some money to buy them, but we had to go to Congress and talk to people about the realities of the situation. We did see a few people, including Lowell Weicker of Connecticut, who is a good guy, a wonderful guy. Teddy Kennedy was the chairman of the Senate Committee on—What was it called then?

Heininger: Labor and Human Resources. The name changes every few years.

Krim: Exactly. To his right was Lowell Weicker, who was vice-chairman. They both listened, and they were interested. Actually, in '87, there was already some legislation passed, called the HOPE [Health Omnibus Programs Extension] Act of 1987, which, for the first time, also considered education as a way to prevent AIDS.

Heininger: Terry wasn't working for Kennedy yet?

Krim: Not yet.

Heininger: OK, and Michael Iskowitz wasn't working for Kennedy yet either.

Krim: No. This is before that.

Heininger: Did you initiate the contact with Kennedy?

Krim: Yes.

Heininger: Or did somebody suggest you to him?

Krim: No. That much I knew. He was a key person there. I did not know him well at all. My husband knew him better. There is a side story to this. My husband was desperate when poor Kennedy was assassinated. He said, "That's it. I'll never go into politics again. I can't take it," et cetera. But he also talked to Ted Kennedy, and Teddy encouraged him not to rock the boat, that the country couldn't afford it, and to stay with what he was doing another year or two. Then [Lyndon] Johnson, in person, pleaded, so Arthur [Krim] could not say no, so he stayed there.

Heininger: You recognized early on that it was going to be necessary to bring Congress into the equation.

Krim: Oh, yes.

Heininger: So you went to see Kennedy and also Weicker.

Krim: Yes, I suppose. I don't remember exactly under what circumstances we talked or the date or anything, because it was so long ago. But Kennedy knew I was interested in the issue, for sure, for that reason that we talked about before.

But one day he called, in '86. He called me personally, and he said that he would like to come and see me. I said sure, and he came. I couldn't believe that he himself would come and see me. It was very funny, because he said, "Mathilde, I need your advice. I need you to recommend somebody who could work for me. I need to have on my Senatorial committee a staff person who knows about AIDS, knows about politics, has good relationships, a certain knowledge of how the Congress works, how the administration works, the NIH, the whole picture. I have a young woman who does this now, but she's eight months pregnant, so I have been looking for somebody else, and hopefully fast, so that she can still brief her. She may have one month to find a person to do the education." He said to me—and this is a funny last word—"I imagine you can recommend, for example, a retired university president," which I thought was a funny idea.

Heininger: Yes.

Krim: Again I thought, Poor kid, if he thinks he can find that.

By then, Terry was already with us, because Terry showed up, I think, in '84. The Comic Relief was in early '85. Terry was so important to us. I have a couple of things here, I think, speeches and comments and so on. We decided, Crinkley and I, that Terry was the only person Crinkley knew who could do the job. I discussed it with Kennedy the day he came to see me. I said, "I have the person, but he works for me, and he is the only person I know who could do it." So we made a deal. Terry would be asked to work 50 percent of the time for the Senator and 50 percent for us. Poor Terry, we committed him without even asking him. There was no time.

I remember Terry coming in, and I had to break the news to him. He always carried a little shoulder bag. He had put his bag down, set it in my living room, and I told him, "You have to pick up and go to Washington half the week. It's a commitment I made." He didn't like the idea, but he picked up the bag and went. That same evening he went. This is how we got him in the picture. The Senator was very satisfied, because Terry was a guy with ideas. He was not somebody who the Senator had to train. Terry would feed him ideas constantly.

There was one idea Terry had while we were in New York, before we were a national organization. There were, from Day One, people with AIDS who had been thrown out of families, of jobs, of apartments—literally dying in the streets. We could see only more of this happening in the future. Terry had the idea of going to all the companies that had headquarters in New York, as there were many. Mostly the entertainment industry is here; it's not in Los Angeles, like most people think. Terry said, "I'm going to visit all these guys." We asked him to ask for a certain amount—the amount required to remove people from the streets and to put them in care. There would be a fund of support for people who were sick and could not afford care. Well, it was a nice idea, and he tried it, but it didn't work. He did not get one company to go along. He was persistent; he really tried.

So when Teddy Kennedy called to tell him to come to Washington, Terry said, "Well, I'm going to try to sell it to the Congress, the idea of having a fund that supports people who are destitute because of AIDS." He proposed it to Kennedy, and Ted Kennedy said it would never work. "We don't have this kind of elected government. They are all narrow minded, prejudiced, et cetera. But if you want to try it, you may go and try it." This was when Terry hired Michael Iskowicz, by the way. The two of them went to work, and it took a lot of time and effort.

Terry was such an inventive, brilliant guy. Do you know what he did, for example? Kennedy had also told Terry, "Don't come back to me with this story about funds, with no support, unless you have 60 votes on it, because I don't want to get filibustered. I'd waste my time." To get 60 votes on something like this, helping poor gay men who were dying in the streets, is not easy. So they had to be inventive, and one of the things they did was invite Elizabeth Taylor to organize hearings. I was on one of them and she was on one. When it's Elizabeth Taylor, of course, the newspaper covers it.

Heininger: Was this the first thing? Had she already begun her work with amfAR [American Foundation for AIDS Research]?

Krim: Yes.

Heininger: So you brought her in to amfAR?

Krim: Yes, in '85. She came with the researchers group in '85.

Heininger: So he knew that she already had a connection with AIDS and that she was an AIDS advocate.

Krim: Yes, absolutely.

Heininger: He came up with the idea of having her do hearings in Congress.

Krim: Yes.

Heininger: Boy, they were big. I remember them.

Krim: You remember them, yes. I was there with her a couple of times, and I was supposed to answer specific questions that came up. Otherwise, let her have the show. She did it beautifully, of course.

She was the ex-wife of Senator [John] Warner, and this reminds me of a very funny story. Senator Warner gave a luncheon in her honor, and he invited a bunch of other Senators, maybe ten, fifteen, and then several of us, and he actually included Elizabeth. He and Elizabeth were already divorced, and they were facing each other across the table. He made a little speech, and it was a joke. I was always sitting next to her, where I was supposed to be of help. She looked at me, and in a loud voice—Everybody heard it—she said, “I can’t believe I was married to this asshole,” like that. *[laughter]* I’m sure I blushed. The other Senators didn’t know how to react. Should they laugh? Should they pretend they hadn’t heard? Elizabeth can be very crude sometimes.

Heininger: So she came and did these hearings for Congress that Terry had set up.

Krim: Yes, she did, several times. Teddy had several ideas, but among those was the fund for care. The federal government is in charge of providing support for research, but not for medical care. The only other program they provide as a treatment program had been voted on several years earlier and it had to do with dialysis for people with terminal kidney disease. They have always regretted it, because it went from a cheap program to a very expensive one.

Heininger: Right.

Krim: So they hate it for that reason, and this is one department that will never forgive them, because it’s like saluting people to death. So when Terry came wanting more treatment money, the idea was not well received. That’s why they brought Elizabeth, for that specific occasion. He had her testify in the morning. There was a hearing. Then in the afternoon, he sent notes to all the Senators, saying, “Ms. Taylor is in town, and she would be delighted to have a photograph with you if you support her on her request.” He got 20 yeses in half an hour. It was incredible.

Heininger: The power of a photograph.

Krim: Yes. They really wanted the photograph. It's incredible. In the end, he got the 60, because once you have 40, then the others feel bad to be left out. He got the 60 votes, and the law was the Ryan White CARE [Comprehensive AIDS Resources Emergency] Act.

Heininger: Well, the first one, I think, was the HOPE Act.

Krim: The HOPE was '87, yes, and then—

Heininger: Which was the first care bill.

Krim: Yes. Actually, the care part—because there was an educational part as well—was what has become ADAP, the AIDS Drug Assistance Program.

Heininger: It was a small component of that first piece of legislation.

Krim: That's right, and it was worth \$30 million, which of course seemed small, but it was enormous then. And it passed. This too has been so important. This is why people get treatment in this country. Otherwise, 90 percent of them could not afford it. It's the kind of thing you can't erase, because it's so necessary—The public knows about it, counts on it—that no Congress could reverse it. The public would raise hell.

Heininger: Do you think one of the reasons it passed was because—and this is before Ryan White, but that very first piece—it was easier to vote for care and treatment than it was for prevention? Did prevention raise all sorts of even-more-problematic issues?

Krim: It's true, because the Congress—thanks to Senator [Jesse] Helms, remember—would refuse grants to organizations that were, in his words, “promoting homosexuality.” That put out the image. For that reason and others, they could not get the education and prevention money. The group in Boston was very good at prevention, but they had to raise that money from the private sector.

Heininger: You were continuing to raise money separately for amfAR during this time period?

Krim: Yes. At first, we did only basic biomedical research, because this is now a philosophy. I still think that it's the most important thing for the private sector to do. First of all, it's difficult to judge what we're funding and what we're not funding. The NIH is known to be very conservative in their decisions when it comes to funding research. They don't want to bet on something that they don't know in advance will be successful. So they are conservative, and they are not timid.

We felt that we needed to start basic research in a very fast and aggressive way, and in the right amount also, to make it pay back soon. So we remained focused on, at least in those days, basic inductive research, while other organizations, like amfAR and others, who were not scientists and physicians, wanted to focus on prevention and support—yes, also economic support for the sick—but mainly prevention. The only thing we had for prevention, and it's still true today, was education and convincing people to take control of their private behavior, which is very difficult

to achieve. In the early days, it was successful with the gay men, because they were so scared. We saw so many people dying around us that it was so frightening. It was enough to motivate people to be careful. But nowadays, they already think it's no problem. They create bills for what?

Heininger: So in the early years, you saw the role of private philanthropy as providing the funds for the basic research that you felt the government was not providing.

Krim: The cutting edge.

Heininger: The cutting-edge research. What did you see as the role of Congress?

Krim: To provide money through the NIH and to provide money for other agencies and for housing. People were losing their apartments if they were rumored to have it, sometimes without proof. Just the rumor was enough for people to be thrown out. We needed housing support and care support. The federal government should do that, and it does, to a large extent. The funding has been generous, I must say. It started with the \$30 million, and it's now up to \$900 million. It's remarkable, and that was Terry's idea. That's the part I wanted to come to, that it's such a naïve idea to ask the companies to pay for the people in the street, and to ask Congress, but it happened through Kennedy's office. The Kennedy office is a very effective, hard-working group of people. They really put their shoulders to that one.

Heininger: When you first started talking to him about AIDS, how much did he know about it? How much were you educating him about AIDS?

Krim: The Senator?

Heininger: Yes.

Krim: I never tried to find out. The way he was speaking, he understood that the situation was grave, that prejudice against gays was totally inappropriate and irrelevant to the solution. That's the problem. He had all the basic attitudes right, and if he didn't, nobody said it. It was not necessary. He was terrific. I never felt that he needed an explanation about anything.

Heininger: Did he use you to help educate other Senators?

Krim: No.

Heininger: Did he draw on you for meetings with other Senators or for, say, dinners at his house with other Senators to educate them about AIDS?

Krim: No, he didn't do that. On the other hand, he knew we were doing it, and I'm sure you know that to the extent we needed Ted Kennedy's support, the office with Terry would have given it. Terry spoke for Ted Kennedy, and they became very good friends.

One of the strategies we were using was talking about the shared fate of the hemophiliacs. All hemophiliacs, men of a certain age, died of AIDS if they got it. Simple. The slate was wiped clean. But what was striking was that their wives and their children were getting it too. This, for

us, was one of the first proofs that this would become a general problem, not just for gay men, because the wives of hemophiliacs in the middle of Pennsylvania were getting AIDS. They had no reason to have it, unless they got it from the husband, and the husband got it from treatments with blood or from blood products that were contaminated.

Heininger: Do you think that the issue of the spread of AIDS among hemophiliacs changed the debate over AIDS?

Krim: To a certain extent, it did. I don't remember exactly. I cannot tell you that it was this case or that case. But we used it in our writings and in our speaking as proof that this was everybody's disease, not just a gay disease.

Heininger: And that there could be heterosexual transmission too?

Krim: That's right, when the first babies were being infected, sure. There are so many stories. Do you remember Elizabeth Glaser, and others?

Heininger: Yes.

Krim: So we were making a case. We were really building an argument around the hemophiliacs and women with babies. Then there was the case of the drug addicts and injectors who were found infected. Clearly, when you studied their way of life, we found that we generally don't allow the public to buy sterile syringes. They feel compelled to inject something, and so they share the syringe with each other. We are still fighting that one. Twenty-five years and they still don't understand it. But what we have been able to bring about in the meantime is a needle-exchange program. That was done illegally to start with. Now I think there are about 36 states that fund needle exchanges themselves, state governments. That's a lot of progress.

Heininger: So amfAR, at this point, was a leader in funding basic research.

Krim: Yes.

Heininger: You also were providing staff to Kennedy, as the Congressional leader in getting legislation passed.

Krim: Yes, they're complementary. We tried to push the government to do the things they should do, and then we took responsibility to do other things that the government was not doing very well.

Heininger: You also had a link with Terry Beirn in between the two.

Krim: Yes.

Heininger: Had Michael Iskowitz also worked for amfAR?

Krim: No.

Heininger: OK, so Terry found Michael and brought him into Kennedy's office.

Krim: Yes, and he was a character too. He was a good guy.

Remember, in those days, there was the case of this young hemophiliac, Ryan White. It was a horrible case, because he was a sick, poor child. Everybody knows why he was sick: he was a hemophiliac, and he got contaminated blood. He also was attacked. People burned his house in the middle of the night. I mean, how can one be so mean? His mother had to flee, and she went to live in Omaha, I think it was, or Columbus, a place in the Midwest. She hid there with her kid. We felt so sorry for him and his mother. Terry took up his little wagon and went to visit them, and he liked the mother and the kid. The kid was intelligent, knew exactly what he had to contend with. Terry liked them, and he brought them to Washington to meet the Senator. The Senator liked them, particularly the kid. It's tough to look in the eyes of a kid that age and have to tell him, "We can't do anything for you right now."

Heininger: I think he was only about 12 then too.

Krim: Yes, he was very young. Apparently, according to Terry—I've never discussed this with Senator Kennedy—the Senator really, in a way, fell in love with that child. He felt that what he was doing, what he ought to do against AIDS, he was doing for Ryan. They became friends, and they saw each other sometimes. When the legislation, the Ryan White CARE Act—This was in 1990 already—was voted on in Congress, he invited Mrs. [Jeanne] White. Ryan had died a few weeks before. She said in the gallery, "Ted Kennedy brought this to the attention of the Senators in the room." That was a good argument. How could they vote no, looking at this mother who had just lost a child? This is something Terry told me—I don't have proof of that; I wasn't there—that when the Senate voted in favor, it was a reauthorization, I think, after five years.

Heininger: Right.

Krim: Of the Ryan White Act, yes. Teddy Kennedy put the file on his desk, slapped the file, and said, "That's for you, Ryan." Have you heard that?

Heininger: Yes.

Krim: Very touching.

Heininger: Did you have any contact with Senator [Orrin] Hatch?

Krim: No, but Kennedy worked on Hatch and brought him around. I know that.

Heininger: What was Hatch's interest?

Krim: I don't know for sure, but I heard that Hatch is not a bad person. He just belongs to another planet. Ted Kennedy convinced him that he had a moral obligation to do something, and he did it.

Heininger: Let's back up into that late-'80s period. How did the public become educated about AIDS?

Krim: There were a number of theatrical productions and books and articles written. They could not deny anymore that women were affected, and that old folks and young folks and hemophiliacs were; although the hemophiliacs got off the hook very easily, because all it took was to change the conditions under which blood products were purified. They could change the concentration or the method of preparation enough to destroy the HIV [Human Immunodeficiency Virus]. I guess they still do use only clean blood, but if there were some HIV in it, it would be killed by the preparation. So the hemophiliacs are completely off the hook now. How the public became educated? They are still not educated enough.

Heininger: What was the role of Dr. Everett Koop?

Krim: Everett Koop. First of all, he started off as an extremely conservative physician, but at least he was honest. He studied the situation and decided to do something about it, and he did. He produced a wonderful pamphlet that came out in—Was it '87? The trouble is, and I think I heard it from him, was that yes, he liked this pamphlet, that yes, it was very useful, but he was never given the funds to print it in Spanish. Isn't that something?

Heininger: Or actually, originally in English either. There's a long story about how he got the funding.

Krim: Really?

Heininger: Yes. The [Ronald] Reagan administration did not want it published.

Krim: Oh, I'm sure.

Heininger: There was a lot of intervention so that he was able to get the money to send it out.

Krim: How interesting. I don't know that story at all. But they knew that he wanted to publish the pamphlet in Spanish, which would, of course, have been very effective and necessary. He was not given the funds to do it. We live in a strange country.

Heininger: If you look back on that late-'80s period, between the identification of AIDS as a problem and up to the Ryan White CARE Act, how did the Congress get beyond, "This is a gay man's disease," to, "This is a disease that we need to treat as a public health issue"? How important was Kennedy to that effort?

Krim: That is difficult for me to evaluate from where I am, because I would listen to what Kennedy had to say personally, but I don't know how—No, much of the public did not listen to news like that, and this is why. I am always flabbergasted at the time people spend listening to television and listening to stupidities instead of to news that deserves attention. There have been some surveys recently, opinion surveys, about what people of different ages or backgrounds think about AIDS, and it's amazing. You still find that 87 percent believe that you can get it from drinking from somebody else's glass, or something like this, or from toilet seats. They are still full of myths and prejudices.

On the other hand, there are enough generous people who have given the means to not-for-profit organizations to do more than we could otherwise, and significantly more. They've helped

educate the public. Because of course, again, the government has not done it directly through the public, except for the Koop pamphlet. In this country, the government cannot advertise its successes.

Heininger: Well, they're not supposed to. Public relations is not something the government is supposed to engage in, in terms of lobbying.

Krim: That's right. Yes, organized efforts.

Heininger: Organized efforts, right.

Krim: To promote what they do, no. This is something that the public must take on. What I've come to admire and be grateful for is what organizations like your university and your program, academia, has managed to do in terms of public education—not only that, but preserving and saving brains to have them available when needed. Every day I watch the Jim Lehrer news, the only news program that I can stand watching, and it's amazing, all these people they bring in for testimonies, et cetera. Ninety-five percent of them come from academic groups. So we have that, at least, going for us. And the fact that people can and will say what's on their mind, and they want to say it, even if it's offensive to others. They carry the brunt, but they can say it if they want.

Heininger: Do you know what Kennedy's relationship was with Dr. Koop?

Krim: I have no idea. I know that Koop became, really, a wise man. It happened a little late, but it happened.

Heininger: What was your sense about the experience that Terry Beirn had as a gay man coming to work for Kennedy?

Krim: He was very comfortable. He didn't speak about apprehension or fear or anything. He was very comfortable.

Heininger: What happened to Terry?

Krim: Terry survived another five or six years after he came to us. He died on July 16, 1991. He died of AIDS, but in the meantime, with no medications, no care, no nothing, he survived and did a fantastic amount of work. Terry really—I read a couple of his articles before you came—planted the seeds of what needed to happen, what needed to be done, and how to do it. He had that figured out. I think Teddy Kennedy spoke a lot with Terry. I heard from Terry that he had long discussions with Ted Kennedy, and apparently they came to one mind in this field, and they worked very well together.

Heininger: What had Terry's background been before he came to work for you?

Krim: He was an investigative reporter.

Heininger: Really?

Krim: Yes. Some of these papers say what it was. He worked for an educational program, television program, in San Francisco.

Heininger: How did you find him?

Krim: I didn't have to look. He came to see me at Sloan-Kettering one afternoon with a young woman named Victoria Hamburg. Victoria and Terry had been friends in New York. Then Terry had gone to San Francisco, and they remained in touch. At some point she heard that Terry was very sick. She went to visit him, and she found him in bed. I don't know if it was in his apartment or where. But she found Terry in bed, and he was very depressed and was letting himself die, because he knew from the symptoms that he had AIDS. She said, "No, somebody like you doesn't die like this. You die fighting. You get up out of the stupid bed and come back with me to New York, and let's go and do something." Isn't that something?

She brought him back, and she put an idea in his head. What she and he could do—because they had, for some reason, some attachments in the entertainment community, some links—was put together the first major benefit on Broadway. Up to that point, all the benefits, even ours, were done all the way downtown, in Chelsea or something, and in little art galleries. We were once on a roof in the summer. But it was never something splashy, never something of broad interest.

They decided to do the first such event, and they thought that AIDS should not be hidden in attics in downtown Manhattan, but rather should be on Broadway. They organized using Lorne Michaels, the producer of *Saturday Night Live*. He was a friend of theirs also, Victoria's friend. They talked him into helping find people who would participate in the event, and we had wonderful people. We had Mike Nichols. We had, oh, there were two comedians, but I don't know their names—two men who were real comedians, experts in comedy—and they were very good.

We did so many of these events over the years. The first event was early '85—planned in '84, unveiled in '85. That's about the time I heard of Gottlieb and Elizabeth Taylor. So '85 was a busy year, because we started raising some serious money, and we brought those two foundations together. The foundation in Los Angeles existed on paper, but they had not done anything yet. We had all the pieces of a machine in place, and we were all ready to go. That was a great thing that we started working together.

Heininger: You've testified in front of Kennedy's Labor Committee, right?

Krim: Yes.

Heininger: What's it like testifying in front of Kennedy? Is he a good questioner? How was he compared to some of the other Senators?

Krim: I think he's better than all of them.

Heininger: Why?

Krim: Because he listens, because he thinks, because he asks plain questions but relevant ones. He doesn't waste time listening to himself speak. He comes always with notes that are perfectly up-to-date and well informed. He's a fantastic guy.

Heininger: Have you worked with him on other issues besides AIDS, or have you testified on other issues?

Krim: No, I have not testified on other issues, but working in a general sense, yes. For example, my husband and I became very interested in Africa, in the independence of certain African nations. We're talking about the early '60s and later. Kennedy was very much part of that group that was pushing for independence and for help for those countries and so forth. I was not involved in any specific way other than being sympathetic to these issues.

Heininger: What has been the importance of the Hollywood connection for AIDS?

Krim: Very important, and this is what helped me so much. I must recognize, in all modesty, that I was lucky, because, number one, I was a woman, when everybody thinks this is a man's problem. Second, I was old enough that they could not say that I was doing it for myself. Third, I had a degree, and that gave me credibility. Fourth, I was the wife of one of the most respected guys in Hollywood. My husband had the reputation of being, really, a class act, as they say, and so that helps. I had never met Elizabeth Taylor in person, but I knew her story and I knew her. I'd heard of her. When we called for me to go visit her, she immediately said yes, that she knew who was coming. All of this was very helpful.

What was the name of one of her husbands, the one with a very short name?

Heininger: Mike Todd?

Krim: Mike Todd, yes. The story I heard is that Mike Todd was really the man she loved more than the others.

Heininger: I've heard that too.

Krim: He was a fine guy, and he was a very good friend of my husband. I remember going to see Elizabeth and saying almost immediately, "Arthur liked Mike Todd," or something like this. "Arthur and Mike Todd were good friends," and she started crying.

Heininger: Touched a button there.

Krim: Touched a button, exactly, yes.

Heininger: Who else has amfAR drawn on in terms of Hollywood?

Krim: Oh, my God, over the years, we've had many people. Richard Gere is one of our good friends—recently, of course, Sharon Stone, but many. If you're interested in a list, I can give it to you. The office has it.

Heininger: What effect does the Hollywood connection have on Congress?

Krim: It could have more effect, because we haven't used them as much as Terry did.

Heininger: They do turn out for Hollywood.

Krim: Yes. Isn't that amazing?

Heininger: Like they all wanted their picture with Elizabeth Taylor.

Krim: Yes, that's right. That's the proof. It's so childish.

Heininger: Just a couple of more questions for you. Was amfAR involved in the issue of the community clinical trials?

Krim: Yes, it was our invention.

Heininger: Why don't you talk about that?

Krim: This is an idea that came, again, from Sonnabend and Terry and me, because by that time, we talked about it and we knew enough of the territory to have an opinion. The idea was that the physicians who knew about AIDS care and who had been involved in it early on were mostly gay. They were mostly in certain urban centers. The universities that do clinical trials are usually not in the center of a city, and they have no gay men among their clientele and maybe no particular interest in this subject.

So when there was talk of early clinical trials, and when some clinical centers tried to organize and do something, with the best of intentions, they found that it was very difficult to recruit subjects for clinical trials. Or they found that people would come once and not come back. Or they would be intimidated, particularly when IDUs, injection drug users, and minorities became important in the sick population. They would have been afraid to go to a university. It was too formal and too official, too imposing. The community physicians—including Sonnabend, who had already, because he was an investigator and a personality, started his own clinical trials—were saying, "Why not other people like me? We should be involved, and we should form local networks of physicians and do ambulatory care, of course, as much as possible. We could start testing things."

By that time—We're talking about '87 and '88—there were already people trying to branch out from AZT and others to test the substances derived from other ones. There were several trials with substances related to AZT going on, to see if some of them would be better than AZT. The question of enrolling patients was a critical one, and we decided to try it, to give some funds, to declare that we would have a program of support for what we called community-based clinical trials, CBCT. We immediately had a dozen groups respond. It was very successful; the idea caught on.

Now, it reached the point, as with many things we did, that it started costing too much for us to support. But never mind. The idea was floating, and so some of these groups had become smart enough and competent enough that they could go directly to industry, and they did, and very successfully, because first of all, they could enroll very fast. The famous example was that while the university enrolled, let's see, three people in nine months, the CBCT group enrolled 200

people in 48 hours, because people were waiting. They were there, but they didn't want to travel two hours to go to the university, and/or they couldn't or they were afraid to or whatever. So it was very successful as a notion, as a method of proceeding. Very soon, we got the support of the industry because the trials are much cheaper through CBCT than through a university. It was a question of cost also.

We started giving the first results, I think, in late 1988, and then in '89, '90, '91, and '92. Then it became expensive for us and less necessary, because industry was funding directly. I don't remember what year, maybe '94 or '95, but we phased it out as one of our programs. It was not necessary, because there were by then, I think, 26 such centers—"sites," as we called them—across the country, enrolling people in clinical trials that were funded by industry.

Heininger: Where was NIH on the issue?

Krim: NIH was not doing that. But because, as everybody else saw, they knew how it was catching on and how some of it was cheap at first, NIH started its own program in '89, and it was called CPCRA [Community Programs for Clinical Research on AIDS]. We've always been proud of the idea that they inspired themselves. I am not sure now how many CBCT people are around. It's still going, I think. I haven't followed it recently, but it's probably still functioning.

Heininger: How supportive was Kennedy of community-based clinical trials?

Krim: He was very supportive of that notion, I'm sure. I don't know how supportive he was in terms of his voting history on the subject. I don't know how he has been recently, because we have stopped following closely.

Heininger: What has Congress' role been on AIDS since this early period?

Krim: The role of Congress?

Heininger: Yes.

Krim: The role of Congress is to take care of the public health. AIDS is still a very serious problem, because we have no vaccine and no life-saving treatment. We have treatments that are effective in that they reduce the load of virus in the blood, and people develop less or later fatal infections than they would without the treatment. But they end up dying of AIDS. So it is a very serious problem. The prevention through education works, provided that people are willing to control their behavior, which is very difficult. Treatments work to the extent that patients are willing to follow prescriptions and regimens of treatment, and some of them are difficult. Drugs have side effects, sometimes even toxic effects, so there is an enormous amount of work that remains to be done. Ted Kennedy knows that. I don't need to remind him. He's an intelligent guy. He knows what goes on.

Heininger: Has amfAR done work on AIDS internationally?

Krim: Yes, and we started very early. In the '80s, already we were doing prevention workshops in Africa. Yesterday was really a comment on this event we had in Dubai two days ago. We raised \$1 million in one night.

Heininger: Wow. You have a lot of money there.

Krim: Yes, there is, but it's nice to get a pot. The interesting thing is that they came to us. We do these events called Cinema Against AIDS. This is a series of events, all following the same model. It's a reception with a silent auction, and then a dinner, and then a live auction at the end. We have people on staff who know how to organize these things, and Sharon Stone enjoys doing them and does them beautifully, I must say. She is really getting the money out of the pockets, and people enjoy it, this rubbing of elbows with the stars, et cetera. We had George Clooney and Sharon Stone in Dubai, and they invited us to come, and they promised to conduct the first class, and apparently they did. It was very successful. Next year I think they will want this again, and they really cherish the idea. They have this link to Hollywood. Isn't that amusing?

Heininger: Hollywood is everywhere.

Krim: Yes, it's amazing.

Heininger: Do you have any last words about Kennedy and about his role on AIDS?

Krim: He's always been absolutely fundamental. He is solid like a rock. He's uncomplicated. He always knows what you're talking about, and he has been absolutely necessary, because in the whole of Congress, he has been the person who has most solidly anchored us.

I should say that there is another one, the Congressman from Los Angeles. Henry Waxman has been very good also, very solid. But of course, in terms of influence, Teddy is unique. The name and his history and the character, I mean, he has everything going for him. He has been a salvation. God knows where I would be without him.

Heininger: That's a perfect note on which to end it.

[END TRANSCRIPT]