



EDWARD M. KENNEDY ORAL HISTORY PROJECT

INTERVIEW WITH ANTHONY S. FAUCI

September 10, 2007
Bethesda, Maryland

Interviewer

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Attending

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TRANSCRIPT

INTERVIEW WITH ANTHONY S. FAUCI

September 10, 2007

Heininger: This is an interview with Dr. Anthony Fauci, on September 10, 2007. Why don't we start at the beginning. Tell us how you first met Kennedy.

Fauci: I knew that was going to be the first question. I've known him for so long that I don't even think I can tell you when I first met him. Probably right in the beginning of the HIV [human immunodeficiency virus] epidemic, before I became the director of the National Institute of Allergy and Infectious Diseases. As you know, I was one of the first people to get involved in HIV back in 1981, and he was among—if not among, then *the* first politician who immediately took a very keen interest. Of course, he had obviously, historically, a great interest in health, particularly health for disenfranchised people. When the first cases came up, I remember getting calls from his staff, wanting a bit of a briefing, first with them, and then with him. So probably the first time that I met him was down at his office in the early years, before I became the director of the Institute, and it was centered around the issue of HIV/AIDS [acquired immunodeficiency syndrome]. HIV was not yet discovered. We didn't even call it AIDS at the time.

Heininger: No.

Fauci: It was the very beginning. I was very excited about the fact that he was interested in it. Of course, I had, very early on, made a decision in my own career to divert away from what I was doing, with just classic immunology and infectious diseases, and begin to start studying this group of people, who were literally measured in handfuls early on. The first case reports from *Morbidity and Mortality Weekly Report* in June of 1981 were of five cases of *Pneumocystis carinii* pneumonia, in individuals in Los Angeles. Then a month later, the second *Morbidity and Mortality Weekly Report* was of about 20-plus patients, who had not only *Pneumocystis* pneumonia, but also Kaposi's sarcoma, from three cities, Los Angeles, San Francisco, and New York.

Heininger: So it was picked up in this country first.

Fauci: It was.

Heininger: Here, before the connection was made to Africa.

Fauci: Absolutely. It definitely was picked up here. So that's the reason why there was that confusion in the beginning: is this a strange disease of gay men? Then, as it evolved, literally week after week after week, you'd get the unfolding and the evolution of the epidemiology, which made it clear that it wasn't restricted just to gay men, that it was a sexually transmitted disease, that it was blood-borne, because injection drug users and recipients of blood and blood products were getting it. Then the first cases of mothers who were injection drug users, who were giving it to their kids. Then the Haitian situation, which was a big red herring, and which was probably a roundabout way of Africa to Haiti, or gay men who went to Haiti for pleasure-type weekends, and were infected. We still don't know whether the gay men from New York infected the Haitians, or the Haitians were the first ones to give it to them when they came back from Africa. It's unclear.

Heininger: Well, let's back up just a minute. The first episodes—because I think we want to pinpoint where Kennedy comes in. The first things you were picking up were in the *Morbidity and Mortality Weekly Reports* coming out of LA [Los Angeles].

Fauci: CDC [Centers for Disease Control].

Heininger: So the CDC reports were coming in, first out of LA, and then they were picked up in San Francisco. Was it linked to gay men at that point?

Fauci: It was all gay men.

Heininger: It was all gay men. So it was picked up initially that way.

Fauci: All gay men in the beginning.

Heininger: With *Pneumocystis*.

Fauci: Right, exactly. The first five cases from Los Angeles were all gay men, and then the others from New York, LA, and San Francisco.

Heininger: So bicoastal.

Fauci: So it was bicoastal, and it was particularly in those areas. I mean, there were a lot of things going on from a sociological standpoint, which was very clear. The Kennedy connection is that Ted had always been very open-minded about gay men, about people who were disenfranchised, any people who didn't have good health coverage, whether you were an injection drug user, or whatever. It was very clear that he was very empathetic towards people in need.

Heininger: Right.

Fauci: And that's the reason why I think, early on, he rose as the champion of helping us in so many different ways.

Heininger: When was it first picked up in the media?

Fauci: It was first picked up in the media in the summer of 1981. Two people to whom you probably should talk would be Larry Altman, who is the medical correspondent of the *New York Times* and David Perlman of the *San Francisco Chronicle*. They were among a very few who wrote many of the first stories on it, and then a lot of other people came in after that.

Heininger: Did Kennedy's interest start this early?

Fauci: You know, to be honest with you, I'm not sure. I'm not 100% sure when his public interest started. It was very clear that by the time I became the director of NIAID [National Institute of Allergy and Infectious Diseases] in 1984 that he was involved, because I almost immediately began testifying at many, many hearings. By 1984, he was very much all over the topic.

Heininger: Do you recall whether it was his staff that picked it up and contacted you initially, or whether he picked it up and went to his staff?

Fauci: I don't know.

Heininger: These are questions we'll ask him, but we also try to ask others.

Fauci: I don't know, because he has such a good relationship with staff, that staff will contact you and it was under the assumption that the Senator was interested in it, not that we're trying to get the Senator interested. It was almost always, when you have a conversation with his staff, that the Senator would like to know such and such, or would you be willing to come down and give us a briefing? The Senator is interested.

Heininger: Do you have any memory of who first contacted you?

Fauci: I'm sorry, I do not remember off hand.

Heininger: Was it Larry Horowitz?

Fauci: Larry Horowitz, for sure, was involved back then, and there was also a young woman. I forgot her name.

Heininger: Mona Sarfaty?

Fauci: Mona, that's right. Yes, Larry and Mona were some of the earliest ones, definitely.

Heininger: I have to see Larry next month. OK, so they were the early—

Fauci: Yes, they were the early ones. I'm sorry I'm not as good a historian, because we've had such a close, continual relationship over the last 20-plus years that it's kind of all merged into one.

So as the epidemic started to unfold, we got the beginnings of understanding what it was. The virus was discovered in 1983 by the French and then confirmed in 1984, and proven to be the cause of AIDS, by [Robert] Gallo and his colleagues. That's the reason why they co-share the credit. Of course, the French actually first identified it in 1983, then Gallo put the finishing touches of the connection, causality between the virus itself and the disease. Once the virus was identified, there was an explosion of information, because you could do a test, and then you did the surveillance. We often used the term "the tip of the iceberg," because when I admitted the first HIV patient here at the NIH [National Institutes of Health] in the summer and fall of 1981, at that time, when I made that strategic decision to stop or phase out what I was doing and concentrate almost completely on this new disease, people thought I was nuts. "Why are you concentrating on this brand new disease of gay men only?" And I was saying, "This is not just going to stay with gay men. Trust me. It's going to be a major, major problem."

Heininger: What made you think that it was going to go far beyond that?

Fauci: Just because I'm an infectious disease person, and in my mind all the cards were stacked up right. It was a sexually transmitted disease, blood and blood products, injection drug use, and the one thing that is very clear is that if there was one thing that we know globally, as a universal given, that's sex. Everybody's having sex. So if you have a sexually transmitted disease, that's a deadly disease, particularly if you have multiple sex partners, as was associated with the brand new-found sexual freedom of the gay community that occurred in the late '60s, with the Stonewall Bar riots. They finally were allowed to essentially do what they wanted to do, without getting harassed by the police or arrested. That sort of gave way to the bathhouse, gay bar culture, and the intensity of the bathhouse culture in New York, San Francisco, and Los Angeles. So it was the perfect storm for an explosion of a sexually transmitted disease.

What we didn't appreciate at the time, but that we started to gain insight into in the early years when we sent a couple of teams to Africa, particularly to Kinshasa in the former Zaire, was that almost all of the transmissibility in Africa was heterosexual transmissibility. So we were saying, wait a minute, this is not going to be confined to the gay population. It's probably going to wind up exploding throughout the world, particularly in those cultures in which sexual permissiveness is culturally different than it is in more of a puritanical country like our own. That was the early '80s, '84 or '85.

Heininger: When was the African connection made?

Fauci: The African connection was made very early, even before the virus was discovered. It was nailed down right around '84, '85, '86, when they started to do sero-surveys, and found out what a very large proportion of populations, particularly pregnant women who would come into clinics, and you'd do screening, or people who were coming in to donate blood. When the test first came out, we found out that the people who were selling their blood in the clinics in Africa, anywhere from 30% to 40% of them, were infected. Because it was the people who needed the money—be they commercial sex workers or what have you—they were the ones who were selling their blood. They were, early on, transmitting it both through blood products as well as through sexual contact.

So it started to become a social issue in the United States, because gay men were frightened. They didn't feel anyone cared about them. They felt that the government wasn't doing enough. I think that was the theme that brought Kennedy in, that the government needs to be doing more. What are we doing? Are we doing everything that we possibly can do? And that was in two arenas. One was getting enough resources for research and health-associated issues. Then as the first drugs started to come about, with AZT [azidothymidine], which was the first approved drug, back in 1987, I believe that's when the Kennedy connection was starting to really be felt, because he wanted fair and equitable treatment for people who could not have access to clinical trials. Clinical trials were very restricted.

Also, there was community. A lot of the trials were confined to the secondary and tertiary medical centers, where it was very difficult for people at the community level, be they poor gay men, African Americans, other minorities, and other people who were in a less-affluent situation, who didn't have health insurance, didn't have connection with a big-time doctor. In reality, and clearly to the perception of Kennedy, they didn't have access to the clinical trials that were being conducted by the NIH, and the drugs that were being evaluated for approval by the FDA [Food and Drug Administration].

The FDA had rather stringent criteria for approval of drugs. What Kennedy did was say, "We've got to have a clinical trial process that reaches out to the community." He was actually the one who pushed very hard and successfully for the community program, for clinical research on AIDS. That was one of his big agenda items; he wanted to get the community access to clinical trials conducted at the community level, as opposed to clinical trials just limited to tertiary centers. Then he hired an HIV-infected person, Terry Beirn, after whom we named our community clinical trials network, the CPCRA [Community Programs for Clinical Research on AIDS]. He actually worked on the staff with Kennedy. So he was an HIV-infected guy who was helping Kennedy get enough information to make a case for this community program for clinical research on AIDS.

Heininger: Now, at the same time, were you getting any feelers of interest from other members of Congress?

Fauci: Ted Weiss from New York's Greenwich Village. [Henry] Waxman from Los Angeles. So Waxman, Weiss, and Kennedy; those were the big three in the early 1980s.

Heininger: That was it?

Fauci: Those were the big three. Others were interested, but these guys were the ones who really stuck their heads out and said we've really got to do something about this.

Heininger: Nothing from [Fortney] Pete Stark?

Fauci: Yes and no. I mean, it isn't that he wasn't involved, it was just he was overshadowed by Kennedy, Ted Weiss, and Waxman. The other thing that Kennedy was—right around the late '90s he was pushing for more funding for HIV. He also was very helpful, because of a program

that I almost got in trouble for, but I didn't. *[laughs]* Maybe Ted was protecting me, but there was a program called "parallel track." He went so far as to be a major pusher of legislation, to put HIV/AIDS on the map. That was during the [Ronald] Reagan administration.

Heininger: Now think about it. That's a seven-year gap between the emergence of the crisis and when we get the first legislation through.

Fauci: Well, yes.

Heininger: Were there attempts earlier than that? From your standpoint, was it necessary to get legislation through before that?

Fauci: I don't want to say if it was necessary or not. It was an evolving problem, and there was certainly Appropriations legislation and language within Appropriations. Kennedy was not Appropriations. The committee that he chaired is the one that puts an authorization and some oversight on the kinds of research that needs to be done.

The other thing was the issue that I mentioned, this idea of parallel track. There was a concept that if you have a clinical trial, it has to be sacrosanct, with very rigid criteria. People who were infected, who had no other possibility of therapy, were objecting that there were a lot of rigid rules that said they could not get into the clinical trial, and therefore could not have access to perhaps the only drug that might prolong their life. Their argument was, "Let *us* take the chance. Let us sign that we appreciate that we may be taking a drug that has some unproven toxicities, but we know, from looking around at all our friends, that in fact we're going to die if we don't get these drugs."

Heininger: You mean what they wanted was to eliminate the control group?

Fauci: No, no. You see, that was a very interesting point, and this is a very important concept. That's the thing that I actually came out publicly for, which was good because it ultimately turned out that that was what was adopted. I knew that Kennedy was on my side, but it was during a period of time when there was, I think, more rigidity in the administration, and even in the Congress, with regard to the FDA. And what it was is this: If you have a clinical trial, the rules say that if it's a brand new drug that's not approved, you could only give it to the people who were in the clinical trial.

Heininger: Right.

Fauci: So it wasn't necessarily a control group or not, if you get into the clinical trial or not. Now, what about all these other people—

Heininger: Oh, I see, I see.

Fauci: —who were geographically not anywhere near where the clinical trial is, or they don't have eligibility criteria. They do not have the right CD4 count for this protocol, or whatever. They still have HIV, and they have no other options.

Heininger: To make it available outside of the clinical trials.

Fauci: Outside of the clinical trial, but keep it—

Heininger: At their own risk.

Fauci: —at their own risk, and that was called the parallel track. The activists were pushing for that because they were very clear that they didn't want to disturb the integrity of a clinical trial that might ultimately prove a drug to be effective or not. On the other hand, they didn't want to block the people who might get some benefit, so long as giving it to them didn't interfere with the data from the clinical trial. Very few people came out in favor of that. All the activists were very much in favor of that. I remember in the late '80s, when I was in San Francisco, I was then totally convinced by the activists that that was the right thing to do. So I went out there, and in front of a lot of press, I made a speech where I came out in favor of parallel track, which caught official Washington somewhat by surprise, because the FDA Commissioner was very much being rigid about that.

Heininger: Who was the Commissioner at the time?

Fauci: Frank Young.

Heininger: OK. This was pre-David Kessler?

Fauci: Yes. And Frank, as soon as he heard what I did in San Francisco—it was kind of interesting. I was getting ready to come home and figured I'm going to have a job or I'm not going to have a job. As it turned out, the cry among, I think reasonable people, including the activists, was that this was absolutely the right thing to do, that I came out in favor of it. So Frank Young, who is a good guy, said, "Well, I'm totally behind Tony Fauci on this. We're going to go ahead and have a parallel track."

So what started out as a risky thing, to get up on a stage in San Francisco, in front of all the activists, and say that I endorse the parallel track (it made the *New York Times* the next day) actually changed a policy. The FDA finally accepted the parallel track as a mechanism whereby you can get drugs available for people outside, or in a parallel track with, the clinical trials, so long as you don't disrupt the integrity of the clinical trials.

Heininger: Were data collected from the people in the parallel track?

Fauci: No.

Heininger: Or simply, the drug was made available.

Fauci: It was made available, and just minimum data were collected. That was one of the things, because we didn't have the resources in the clinical trial apparatus to collect anything but safety

data. So we did collect safety data on them. That was one of the first breaking of the logjam of rigidity in clinical trials.

Heininger: And Kennedy backed it too?

Fauci: Well, he was always for it—that's when our relationship started to get really good, because I was pushing for things that he was very much sympathetic to, but it was not necessarily within his purview to speak out about it. Kennedy's not afraid to speak out against anything or for anything, but it was good to know that he was behind me, in the sense that he was very much approving, pushing the envelope to get accessibility of drugs. In fact, the fact that Kennedy was out there pushing that concept made it much easier for me, during a more conservative administration, to do it. I think that was the beginning of a very special relationship with Kennedy, because I don't think anybody would screw around with me if he was very favorably disposed to the things that I was trying to do.

Heininger: Now, where was [Orrin] Hatch at the time?

Fauci: Hatch was terrific. I have to tell you, Hatch and Kennedy also have a great relationship. Hatch was always the one who was obviously a bit more conservative than Kennedy, because Kennedy is quite liberal, but he was never an obstruction to any of the things we wanted to do, never. Hatch was of a different party and a bit more conservative, but clearly he had a similar version of that simpatico that Kennedy had. Kennedy was always phenomenally open-minded about what we needed to do for better access, for better care, for more research, for doing the best we can, even though we were dealing fundamentally with what was considered to be a disenfranchised population, particularly during administrations that were quite more conservative than he was.

I do have, and still do have, a great deal of respect for the administration people, the Reagan administration and then the first [George H. W.] Bush administration, because they were really—at least father Bush was really quite good in not necessarily being the outspoken spokesperson for it, but for allowing me to push the envelope for doing things. Kennedy was always right up there, kind of giving his active approval of pushing the envelope, of getting more and more done. So it was great to have a person of his stature and influence not only doing things like that law, but expressing approval of those of us who were trying to push the envelope from within the executive branch.

Heininger: How critical do you think it was having somebody like Hatch backing you at this time, in terms of dealing with the administration?

Fauci: It was quite important. I think the relationship between Kennedy and Hatch was great for us, because they were not seen as polar opposites. They were seen almost as a team. You could say you were doing things for the team and say that you're in agreement with Hatch, and you were able to get these things done.

Heininger: Did you have the same kind of backing on the Appropriations Committee?

Fauci: The Appropriations Committee was a different story. The Appropriations Committee was continually trying to get more resources for us. Lowell Weicker, when he was the chair of our Senate Appropriations Committee, and on the House side way back then it was—oh God, the gentleman from Kentucky. What's his name, Patty?

Heininger: Wendell Ford?

Fauci: No, no, no.

Heininger: Earlier than that?

Fauci: Old gentleman. Always used to wear a three-piece suit, with a very starched shirt. I remember now; it was Chairman William Natcher.

But the answer to your question is that it was very clear that the appropriators were always putting more money in than OMB [Office of Management and Budget] would ask for. This worked both ways; so it wasn't just when it was a Democratic Congress and a Republican President or vice versa. It was just always bipartisan. So in the early years the appropriators were always putting more money into HIV/AIDS than the Administrations asked for.

Heininger: So, where do you have the problems then? If you've got big authorizers on the Senate side and you've got appropriators on both sides, where's your problem?

Fauci: When you say "the problem," I think the problem fundamentally, early on, was really a scientific problem, in the sense of development of the right drugs, which we now have. For example, 1996 was an absolute breakthrough year because that was the year when the first protease inhibitors were approved. Then the triple combination of drugs really led to a dramatic turnaround in the clinical course of HIV-infected individuals. So that was a big, big deal then. Even up to today, now, ten years later, three million years of life have been saved by these therapies.

The problem, whether it really was a problem, is that early on in the very early years, the Reagan administration did not take an aggressive leadership role in calling attention to the problem. The big, unfortunate rap on Reagan, even though he was a good guy, was that he didn't mention the word AIDS for years into the epidemic. So that slowed down the ability of the government to get the message out about preventive measures. George H. W. Bush was clearly better in this regard.

Heininger: Do you have a sense as to why?

Fauci: I just think he was much more moderate. Although he had a strong conservative base, he was driven much more by doing the right thing regardless of ideology. When he first came to the NIH as Vice President, that's when I developed my relationship, the early part of my relationship with him. I was asked to show him around because I was the AIDS person here. We developed a good friendship that has lasted even up to today.

As President, he kept on asking me to come down to the White House and explain to him the need for this and the need for that. He became very sympathetic and actually increased the budget a fair amount.

Heininger: So you think a lot of the progress has been because you've been able to foster it by developing relationships with people.

Fauci: I certainly was not alone in this. There were others that were pushing. Regardless of who is involved, when it comes to government, it really does have a lot to do with relationships with people. I received an award in April of '07 from the Association of American Physicians. The Kober Medal is given to physician-scientists for life-long, career accomplishments. You have to give a short, 15-minute acceptance speech about what you feel are the important things that got you to where you were. Actually, the point that I mentioned was relationships, and I specifically pointed out Ted Kennedy. I showed a slide of Ted and me, saying that particularly from the very beginning, he was always extremely supportive of what I did, but also he was a leader in the sense that he was always pushing the envelope himself.

So you can really look at it from two sides of the coin. It wasn't that he was supportive of things that I did and that other people like me did. He was indeed very supportive, but he also, himself, was continually probing about how much more you can push appropriately, both scientifically and public healthwise.

Heininger: When you get into the battle over the first AIDS legislation in '88, and then subsequently even more so with the Ryan White Act, there was a transition in making it a public health versus a gay rights issue.

Fauci: Right.

Heininger: What did it take to turn AIDS from a gay rights issue into a public health issue?

Fauci: I think it was the realization of what you asked me about when I first decided to change the direction of my laboratory, because it was very clear that it did go well beyond the gay population. That's the reason why we have the Ryan White Act—I mean, Ryan White was a hemophiliac, and there were people who were infected who were not just within the gay population. Clearly, even today, it's a continually evolving disease, and Kennedy knows that, which is one of the reasons why he was also very much pushing the envelope regarding clinical trials, and having clinical trials provide equal opportunities for people to get access to things that they would not otherwise have access to. So if you look at now, 2007, it reflects the continuing evolution of what Kennedy is very sensitive to, even today.

There are 40,000 new infections in this country each year. Of the 40,000 new infections among men, 49% of them are among African-American men, even though African Americans comprise only 12% of our population. Of the new infections in women, 60% to 65% are among African-American women, even though only 12% of the population is African American. So there really is a health disparity there, which is the reason why, in everything we do—in the design of our clinical trials, in the accessibility of our clinical trials, in the messages that the CDC needs to get

out—you need to target at risk people, you need to be open about your messages. There’s a great concern that if you explicitly talk about certain things, that’s going to offend the general public. Well, that’s one of the things that Kennedy was very much against; namely, you have to be realistic in tailoring your message to get to the people who really need to understand the message.

Heininger: But in the battles within the Senate itself, when it came to Ryan White particularly, your chief opponent there was [Jesse] Helms.

Fauci: Right.

Heininger: What did it take to get the whole Senate to see this principally as a public health rather than a gay rights issue?

Fauci: I don’t know, to be honest with you. I can tell you what my impression is, but it’s a very complicated issue. I think it has a lot to do with behind the scenes bargaining back and forth, with the leadership of somebody like Kennedy. I mean, that’s Kennedy at his best. That’s him at his very best. Sure, it’s a public health issue more than it is a gay person issue, but you still can’t get around the numbers. At the time that the Ryan White legislation was passed, it was very clear that in the U.S.A. it was still predominantly a disease of gay men—the majority of cases were among gay men. The disease severely hit hemophiliacs, but in the big picture of the country, that was a relatively small number. There were some transfusion cases. You know, the famous examples of the 65-year-old grandmother who gets a mastectomy for breast cancer, gets transfused before the screening, and now she’s got HIV/AIDS. Those kinds of things.

True, it is a public health issue in this country that goes beyond gay men. It goes to injection drug users. It goes to transfusion, which has now obviously stopped because of the screening of blood. It goes to hemophiliacs, which has obviously stopped now. But what I think it is, the people who are fundamentally reticent to do something for the gay population could point to the hemophiliacs as the so-called—and I hate to use that word—innocent victims, as opposed to the people who “did some bad thing” to get infected. So if that’s what it took to get certain lawmakers to support something like the Ryan White Act, fine. It was almost as if Kennedy really didn’t care what you hung your hat on, about why you were going to approve it, as long as it gets approved, because he realized that we desperately needed a Ryan White CARE [Comprehensive AIDS Resources Emergency] Act. It was very clear that we needed that. He pushed for it, and he got enough votes to get it.

Heininger: Talk about the change in the public perceptions of this too. What did it take to change public perceptions?

Fauci: When you say change them, you mean change them from making this a stigmatized disease versus a disease where we need to take care of these people?

Heininger: Yes. I’m assuming there are various actors in this, and you get Congressional action, international issues.

Fauci: I think it was several things. It's how the disease evolved, to the point where whether you were a conservative or a moderate or a liberal, within a reasonable period of time, as we got into the epidemic, from the very early '80s to the late '80s, virtually everybody knew somebody or had heard of somebody that they knew and liked, who was HIV-infected. Then you get a couple of very prominent celebrities—[Earvin] Magic Johnson, Rock Hudson, ballet dancers, [Rudolf] Nureyev and others.

Heininger: Nureyev, right.

Fauci: All of these people were public figures who were admired, without concern or suspicion or even care about what their sexual persuasion was. I think those are the kind of things that got people to lessen the issue of stigma. The egregious injustice of burning down the homes of hemophiliac kids who live in a community because some people wanted them to leave so they wouldn't go to their public schools. The terrible discrimination against young kids. That's the thing that really moves people. You could have this distorted view towards gay men, for whatever your personal reasons are, but it's very tough to hate a kid who got infected through a transfusion.

Heininger: So that goes back to the question of being transferred into “innocent victims” that allowed—from what you're saying, that allowed people to begin to say, Wait a minute, it's not just *them*.

Fauci: Right, exactly.

Heininger: It's the innocent ones too. Who were some of the other early actors in the AIDS crisis?

Fauci: Mathilde [Krim].

Heininger: Why? What did she do?

Fauci: She was, again, a very outspoken advocate for removal of the stigma; that a virus is the enemy, not the person. We need to treat people with respect, and as much as possible, avoid and remove stigma.

Heininger: What was her relationship with Kennedy?

Fauci: Good. Yes, I believe they were good friends. Then there were activists. Larry Kramer. Iconoclastic Larry is a big player in this. Marty Delaney from San Francisco is a big player. Merv Silverman? Yes. The guy who was the head of the Department of Health in San Francisco, who tried to close the bathhouses. And then there was the handful of early scientists who were involved in it. At the CDC there was Jim Curran. Up here it was me and Bob Gallo. In San Francisco it was Paul Volberding.

Heininger: What's his last name?

Fauci: Volberding. He's still in the University of California, in San Francisco.

Heininger: Did he have any relationship with Kennedy?

Fauci: I'm not sure. I don't think so.

Heininger: What about the international dimension? What effect do you think that the spread of the disease worldwide had?

Fauci: It has completely transformed how we look at global health; it's been a very interesting phenomenon that has occurred. The way I tell the story is that we became interested in HIV/AIDS as a nation because it was first recognized in the developed world, even though it originated in the developing world. It was only because of our ability to diagnose such a catastrophically devastating disease, whereas if you're living in the middle of sub-Saharan Africa, there are so many other things that kill you that you can go unnoticed having a disease like this. So we first noticed it, and then it became clear, from a number of studies, one of which we, together with the CDC and the University of Antwerp in Belgium, started. In fact, there were two studies: one in Haiti and one in Kinshasa, Zaire, back in the very early '80s. Both of those studies made it very clear that this was a heterosexual disease. As we began to do monitoring in Africa, it became very clear that this was overwhelmingly devastating the continent, sub-Saharan Africa, not to mention the Caribbean, certain parts of South America, and then in certain countries in Asia.

So there was an interesting twist in that. The twist was, when we got to these countries, we saw that AIDS was completely out of control, with over 30 million people infected with HIV. There was a total of about 60 million, and more than 20 million are already dead. Ninety percent of the cases are in the developing world and two thirds of all the cases are in sub-Saharan Africa. So we see this enormous problem. But when we get there, we find out that there is almost an equally enormous problem of malaria, tuberculosis, diarrheal diseases, respiratory diseases, as well as an entire spectrum of neglected tropical diseases that nobody can even pronounce, much less care about, that are creating a terrible degree of morbidity and mortality. AIDS, malaria, and TB [tuberculosis] are the three big killers; but diseases like schistosomiasis and trypanosomiasis and leishmaniasis, and all of those other diseases that cause a great deal of disease burden, interfere with economic development, interfere with the gross national product, which I think helped trigger the broader interest in global health in general.

Now, that's noteworthy because Kennedy has always been interested in global health. So we found that our old ally was a new ally and a new advocate. In fact, we had this big conference down at GW [George Washington University] on neglected tropical diseases, and Kennedy gave a little clip, a video clip, to open the conference. So again, when you have somebody of the stature and legendary capability of Kennedy who's a backer of a particular effort that you're trying to do, it adds a phenomenal degree of momentum and credibility to it.

I talk about global health all the time. That's one of the main agenda items of my institute, since it's the National Institute of Allergy and Infectious Diseases. Even up to today, I talk to somebody like Kennedy, who is very interested. He's interested in a lot of things, but he's also

interested in the things that are of enormous global health magnitude, like the relationship between TB and malaria, HIV, and the so-called neglected tropical diseases. He continually emphasizes that with a relatively small amount of money, you could have a major impact on some of these diseases, and why it's important to develop vaccines and treatments for them.

Heininger: How important was [Jimmy] Carter's Guinea worm initiative?

Fauci: It was very important because it showed that if you partner with a pharmaceutical company, and you pick out a disease whose epidemiological profile makes it amenable to eradication, when you have a very low-cost drug, you can in essence phenomenally modify the disease in a particular, well-defined country or group of countries. So it's a very good model, because there are other diseases that you could probably do that with, some of the rarer diseases. If you get enough interest, you get industry involved in it, you put some money and you go in and you treat it, you could probably decrease dramatically the prevalence of some of those neglected tropical diseases in much the same way as we did with Guinea worm.

Heininger: So if you target things that in fact can be eradicated with a low-cost drug, it's a model for dealing with these neglected diseases?

Fauci: Right.

Heininger: And how do you deal with a thing like malaria?

Fauci: There are two pathways in malaria. One is the quest for a vaccine. We're making more progress with a vaccine in the last 15 years than we've made in the previous many years, because we kind of graduated malaria vaccinology into the technology of the 21st century. Today there are some reasonably good vaccine candidates in the pipeline; however, there are also some low-hanging fruit that can be addressed right now. Take, for example, the President's Malaria Initiative, which is a combination of limited spraying of the indoor, lower parts of huts, insecticide-embedded bed nets, combination artemisinin therapy, and treatment and prevention of malaria in pregnant women. There has been a dramatic decrease in malaria where those programs have been implemented in places like Zanzibar and Mozambique. There are some things that can be done practically with malaria, action items that we are already able to do, and then there's the investment, the long-term investment in the development of a vaccine. If we get a vaccine for malaria, that's going to transform many of these developing nations whose economic development is severely impeded by the burden of malaria.

Heininger: How important have been efforts of people like Paul Farmer and the Gates Foundation efforts been?

Fauci: The Gates Foundation efforts have been very important. Almost all of the malaria research prior to [Bill and Melinda] Gates getting involved was supported either by NIAID or the Department of Defense. So most of the research action came from us. What the Gates Foundation did that was so important is that they put a lot of money, not necessarily into research, but into programs to control diseases, where you can take a substantial amount of money, not \$5 million, \$10 million, but hundreds of millions of dollars, from an NGO

[nongovernmental organization], a philanthropic organization, and do what needs to be done to look directly at the gaps and fill them in. I think the Gates Foundation has transformed the whole issue of global health now, by being an additional important player. If you look at the money the United States Federal Government, the Department of Health and Human Services, puts into these things, it still dwarfs anything that the Gates Foundation does. But to have another nongovernment player be involved is very important, because it also galvanizes others to get involved.

Paul Farmer's contribution is a bit different. His contribution is incredibly important, because what Paul has done is completely destroy the misconception that you cannot deliver drugs or treat a serious disease in a rural health care setting because you will never be able to obtain and administer the drugs that are needed to be given to somebody on a daily basis. The first model was the establishment of the DOTS, directly observed therapy, short course (for tuberculosis), for which he was one of the major advocates. He proved that if you go into the bush in Haiti, and implement DOTS, you can effectively control and practically eliminate the issue of multiple drug-resistant tuberculosis. He used that same model to get drugs available to rural areas in Haiti for HIV and he is now doing the same thing in Rwanda. Of course, there were a lot of people who said it was futile even to think that you're ever going to be able to treat people with HIV in developing countries.

I had the Farmer model in mind when I helped with the development of the President's Emergency Plan for AIDS Relief [PEPFAR], when the President sent me and Tommy Thompson to Africa to come back with some suggestions about how the United States could have a major impact on HIV in developing nations. We first proposed the \$500 million, mother-to-child-transmission prevention program. But then, when I presented it to the President, as I finished presenting it to him, he said, "I want you to go now and put together, without any consideration for how much it will cost, a doable, accountable, responsible transforming program to get drugs to the people in Africa." We ultimately targeted 12 African countries, two Caribbean countries, and then ultimately one Asian country, which was Vietnam. The President went on to say: "Map out a program about how we're going to do that; in what countries and how much it's going to cost." So I did that. It took me about eight months to do that. I came back and presented it to him, and that's what ultimately came to be the President's Emergency Plan for AIDS Relief, or PEPFAR, which is a very successful program.

Heininger: This was under [William] Clinton?

Fauci: No, no. This is George W. Bush.

Heininger: This predated Clinton?

Fauci: No, no, George W., *after* Clinton.

Heininger: Really?

Fauci: Yes. In fact, it's the largest public health program for a single disease ever implemented by any country. We put the program together throughout the summer and fall of 2002, and he announced it in the State of the Union Address in 2003.

Heininger: I'd forgotten the timing on this.

Fauci: Yes. So that's called the PEPFAR, the President's Emergency Plan for AIDS Relief. Simultaneous with that, former-President Clinton was helping to negotiate down the prices of drugs. That's one of his major accomplishments following his Presidency.

Heininger: With his Clinton Foundation.

Fauci: The Clinton Foundation, but that's after he left the Presidency. But we were talking about Paul Farmer, and that's why I gave you the long-winded discussion about PEPFAR. So, when we finally had to convince the President, President George W. Bush, that this was something worth putting \$15 billion of taxpayers' money into, it was the largest amount of money ever put into a health care program for a single disease. It was \$15 billion over five years, and he just requested its renewal for \$30 billion for the next five years. We had to get some confirmation that this is something that's actually feasible. He asked me to get three or four people of my choice, to come to the White House to say that this isn't just Tony Fauci's fantasy, that it actually can be done. I got Peter Mugenyi from Uganda, Bill Pape from Haiti, Paul Farmer from Haiti, and Eric Goosby, who was in Rwanda at the time. It was Paul Farmer's model of going into the sticks, into the rural area of Haiti, and Peter Mugenyi's Uganda, that argued that this could be done. That's how the program was launched. Anyway, that's the long-winded answer to your Paul Farmer question.

Heininger: So it's basically been his model that has demonstrated that it can be done.

Fauci: That it can be done. That you *can* get drugs to be given to people in rural settings on a daily basis.

Heininger: Where has Kennedy been on this, and what's his relationship been with Paul Farmer?

Fauci: I don't know. I'm sure that they know each other quite well because Farmer is from the Brigham and Women's Hospital in Boston. There's no way that he'd be a Boston guy without Kennedy knowing him.

Heininger: True. What was Elizabeth Taylor's role?

Fauci: Elizabeth was part of the Mathilde Krim connection. Krim, because of her access to the Hollywood elite, got Elizabeth Taylor to be a celebrity spokesperson for HIV/AIDS. Elizabeth is one of those people who is very generous of her time, to be an advocate for more AIDS research, removal of stigmatizing AIDS. Also, she was very good friends with Rock Hudson, and I think she was pretty much shaken by Hudson's death. Mathilde was very influential in stoking the

Hollywood community to get involved and support an open destigmatization of HIV, and that was due to connections of her husband.

Heininger: What had Arthur [Krim] done?

Fauci: He was a major Hollywood producer.

Heininger: He ended up at Columbia, didn't he?

Fauci: I don't know.

Heininger: Yes, I think he ended up at Columbia eventually. So you've done a lot with him. Well, tell me about [C. Everett] Koop.

Fauci: Oh, it's a long story with Koop.

Heininger: I'm going to see him, probably in a couple weeks.

Fauci: When Koop became Surgeon General, it was an interesting situation. Of course, Kennedy had a great deal of skepticism about Koop, because Koop was known for his pro-life stand and was felt to be quite conservative. He was one of the most famous pediatric surgeons of all time, and he was very much for trying to save lives, even kids who were born with terrible disorders and dysfunctions. He was a champion of pro-life for everyone. He treats life with a great deal of sanctity. So when they put him up for Surgeon General, there was a concern that he would be a very right-wing type of person. Kennedy was concerned about that, so initially Kennedy had some great skepticism about Koop.

Heininger: He did about David Souter too.

Fauci: When Koop came, I got to know him because his confirmation was being delayed, and he had one hearing after the other. There was a great deal of skepticism about him. He was very stressed, so I am—at the time and still am, but to a lesser extent—considered the internist for the people around who need a doctor, since I take medical care of a lot of people. Chick Koop came to me because he was so stressed out. I became his sympathetic ear about the Federal Government, of which he had not much knowledge.

So to make a long story short, when he was finally confirmed, we remained very good friends. He took an interest in HIV and I would literally spend hours and hours with him, talking about HIV, what it was, the kinds of things we need to do. He then said, "This is great. I've got to do something about this." So he was agitating to do something about it, until finally President Reagan asked him to put together a report, thinking that the report never would go anywhere. Chick absolutely made this his passion, and started studying it like you wouldn't believe, until he knew everything available about the disease. He interviewed me and a bunch of other people many, many times, until he got out this report, which is interesting because they wouldn't give him any money to send it out. You know, that letter to the American public? So we did a

material transfer agreement; I gave him some of the money from my institute. They thought they were going to block him by not giving him enough money, but we got around that.

Anyway, he gave the report, which was the first official government document about all the facts you need to know about HIV. He mentioned, in a very explicit way, things like gay sex, anal sex, injection drug use, prostitution, oral sex, et cetera, et cetera, which got a lot of the ultraconservative people in the administration a little bit upset about that. But he didn't care, and as it turned out, he made the administration look good, in many respects, with that. That's when it was very clear that Kennedy changed his mind about Chick, because he saw that this guy is for real. But I think he realized that beforehand, so he was fair. He was never unfair with him. He just had some skepticism early on.

Heininger: Have you heard the story about whether or not Kennedy intervened with Reagan, on Koop's behalf, to get out that report?

Fauci: I don't know. He very well may have.

Heininger: I have to ask him about that.

Fauci: Yes. He very well may have.

Heininger: Because I've seen that written up, that he called Kennedy and he said, "Can you help?" And Kennedy called the President.

Fauci: There were two things. There was the Surgeon General's report and then there was the letter.

Heininger: Then there was the letter. It may have been on the letter.

Fauci: The letter is the one that he didn't have any money for, so that's when I—

Heininger: So you got him the money for the letter.

Fauci: The letter. *[laughs]*

Heininger: OK. I think it was the letter that he asked Kennedy.

Fauci: I didn't get him the money, I gave it to him. I did an interagency transfer.

Heininger: Anyone who's had experience in appropriations knows how to do these things.

Fauci: Yes.

Heininger: Let's go back to when you testify in front of Congress. We have yet to actually talk to anybody, to ask them this particular question. What is it like testifying in front of Kennedy? What's he like as a questioner?

Fauci: He's tough. He's tough, but he's fair and he—[*pauses*] it depends on who the witness is. Let me give you an example of how our relationship evolved over the years. As the years went by, I got to like him more and respect him more. When Reagan was President, when Bush was President, he would get up and I would be the government witness. He would be up there, beating the heck out of me publicly, because of the fact that I'm the administration witness. And when it was all over, he would come down off the podium and just put his arm around me and say, "Nothing personal Tony, but we've just got to get things moving." [*laughs*] He was very good at that. He was very good at making his point. You know, not being mean, but being tough. Being tough when he felt that the witnesses or the institutions that the witnesses represented were not doing what he felt they should be doing.

Heininger: How did he differ from other Senators in terms of the questioning?

Fauci: Gee, I'm not going to tell you which other Senators.

Heininger: No, just in general. I mean, if you compared him to other Senators.

Fauci: He was unbelievably well informed. He was similar to Tim Russert on *Meet the Press*, when he has every single fact at his fingertips; you said this then, you said this another time, what about this now?

Heininger: OK, that's the "ouch" factor.

Fauci: He was so well prepared it was incredible. We've gotten to the point now where testimonies before him are not stressful, but I wouldn't say easy; we're like two old people who have been engaging back and forth, across the table, for 25 years, and we know each other real well and like each other a lot.

Heininger: Well, it's true; you have been.

Fauci: So now there's a very special kind of thing that I'm always absolutely open with him. I don't hold anything back with him, and he knows that. And he respects me for that. But I also know that he's going to ask me tough questions, and you'd better come up with answers that are reasonable answers. But I've seen him, for example, when Frank Young was testifying once, and I was sitting next to him sort of wincing because I was saying to myself, *Frank, don't do this, you're going to get killed*. Frank Young was the FDA Director. Kennedy asked him to testify, and he got up with these elaborate posters that just didn't make any rational sense. He got about four minutes into his testimony and Kennedy just says, "All right, enough." He wouldn't even let him get through the oral testimony. Frank underestimated Kennedy's knowledge of the subject. That's a big mistake.

Heininger: But if you look at the rest of the audience, perhaps he was speaking to the rest of the audience.

Fauci: No, no, no. He was looking at the Senator. [*laughter*] He made a big mistake.

Heininger: Got it.

Fauci: He made a big mistake.

Heininger: So, never underestimate what Kennedy might know because he's bound to already know it.

Fauci: Yes, indeed.

Heininger: OK.

Fauci: And always give the straight answer.

Heininger: Well, obfuscating is never a good thing to do in front of Congress.

Fauci: No.

Heininger: Never.

Fauci: But the thing about him is that he's incredibly supportive of certain things, and he'll say it. He says, I really do appreciate your doing this and this and that. Even with people whose performance he's not particularly pleased with, he'll let them know about it but he doesn't try to degrade anybody. He sometime gets angry. I've seen him get angry at hearings.

Heininger: What's Kennedy's staff like?

Fauci: Good. I mean, very good. They work hard. *[laughs]*

Heininger: They're legendary.

Fauci: They work very hard. They go to meetings that you're at and even talks that you might give, and then they'll call you up to follow up, asking questions. People like David Bowen, right now, who is one of his main people, is very knowledgeable but also very probing. You develop a relationship over the years, where they'll just get on the phone and say, "Hey, can you help us out with this? I heard this about this and that about that, what do you think? What's going on?"

Heininger: So his staff cultivates the relationships?

Fauci: Yes.

Heininger: Tell us about dinners at Kennedy's house. Have you been involved in that process?

Fauci: No.

Heininger: You've not done any of the dinner briefings at his house?

Fauci: No.

Heininger: That's interesting. You've been spared. *[laughs]*

Fauci: I haven't.

Heininger: No, probably not. They can be very—a gathering of experts in an area, and then you think he's not listening and then find, three hours later, that he picks up on something that has been said three hours earlier. It's tough.

What other issues have you dealt with him on, since your brief goes beyond HIV/AIDS? Medical experimentation? Ethical issues?

Fauci: We have engaged in the tuberculosis issues, about the multiple drug-resistant tuberculosis. I usually am testifying in front of his committee on health issues, including biodefense, and including the preparedness of the Federal Government to protect its citizens from emerging threats, including biodefense.

Usually he'll question the CDC about making sure that they're doing what they're supposed to be doing. I testify a lot, together with the CDC. Kennedy wants to make sure that the money that gets invested in these particular agencies is being spent in the manner that is to the benefit of the entire American people. So the questions to me are regarding the kinds of research we're doing. But he'll ask me my opinion of a general, broad issue because I think he respects the fact that I will give him a straight answer, like I always give him. There have been the issues of—I haven't had stem cell hearings with him. I've had discussions during hearings about ethics of clinical trials with him. I've had issues concerning minority access to clinical trials. I have had discussions, every which way, of every different type of HIV/AIDS issue, and there were many, many hearings there.

But there were also issues, as you said, of the ethical conduct of clinical trials, the access of minority populations to health in general, including the programs that are supported by NIH. There were issues of emerging and reemerging infections, West Nile virus, SARS [severe acute respiratory syndrome], all the things that are threats to health. So we've been involved in everything from SARS to influenza to extensively drug-resistant tuberculosis, and minority access to clinical trials. You could write a whole textbook of health on the issues that have gone back and forth over the years.

Heininger: Has he ever thrown you a curveball in a hearing?

Fauci: You mean try to catch me on something?

Heininger: Well, not necessarily deliberately, but thrown you a question that you've wondered where it's come from.

Fauci: I don't recall. Likely, but by the time we had our back and forth, we had figured out what the issue was. I mean, he may say, "What is this I hear about this?" And I might say, "Well, Mr. Chairman or Senator, I'm not quite sure. Do you mean this, this, and this?" And then he'd whisper over to his staff. "Yes, that's what I'm talking about." You know, that kind of thing. Yes, we've had that, but I wouldn't exactly call that a curveball.

Heininger: No. It's more that, since his manner of speaking sometimes isn't comprehensible, since he doesn't always speak in full sentences, do you ever get questions where his thought process has gone off into something, or does he maintain a real sense of discipline when he's in hearings?

Fauci: I think I know what you're getting at. I've never been to any of these dinner meetings, but I've been to a lot of briefings in his office, and you're right. He can sometimes dwindle around, have multiple things on his mind, particularly if he's been working really hard and he's tired. But when he's in a hearing, for the most part, when he's at a hearing, he generally zeroes in pretty much like a laser.

Heininger: We've had a lot of people tell us about how his mind will ping pong from thing to thing, simply because his knowledge base, stretched out over all these years, is so extensive that people will—he'll come up with something because his mind is this far ahead and tangentially moved on to something else.

Fauci: Right.

Heininger: So it's interesting to hear you say that when he gets into these hearings, he maintains his laser focus on the hearing.

Fauci: Let me tell you one thing that is very Kennedy-ish, that maybe others have told you. In fact, this may be one of the most important things that I say about him, why I respect him so much and like him. There are some Senators or Congressmen who get a list of questions from the staff and they'll say, "All right, Dr. Fauci. There are six clouds in the sky. Would you say that it is a cloudy day or not?" And I say, "The leaves on the tree are very green, and there are several squirrels on the tree." "Thank you very much, next question." They don't have a clue of what it is they're asking and what the answer is.

When he asks you a question, he follows your answer, and you can see, if he doesn't quite think or get what you're saying, he'll say, "Now wait a minute, how does that fit in with this?" So there are no non sequiturs there. He'll ask you a question. If you start to answer a different question, he'll say, "That's not the question I've asked you." To be honest with you, it's never happened with me because I have watched him at work, and I don't do that. But I've seen him say to the person next to me, "What are you talking about? That's not the question I asked you." So it isn't as if he's asking the question just to get the question asked, and then whatever your answer is, it doesn't make any difference. He follows your answer.

Heininger: So he's really listening.

Fauci: Yes.

Heininger: Well, there is a technique of just asking questions for the purpose of getting them out there, but I understand what you're saying. When he asks a question, he wants an answer to it.

Fauci: Right.

Heininger: Yes. What else should we know about him? What will people in the future want to know about him, and what his role has been on this, particularly in HIV/AIDS?

Fauci: Right now, 25, 26 years into it, I think people should know that he was a very staunch advocate for government fulfilling its responsibility, for a removal of stigma associated with diseases that afflict populations that are somewhat disenfranchised to begin with, and ultimately fairness.

Heininger: Not a bad legacy.

Fauci: He came into the Senate as a very young guy, when he was 30 years old, to take his brother's seat, and he has gotten better and better and better and better. So now he has not only such an incredible track record of accomplishment, but he's a very wise person. You have to understand, he's a very liberal guy. So if you're a conservative person, or even if you're moderate to conservative, there are things that he'll push you on, whoever you may be.

But the one thing that is unarguable, as far as I'm concerned, whether you're over here or you're over there or you're in the middle, is that here's a guy who's been doing this for many, many, many years, he sticks to message, is very effective, has an incredible staff, works hard, and is—they call him the “Lion of the Senate.” He really is, he really is. It's going to be a very sad day when he retires, I think, a very sad day, because he just has this incredible, this wonderful credibility and fount of knowledge and experience, and a real empathy for people. You can tell when he's doing this that he's not doing it because he wants to be President. He's not doing it because he wants to be majority leader. He's doing it because this is what he believes in. You get a very good feeling when you're dealing with him, whether it's on the phone and he's calling you up and asking you a question, or whether you see him at a reception, or whether he comes and visits the NIH, or whether you're sitting across the table from him at a hearing. He's doing it because he really believes in it. To me, that's a great legacy.

Heininger: What explains his ability to work with people across the aisle?

Fauci: He's a great politician and he knows how to get things done. He's also a very nice guy, and people like him. I think that explains his relationship with Orrin Hatch and others. In the beginning of the Bush administration, he developed a pretty good relationship with our current President. They parted ways on things, but he developed a pretty good relationship. The other thing—he was probably that way earlier on, but he's certainly that way now—he's not afraid of anybody. No, he's not.

Heininger: No. Maybe his mother, but we're all afraid of our mothers. *[laughter]*

Well, this has been very useful.

Fauci: Great.

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