Interview with Frank Rhame
Interviewed by Fraser Nelson
Interviewed on May 30, 1994,
at Rhame's home in Minneapolis

FN: When did you become aware of AIDS? Can you remember what it was like when you learned about it?

FR: I learned about AIDS from the publication on the day it came out in the Morbidity and Mortality Weekly Report. Everybody who read that first thing in June of 1981 was completely mystified by it. It was a very strange thing, these five cases of PCP and then the twenty-five cases it leapt to within a month, all in gay men, of diseases we previously only saw in immunodepressed people. That's very bizarre.

Personally, I didn't encounter the situation until the end of 1981, when Bruce Brockway was actually hospitalized and I went to go see him. He had been followed for maybe six months by the hematologists because he had a low hemoglobin, something we now know is very common in HIV. They had done bone marrows and found him to be lymphocyte depleted, had evaluated him, and really they didn't figure it out until right before they called me that he might be part of this problem.

I went to see him on old Station 30 in the old University Hospital--it's where the hospital attorney is right now. And that was my introduction not only to AIDS, but it was my introduction to the world of gay men, because, as people who--there's not too many of us around--were on the gay scene back in those years would have known, Bruce was one of the most outspoken advocates for gay men there was.

1. The federal Centers for Disease Control and Prevention's weekly epidemiological report of diseases in the United States.

2. Pneumocystis carinii pneumonia, a common opportunistic infection among persons with AIDS. PCP was one of the first AIDS-defining illnesses identified.

3. Bruce Brockway was the first person in Minnesota recognized as being involved in this new illness.
He had been actually the founder of GLC Voice, which was subsequently taken over by Tim Campbell. I remember going into his room, and Bruce had this picture on his bedside table of his current lover, who I actually now take care of. The guy was in a scantily attired thing with an absolutely wonderful pair of buttocks, looking back over his shoulder. Bruce made no bones about his gay-ness or his out-ness. He was part of the education process for me. He was a stern task master in that regard, because he--without being unpleasant about it--I presume because he recognized that I was willing to learn. [He] was also very pointed at every point that I made a faux pas with respect to gayness; he was very prompt to correct me.

**FN:** When you encountered your first case, what did AIDS mean to you at that point? Did you have a sense of what was going to happen?

**FR:** Nobody had the foggiest idea what was going to happen. The first publications after the two MMRW articles did not come out until early 1982. Then it became apparent that something much worse was going on, that it was going to spread. What was really scary initially was how unprecedented it was, how completely unlike anything that we had seen before. When we had new diseases like Legionnaire's disease or Lyme's disease or this new Hanta Virus thing, you've always been able to recognize that there is some upper bound to what could happen.

For instance, in the original Legionnaire's outbreak, which a lot of people have looked at extremely carefully, what happened was they all got sick at an American Legion convention, they all went home, and a lot of them got sick and some of them died. But they looked extremely carefully at all the family contacts, and none of the family contacts had anything like it. So you could tell that it wasn't going to go terribly far. Couldn't tell what it was, but it was one event, it was one point source, and all these people had the same thing.

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4. **GLC Voice** was a gay community newspaper published in the Twin Cities.

5. A viral infection first identified in 1994 in New Mexico, causing acute respiratory collapse.
These original AIDS cases weren't linked to each other at all, and what was happening wasn't the standard pneumonia. The Legionnaire's people died of a standard pneumonia. It was clear it was a new bug, that's all. But it was a pneumonia like we'd all seen. This thing was really very different.

I supposed Bruce's illness was disconcerting because he melted away before my eyes. He was robust, obviously, but his marrow was failing. He got cryptococcal meningitis, and then got a lymphoma of the brain. He ultimately got encephalopathy. We recognize that now, but at the time he'd had brain irradiation for the lymphoma, and I didn't know whether this was the irradiation or what we now know as HIV encephalopathy. I talked to a lot of radiologists about it and they said, "No, this is not what happens when you irradiate someone's brain. They don't become encephalopathic." And he did.

**FN:** How long did he live?

**FR:** I think he lived another year. And that in itself--there were all these strange things. His fingertip started to fall off. He developed this big sore on his finger, and by the time we figured out two months later what it was, about a third of his finger was gone. It was a herpes simplex infection. Now that was just completely unheard of. I think of herpes simplex around the mouth, the genitals, around the anus, but herpes simplex infection of the finger? Leading to necrosis of the tip of the finger? I mean that just wasn't--it just wasn't within my realm of possible thought.

**FN:** When you think about when you first become aware of the magnitude of what you were facing, how does that magnitude play out ten years later? Do you think you could have predicted for yourself what has happened?

**FR:** It would have been good if I had tried to put some

6. A fungal infection of the brain.


8. An inflammation of the brain.
predictions down. I probably would have guessed that there would have been more heterosexual spread than there has been. For the first five or eight years of the outbreak I was on the "more spread" side of the prediction spectrum. And then as the rest of the country figured out that heterosexual transmission was going to be a problem, they sort of became more worried about it than I did, so I was on the "less grave" end of the spectrum. Now I'm back on the "more" end. Everyone has sort of decided that it's not going to be a big problem, so in my view I've had a more constant fear of it. The public perception first of all discounted it, then got too worried about it, and now is discounting it too much.

**FN:** You have treated a lot of people with AIDS since 1981. You have had a lot of patients die. How has this epidemic affected you personally?

**FR:** I think it has affected me profoundly in ways which I am not sure are very healthy. I went into infectious disease in part because it's an area where either the patients get better or they die. As opposed to almost any other subspecialties, our patients go back to where they were before. I mean, if you are a cardiologist, your patient gets a heart attack, and that heart muscle is dead; it is never back to where it was before. And if you treat kidney failure, those patients basically get worse at varying speeds. But an infectious disease, if it doesn't kill you—as it sometimes does, but usually doesn't—you got better. You go back to being as sound as you were the day you got the infection.

Now effectively I'm an oncologist. I take care of people with inexorably progressive disease. I'm sure it does take a toll on me. I don't admit it readily, but... [Laughs]

**FN:** What kind of toll does it take on you?

**FR:** It probably takes a toll on me in part because patients with fatal illness are more demanding. And that's not bad; if you've got a fatal illness you've got every right to be

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9. The field of infectious diseases is a medical specialty which focuses on prevention, diagnosis and treatment of infections.

10. Oncology is a medical specialty focusing on treatment of cancer.
demanding. But they want me to fix them, and I think I should be able to fix them, and when I don't fix them, that's distressing to them and that gets them upset at me, and that makes me upset too, that I can't do it.

As irrational as it might be, I have some sense of failure every time a patient dies, even though that's really stupid. I mean, I still think I could have done it better, and my job is to fix them and I didn't and they are dead now.

FN: How many patients have you lost now?

FR: I have probably cared for in the range of five hundred people. It can't be that high. Can it be? It probably is. We've taken care of about one thousand HIV-infected people at the University. It depends on whether or not you count the people who I had not much to do with. Of those that I have been really, really closely involved with, it's probably in the range of three hundred.

FN: You said you've found yourself seeing yourself as an oncologist. Was there a moment when that was defined for you?

FR: I think there are a lot of little epiphanies along the way. Every once in a while, just because I keep records, I examine our records and what's happened over time--maybe a little more carefully because I'm an academic. And you go back and you look through and you look at that list of people, and you get distressed because you've forgotten some of them. You can't believe it, but you have forgotten some of them. You get distressed because some of them were just such wonderful people, and you think about all they suffered. It's very painful to go back over the list. So when you do it--I think back on some of the first patients who were so involved in it, and the shifts in emotion that they went through. And you think about the people who were involved in their care, and their support.

You start with Bruce. Bruce had a lot of really close friends. I remember that they were, and to this minute still are, very grateful for my attentiveness in his care. Yet, at the time, it didn't seem particularly notable to me. You were just doing what you could. And that's a--you get a sense that what you are giving is somehow appreciated even through you don't do enough good.
I remember some of my other instructors. One would be Bill Runyon.\textsuperscript{11} I don't know if you knew Billy. Billy was the opposite of Bruce. Bruce was an intellectual and a militant, and humorless at times. I'm not sure I saw Bruce with a light touch. Billy, on the other hand, was a guy who didn't take things seriously. It was all a joke for him for much of the time. He got publicity and revel in the publicity. And it wasn't until a year or two into it, when he figured out that he really was going to die, that he realized how bad this thing was. And then it became awful for him. Because he just wasn't intellectually capable of dealing with it all.

**FN:** [unclear]

**FR:** He told me a story once. He went public in '83 and was on the tube about twenty times in '83 and '84, and he died in '85. And he told me once within six months of his death that he went to bar and sat down with somebody, and somebody looked at him and said, "Ah, Billy, you're still alive!" They had seen him in his flurry of television appearances in '83, and when they saw him in '85 presumed he was dead. And that was very telling for him.

I remember another one of my little notable things. Billy always came with a guy named Jeremiah Gordon, who was equally funny and something of a con man. He was an antiques dealer, but a very good-hearted soul and looked after Billy very carefully. And one day he said, "Do you mind looking in my mouth, too?" and I looked in his mouth and he had bad thrush. He was the first patient I had where I came to know him before I realized that he was part of it.

And that was a moment for me where I realized somehow when the patient first comes to you and you know that they are infected from the first moment you see them, their death doesn't seem quite as potent, because you can somehow factor AIDS into your thinking from the first moment you see them. But Jeremiah I knew for a year or two before without realizing he was part of it. And now all of a sudden I realized he was part of it when I looked into his mouth and it was full of thrush. And so I had to re-do my thinking.

\textsuperscript{10} Bill Runyon was Minnesota's first publicly identified AIDS patient.
That taught me that however bad it might be for me, for the gay docs it's worse, because many of their patients they knew first as HIV-uninvolved people, before they realized they were involved people. It's worse, it's harder, you discount it. You can protect yourself in advance a little bit if you know.

You don't, though; that's another bizarre thing. We talk about patient denial all the time, but in fact there is health care worker and physician denial too. Although I am not sure that protects me as much as it used to.

FN: What do you mean?

FR: I mean, you can't deal with this parade of people if you think to yourself they are going to die every time you see them. So that you somehow get surprised when they get sick, each time.

FN: What about the people on the list you've forgotten? What happens when you see their names?

FR: It is really sad. I just say, "Oh yeah, I remember that" and I think back on some of the memories. With that many names? Nobody remembers, especially if you have a bad memory.

FN: Do you have favorite patients? Do you play favorite?

FR: Yes, undoubtedly.

FN: How does that show up?

FR: I think you tend to take care of--I hope I minimize it, but I think it's probably correct that people who are own age or of your own mind set you're going to do a better job of. Our clinic is probably now twenty to twenty-five percent black. I know that there are barriers between me and those patients which are strongly felt by them, perhaps more strongly felt by them than by me. But they do constitute obstacles. I think we have a major deficit of physicians and nurses who are black who can interact with those patients in this town. There isn't a black physician who has made a special interest in AIDS care to my knowledge in this town. And there isn't a black nurse working at the University Hospital who seems to have an interest in it, which really
would do us a lot of good.

FN: Have you tried to do anything to change that?

FR: I don't have control over who works in the clinic all that well, but I know very well that people who select people who work in our clinic are cognizant of that need. If a black candidate of sufficient quality came along--I don't think we've had a black applicant for any of the positions.

Playing favorites is a tougher question. I haven't done justice to that question yet because it takes a little more soul searching.

The amount of time you spend with a patient. The quickness of returning a phone call. Your willingness to prescribe them pain medication. The degree of empathy. Do you ask them more about what they are doing this summer? Or how's it going with their support system, whatever it happens to be? Those would be the measures of it. And you can hope that you compensate for your attraction for some patients compared to others, but I don't imagine that any of us do it all that well.

FN: What are the kinds of patients you are more likely to forget compared to the ones you favor?

FR: It is always difficult to deal with patients who don't take care of themselves very well. You can bust your ass taking care of some patient, and think hard, and spend time talking with the pathologist about the biopsy report, or tracking down this or that bit of information. It's all time, and overcoming inertia with respect to applying some thought. And then if the patient doesn't show up, or doesn't take the meds or continues to self-abuse somehow, that's depressing. In theory you should be able to apply your efforts just as willingly to anyone, but it is depressing when they don't take care of themselves.

FN: [Unclear]

FR: I still have about fifty percent gay men, twenty percent hemophilia, and thirty percent injecting-drug-use underclass, and there is clearly a difference in how carefully such people take care of themselves.
FN: How prevalent is AIDS in your life? How large an impact has this had on your consciousness, your thinking?

FR: In my consciousness I can define that very well. I probably spend twenty to thirty hours a week on the care of persons with AIDS, and another ten hours on AIDS-related writing or reading. The hard question is how much of an impact does it have on my subconscious. You'll have to talk to my shrink about that. [Laughs].

FN: How does the issue of AIDS affect you personally?

FR: I probably drink more than I would otherwise if I didn't have this kind of stress. It's nice to forget about it. I probably recreate a little more aggressively. I try to get out and do something a little more obviously. I don't know. I would tend to be more concrete in these things. I think it probably weighs upon my psyche in more important ways.

FN: What about the other commitments in your life? What are the top commitments, and where do they fit into your work with AIDS?

FR: Well, my major commitments in my life are my kids. Probably my second-most important commitment is my job. AIDS takes away from things which I am supposed to be doing in both regards. There is a lot I would rather do, but nobody else seems to it. I would rather be working on some infection control research, and I can't do it because I've got to plunk down thirty hours on the care of people with AIDS. On the one hand, I could stop doing it, but it doesn't seem to me that, at least at my institution, there is anyone who is particularly interested in picking up that slack.

FN: How has the amount of AIDS care, and the number of patients, affected you? All the death you have witnessed?

FR: It has made me a less communicative person. I think it has made me a more isolated person.

FN: How does that manifest itself? How do you cope?

FR: [Laughs]. That's tough. Denial is my primary psychiatric mechanism for dealing with adversity. For me, denial is reading the newspaper and reading some journals and sitting there, perhaps in the same room with other people but
not communicating with them very well. I would say that I do that more.

FN: Has that been a change, or is that the way you have always been?

FR: It's aggravated it, I think. I don't like to really admit that, because I would like to think that I am in control of my psyche, and I think I probably am to a greater extent than I think I may have just implied. I am afraid that there is at least some truth to that.

FN: Does faith play any role in your life?

FR: Faith in what?

FN: However you'd define it.

FR: No, faith has no role in my life. Show me the data! [Laughs]. If I can't see the data, I don't believe it.

FN: How do you interact with patients who are religious?

FR: The hypocritical part of it is that I don't always come out the closet with respect to my atheism. I don't disclose it always. I don't lie, but it will happen to me not infrequently that a patient will say to me something like, "God will take care of it," or "I know I will be in God's hands." I say, "That must be comforting," or something like that, rather than... These are an invitation from the patient to say, "Yes, have faith in God and that will help you," or "I too share your faith in God," or something like that. So I am not quite so hypocritical as to say something like that, but I also don't disclose my actual feelings.

FN: Do you have faith in science?

FR: No, it is not a question of faith, it's a question of data. The only thing I have faith in is that they have reported their study accurately, because I can't really verify that. Otherwise it is a question of looking to see if someone else comes up with the same answer or not having done it the same way.

FN: Do you have any faith that we'll see an end to AIDS?
**FR:** No, not in my lifetime.

**FN:** Do you think your atheism has gotten stronger?

**FR:** It has been pretty strong. It's been pretty strong since I first started thinking about it. [Laughs]. I just have never had much--religion is nice, but the very fact that it is a nice idea is to me the evidence that it doesn't correspond to the reality. People manufacture it because it is nice.

**FN:** How do you interact with Sister Joanne Lucid, given her role in your clinic?12

**FR:** In the clinic there is not a problem, but I socialize with Joanne from time to time and every once in a while I press her on things religious. She, of course, is much too skillful to ever engage me directly. [Laughs].

**FN:** Does anger have any role in your response to AIDS?

**FR:** I am not a very angry guy. I don't—I mean, tense, but...

**FN:** Were you angry when Louise13 died?

**FR:** I got pissed off, I don't know. It is just so stupid and so senseless and so unfair. Anger? I don't know. Anger implies that you think somebody did something that they shouldn't have done. I'm mad in a more abstract sense, but not in a sense that I can identify someone that did something that makes me mad.

**FN:** You were angry at Louise's funeral.

**FR:** How can you rail at randomness? Randomness is a feature. How do you really get angry at that? She shot up one day and picked the wrong needle, and if she would have picked up a different needle or shot up an hour earlier or an

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11. Sister Joanne Lucid, B.V.M, is the director of the Archdiocesan AIDS Ministry program. She attends the University of Minnesota HIV Clinic on a regular basis and provides spiritual counseling and volunteer support to many patients. Her narration is a part of this collection.

12. Louise Hoelscher died at age twenty-seven in June of 1993. Dr. Rhame spoke at her funeral.
hour later she might not have been HIV infected, you know? And that's random, and that is just really...

I don't know. If anything, the only anger I sense in that was--it's not anger, it's just impatience with people who saw some good in that or found something that made sense. If anything made me angry, it's that. Because there isn't anything in her death that makes any sense.

Well, people do that all the time. They say, "It is God's will," or they say, "We were so much strengthened by Louise's adversity that we became better people," or "Think of the insight she gained in her years of being HIV infected." I mean, people are always trying to find the good side of things, and there is no good side to Louise's AIDS. There is just bad.

Sure, okay, there is nothing that didn't have some good to it, but the thought that in any way comes close to compensating for her premature removal from the earth--I mean they are not even close.

FN: When you talk about your commitments and your patients' support systems. How would you describe the community that you have? How and where do you find community?

FR: I don't have much of a support system.

FN: Why not?

FR: [Laughs] Probably because I am too deeply into denial. [Laughs]. It is probably testosterone poisoning too. Joanne Lucid organized AIDS care giver retreats from time to time. She hasn't done one in a while, probably because they didn't work all that well. And I went to all of them. But it was clear that I was in a different place from most of those people. Most of the people who went there were in their first year or two of AIDS care. Joanne didn't organize her first until the late eighties, by which time I had been into this for five or eight years, whatever.

What was bothering me was that I wasn't caring enough. And what was bothering them was the tragedy and sadness of it all.

FN: What do you mean you weren't caring enough?
**FR:** After you've seen enough people die, it doesn't affect you as much as it ought to. Death is a pretty awful thing. If a death would have affected me profoundly when it was my tenth death and doesn't when affect profoundly when it is my three-hundredth death, one or the other is wrong. It affected me too profoundly the first time, or it didn't affect me profoundly enough the last time.

After a while you don't feel as sad as you did when you started out, and that is not right. It is just as sad. And that's not a notion that--there wasn't anybody else in any of these [care giver retreats] that really had that as an anxiety or point of sadness.

**FN:** What causes that?

**FR:** Dulling of the consciousness due to repeated assault.

**FN:** So without a community, how do you sustain yourself in this work? Who do you talk to?

**FR:** I don't know. I precipitated two dinners with Scott Strickland,¹⁴ him and me, and he didn't precipitate a third, so I figured that was not what he wanted to do. I don't feel a huge affinity for any of the other AIDS clinicians in town, except for maybe John Weiser,¹⁵ and I never did bother to really make social contact with John. That was probably a mistake, but it is too late now.

Every once in a while I fantasize about bringing the major AIDS clinicians, you know, the half dozen or so major AIDS clinicians together for dinner once a year, or for a weekend drunken retreat. But there is enough rivalry I am not sure it would work.

**FN:** How much longer will you be able to stay in this work?

**FR:** Well, I am not sure I will for much longer.

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¹³. Scott Strickland is an HIV physician with Park Nicollet Hospital in the Twin Cities.

¹⁴. John Weiser, M.D., treated persons with HIV disease at Clinic 42. He moved to New York in 1994. His narration is a part of this collection.
FN: [unclear]

FR: You feel like you need somebody else to take your place before you leave, and of course that is probably not going to happen. A question like that, there are so many things that impinge on it beyond the simple AIDS aspect of it. Other employment aspects, personal issues.

FN: What are you doing to sustain yourself right now?

FR: I have done very little to sustain myself in the last year.

FN: I am curious. It sounds like you are very isolated, very much alone in this. What keeps you going? Why continue? Why not walk away?

FR: I think I do some good. Ultimately, you need to have a sense that you are doing something good for somebody. I think, in fact, a lot of people go through life without doing much good for anybody. And that includes a lot of docs. Most docs take care of people who basically have self-limited illness, or illness which they can't affect one way or the other, and I do think that I stave off death, and I think that I probably do help people in the course of coming to that outcome.

FN: Is it interesting still?

FR: The care part is not very stimulating intellectually because I have done it so often. Every once in a while you come into a new question, but mostly you don't. That's not to say there aren't new things all the time, or that to say that it is often not the slightest bit obvious what is going wrong with somebody when you first start out with it and you have to work away at it and you figure it out, finally.

But I haven't encountered stuff that is terribly new for the last couple of years. Some of it is a little new. When you first got into it, there was something new at every turn. The first five or ten years there was new stuff being figured out, and now I think it is only the lacunae which remain to be filled. And the major outlines are available. This makes it like most of medicine. Advancement for most of medicine is very slow. And it gets harder to achieve at each--understanding the first half of any illness is much easier
than the next forty percent. When you chip away at the remaining ten percent, it's harder, and when you chip away at the remaining two percent it is very hard. So I think that AIDS is back to what medicine is ordinarily like.

For the first five years of AIDS care it was just one new thing after another. It was quite exhilarating. In fact, I have guilt about that. I wonder if in part I didn't get into it just because if the excitement of it—the intellectual excitement about it rather than because of the need.

**FN:** [Unclear]

**FR:** You don't like to think of AIDS care as providing entertainment. It is not exactly a valid—well, getting entertainment out of people's suffering is a little tricky. You have to conceal it. [Laughs]

**FN:** How do define felicity in your life? Where do you find it?

**FR:** Felicity is happiness to my way of thinking. What gives it to me? I guess successful completion of any task gives you felicity. Whatever task you set yourself to doing, you get it done and that's felicity. You get a chapter done, you get it off, you get a study organized. I think our Vancomycin-resistant enterococcus outbreak, we've got some stuff in place which is coping with it.

**FN:** Personally?

**FR:** Well, that's the part that I'm not so hot to describe in the tape. Watching my daughters grow and interact with the world is a major source of felicity. That's ultimately what is the most profound source of joy for me.

**FN:** How has AIDS impaired your ability to have felicity?

**FR:** I think it has probably been an obstacle in one way with those things because it has made me more insular. I think it has been a benefit with respect to my younger daughter, because she has a particular affinity for the downtrodden and it has helped—she has thought more highly of me because she

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15. A highly antibiotic-resistant organism that can cause outbreaks of infection in hospitals.
has, in this regard, seen me as a defender of the downtrodden. But in some ways, being on your daughter's pedestal is a dangerous place to be, since we all have feet of clay.

**FN:** What do you do to make yourself feel better?

**FR:** [Laughs]. The best I can manage these days is reading the newspaper, having a meal and watching a movie. I rather hope before long to be able to improve on that.

**FN:** What state do you think America is in?

**FR:** I've got a lot of complaints about that. I think AIDS is a paradigm, it is a probe, it is a way of telling what is good and what's is bad about things. People respond well to it or respond poorly to it. The most obvious area here is the attitude of humanity in general, or heterosexual humanity in general toward homosexuality, which is just stupifyingly negative. And AIDS certainly does demonstrate that, or bring that out. AIDS is still a highly stigmatized disease.

[interview ends prematurely because of an error in recording]