

**Interview with John Weiser**

**Interviewed by Fraser Nelson**

**Interviewed June 9, 1994,  
at Clinic 42, Abbott Northwestern Hospital, Minneapolis**

**FN:** If you can think back to when you first heard of AIDS and what you thought of it then, what did you anticipate?

**JW:** My very earliest recollection was in the library at North Memorial Hospital [in Minneapolis] in 1981. I was a resident, and one of the other residents pointed out the New England Journal [of Medicine] article on cases of pneumocystis pneumonia and KS<sup>1</sup> in homosexuals in L.A. and New York. He was sort of taken by that more than I was, actually. I really didn't make too much of it, I don't think. Then there was a grand rounds<sup>2</sup> that [Doctor] Gary Schrock did at North Memorial within several months. [Doctor] Seymour Handler, a pathologist at North Memorial, was very interested in that too, and thought that this was the beginning of something big. Then Gary Schrock did the grand rounds, and by then it was a described entity. Still most people still hadn't heard of it. I think that's when I started to realize that this was probably going to really grow and have a major impact on the gay community. We didn't realize then how much of an impact it would have on the society in general.

I think that's when the fear started and the sense of almost panic, definitely urgency, about what needed to be done to try to protect people, and about where this was going to go.

**FN:** What did you do to respond to that sense of urgency?

**JW:** There was a forum being held at Mount Sinai Hospital [in Minneapolis] of interested people in the community: Bruce

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<sup>1</sup>Pneumocystis carinii pneumonia and Kaposi Sarcoma cancer, two common forms of AIDS-related opportunistic infections.

<sup>2</sup>An educational presentation for staff physicians and residents.

Brockway, Bill Runyon, Ford Campbell, John White, Tom Wilson-Weinberg, Morris Floyd were involved maybe at that point. And Fred Kean and I started attending that. These were the founders of the AIDS Project,<sup>3</sup> basically. It was to do some planning about prevention, services for infected people, education for the community.

That was my first time in a room with someone I knew who had HIV, Bruce Brockway and Bill Runyon. It was very strange.

**FN:** In what way?

**JW:** They were stigmatized. They were homosexuals with this homosexual disease. I was very aware that they were singled out, they were different. There was a just sort of a sense of awe, almost, just looking at them and sort of soaking it up. These were people with this entity which was now being described all over the country, and which we knew was going to be something huge. And that they were going to die. That was a phenomenal realization. They were people--young people, peers--who were going to die, and who were going to have strange things medically happen to them in the meantime.

**FN:** When you use the word "peer," as a gay physician, when did it first really strike you, the impact that this disease would have on your community? Can you think of a defining moment?

**JW:** I think each of those, the Grand Rounds, the forum with Bill and Bruce being present. I think then. I think that was when we knew that it was going to be really big. Although it was kind of strange, because I sort of had that awareness, but hardly anyone else did around me. I mean, the idea of condoms or safe sex hadn't even surfaced.

**FN:** Why do you think you had that awareness?

**JW:** Well, we knew already what the epidemiological pattern was and how quickly it was spreading. It was doubling every six months at that time, the number of cases. And nobody knew what it was, so we were pretty clear that it going to continue and be massive.

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2. The Minnesota AIDS Project, the state's first organization to provide AIDS education and services.

And how has that changed over time? The sense of the effect that is has had on the community. The one really big thing in terms of the community perspective is that it has been normalized. It is now normal for people to have life-threatening illnesses. It is normal for people to be dying. It is normal for people to be taking care of people who are sick and dying.

**FN:** Do you accept that as normal?

**JW:** Yes, I think I do, unfortunately. It is a normal part of my life now.

**FN:** When did it become normal?

**JW:** I think when I started having friends who were declining. My [medical practice] partner, Bill Charles, M.D.,<sup>4</sup> got sick and next he died. That brought it into the workplace and made it a normal part of the workplace too, to have a colleague become sick and disabled and to be dealing with all that.

**FN:** One thing that I think stands out in your experience for me is that you probably knew many folks in the gay community before you knew that they had AIDS. Can you describe the difference between meeting someone for the first time knowing that they are HIV infected and having had friends who have become infected?

**JW:** Well, as it became normal, the sort of sense of strangeness, and fear, and awe kind of wore off. When I first was socialized with Bill Runyon, I was aware that he had contagious fatal disease, and even though I knew I couldn't get it from him, there was still a certain awareness of my physical presence with him. It was an awareness that I didn't have with other people. And that eventually went away. I really don't have that any more.

Two of my patients who have AIDS had me over for dinner the other night. It occurred to me how normal the evening was. Our conversation really had very little to do with AIDS; we

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3. Bill T. Charles, M.D., was a physician and partner in the medical practice at "The Doctors" and Clinic 42 in 1991 and 1992.

talked about a lot of other things, they made me dinner. I just realized how unconcerned I was about any risk of contagion, or simply the fact that I was in the room with people who were going to die fairly soon. That is an example of how it has become normal.

**FN:** How does AIDS fit into your broader commitments, and how would you describe other commitments you have in your life? What other areas are you active in, and do you feel are core to your existence?

**JW:** That's interesting. This shift sort of parallels a change that has happened in the degree to which I have identified with the gay community. Over the last several years I have identified less with the gay community than I did at one time. I think that is a function of being more comfortable with myself, more accepting of myself, completely open, and the fact that I just don't experience overt prejudice and discrimination against me, myself.

Plus the fact that I think that I've tended to identify more with a variety of different people and a variety of different interests which we have in common. There is less need to bond with other gay people, and so I feel like I'm free to form important connections with various people who I have different things in common with. And along the same lines, I don't see AIDS as the only important issue out there--health issue or issue affecting a community.

**FN:** What other issues do you feel are important?

**JW:** Well, to not leave AIDS, I'm increasingly interested in other populations infected with HIV. In fact, I'll be doing a lot of maternal-child work in New York.<sup>5</sup> Actually, I am very excited about taking the some of the skills and sensitivities I've learned and applying it to other underserved populations. Gay men really are not so underserved any more. They are underserved only in the sense that there is a special sensitivity that is required to provide optimal care. But certainly in terms of access to resources, for the most part, at least in Minneapolis, that

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<sup>5</sup>At the time of the interview Weiser was moving to New York to help establish community-centered health care clinics in the poverty-stricken South Bronx.

is not a problem. So it is exciting to me to take some of the technical skills and the interpersonal knowledge and understanding and apply it to another population that probably hasn't been as privileged.

But aside from AIDS, I'm increasingly interested in addiction. I have always been interested in preventive health care for all people, and I am very interested in utilizing the models that have developed to care for people with HIV to care for people with other chronic illnesses as well. Cancer, diabetes, mental illness, substance abuse problems. That is one thing I am hoping to do to, to utilize the case management model, develop home care more, other alternative sites for providing care, like foster care and day care. I think that is really one of the wonderful things that has come out of this, that we have learned how to operate in these models.

**FN:** What about your personal commitments? You talk a lot about professional commitment, and it sounds like you have integrated a great deal from what you've learned about AIDS in your professional role. Your commitment to the gay community, though it sounds solid, may be more dispersed than it used to be. What has replaced that, or has anything?

**JW:** In the broad sense, I think my commitments to myself are to make a contribution, to love people, and to have as much fun as possible. [Laughs].

**FN:** Was fun important before?

**JW:** Yes, fun has always been important, although because of a personal life-threatening experience, not AIDS-related, and because of the awareness AIDS has inculcated in me of the intransigence of life, I am much less inclined to deny myself fun because of standards that don't really pertain to me or any unnecessary restraints. So I am more apt to have fun now than I was, because I realize that life is really not that long, and there is a lot of world out there.

**FN:** Does faith play any role in your commitments or in your life, and how would you describe that?

**JW:** I don't think that is a central factor in my life. I grew up in an unreligious home without any really any concept of spirituality. I think there were very strong personal

values. I have explored various aspects of spirituality at times, but it is not a central concern of mine right now. Values are. Maybe it is something to explore in the future. There have been times when I was very interested in Eastern philosophy and yoga and other forms of meditation, and I may get back to that someday.

**FN:** Has the amount of death you've seen impacted your definition of faith at all?

**JW:** Well, maybe in that it has reinforced a sense of powerlessness, that there are forces greater than ourselves that influence the outcomes of our lives. I never have attributed that, and I still don't, to any particular force or entity or God, but I am aware that personally and professionally that there are definite limits to what we can do, and I have gained some acceptance of that.

**FN:** Does anger play a role at all in your response to HIV? Is there anger in your life?

**JW:** My anger is mostly directed at forces in society that are insensitive and uncaring, judgmental and deprecating, and, as a result of that, unhelpful.

Yes, it makes me really angry when the immigration laws<sup>6</sup> continue to be a factor to the extent that the International AIDS Conference can't be held in this country. And to see politicians initially promote fairness in public policy and then back away from it when it is not politically convenient to them any longer--like the change in the immigration laws, for instance.

**FN:** How do you express that anger?

**JW:** I write letters, I speak out, I think, maybe just in personal conversations. I vote. At an earlier point in my life I would have been more inclined to be out on the street, demonstrating and screaming and yelling, but that is just not my personal style anymore. But I don't object to people who do that. It has a place.

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4. Immigration and naturalization laws which bar persons with HIV disease from freely entering the United States.

**FN:** I know you are moving. How would you define community in your life, and where do you find it? How do you anticipate finding community in New York?

**JW:** Community is the sharing of values, primarily. To go back to what I said earlier, that is a bigger part of my definition of community than the sharing of sexual orientation. There are a lot of gay people that I don't have much in common with. And I think there are some negative attributes in the gay community also which make me more cautious about any kind of unrestrained identification with that being my community.

**FN:** Can you describe those attributes?

**JW:** I think that there is a certain--this may be a harsh word, but--narcissism and self-centeredness. And by nature of being a small, tight-knit, inbred community, there is a certain predisposition to gossip.

**FN:** What are the values that you describe or find in your community?

**JW:** Passionate commitment to beliefs having to do with the well being of people and society. I think I identify most with people who are passionately committed to their cause, whatever it is.

**FN:** How do you find those people?

**JW:** There are two professional colleagues I am going to have who I feel that with already, although I don't know them that well. I think I will just know it when I find it.

**FN:** In Minnesota, how did you find and ask for support?

**JW:** A wonderfully rich part of my life here has been the personal support that I have. I have friends who I have been with for twelve, thirteen, fourteen years, and they are just very solid friendships. People I have met at work, people I have met socially. I think it is partly because I have been willing to commit to those friendships that they have grown and become trusting and solid.

But there is also the whole work part, too. I get a lot of support and feel a bond with some of my colleagues like here

at Clinic 42, for instance. One of the reasons that we started Clinic 42 was because it is taxing--not only logistically but emotionally--to take care of dying people alone. So by forming a team, in addition to filling in the various technical pieces, we also support each other formally and informally. We have a support group that meets periodically, but also we just share the decline and eventual loss of another person who has become important. That is bonding. I guess I wouldn't leave out the part about humor, too, being an important part of the community. I think that is the shortest distance between two people, and we use it a lot.

**FN:** In your community outside of work, does AIDS come up much?

**JW:** No. It was odd that for so long I did not have any close friends who were sick. Bill Charles was the first. He died in the summer of 1992. We knew that he was HIV positive when he joined the practice, and his T cells<sup>7</sup> were low, but he was such an excellent physician and such a wonderful person that we wanted him to join our practice knowing that there were going to be some difficult times. After he was with us for about six months he started having some complications and he needed to be away more and more. He wasn't able to socialize as much. It was just a gradual decline in our relationship in terms of the usual things that we could do together. But a whole new dimension developed.

**FN:** Did you provide his medical care?

**JW:** No, but I provided personal care. When he was homebound I would give him his bath. He was very endemitious, not very mobile and had trouble getting to the tub and back and in and out of the tub.

**FN:** Have you provided that kind of personal care since?

**JW:** No, no. No, I haven't. I assume I will.

**FN:** Why do you stay in this work?

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5. T cells or CD4 cells provide a marker for the progression of HIV infection. Persons with CD4 counts under two hundred are considered to have AIDS; normal counts range between 800 and 1,000.

**JW:** I love it! It is very rewarding, in many dimensions. It is intellectually challenging. It places me at a cutting edge--some would say a bleeding edge--of society and medicine. People are very appreciative of the work. There is a satisfaction knowing that I can provide a special sensitivity that not everyone can. It is very personally rewarding to learn about death and to get over some of the fears that I had about it, and to get to some insight into my own mortality and how I want to handle that when the time comes.

**FN:** What did you mean by "bleeding edge of society"?

**JW:** Well, it is sort of an extreme of the cutting edge. It is not only on the social and political forefront; the emotional intensity heightens the whole cutting edge feeling about it.

**FN:** Do you think a lot about your own death?

**JW:** Yes, I do.

**FN:** Can you describe that?

**JW:** Well, I mentioned that I had a life-threatening experience four years ago, and I have been very aware of my own mortality since then. Plus the fact that so many people around me are dying and watching that process.

**FN:** How does that manifest itself?

**JW:** I am more inclined to make sure I don't miss anything in life, to take advantage of opportunities that I can, to not wait any longer than I have to do that. I don't know if urgency is the word, but freedom, if anything. Freedom to be unrestrained.

And I think a lot about how I want to die. I watch a lot of people who have a very hard time, despite our efforts, facing the process and making decisions. I hope that when my time comes I will see it as another challenge, probably the biggest challenge yet, as opposed to a failure.

**FN:** So it is not a morbid--

**JW:** No, not at all. And I hope it is not morbid. I realize that there will be losses to deal with and grief to go through. I would hope that I can be in sync with the forces beyond myself that I am not in control of, and live fully until I can't anymore. I would hope that I don't cling so tightly to life that I prolong it into a phase that is really not rewarding. I would hope that I can believe, when the time approaches, that length of time is not the number one issue; that it's quality.

**FN:** How does that translate into your ability to sustain yourself in this work? What kind of things do you do to sustain yourself? I am struck by what you say about not staying in life too long. Is it possible to stay in this work too long?

**JW:** Well, there is such a thing as burnout. I believe burnout is when you cut off your feelings to protect them. Because when you shut yourself off from pain, you also shut yourself off from the joy of the work and the relationships, and then it becomes empty and meaningless, and that is when the drudgery takes over. And that is what I think burnout is.

What I do to not get burnt out is to stay in there on a feeling level. And to continue to grow personally. Naturally there are some patients that I just don't click with, that I just don't connect with. But there are others, there are a few, with whom I do. I allow myself to have those feelings and have feelings of loss. I have learned very recently--largely with the help of some of the nurturing care givers I work with, nurses in particular--to really stay in there for the duration and walk the whole distance with them. That means making home visits in the end, talking with them about their death, maybe helping them plan their death, being there for it. That has been very rewarding in terms of the relationships I have with these people, but also in terms of understanding the life and death process and how that applies to myself. So I get a lot of personal growth out of the work.

**FN:** How do you take time for that personal growth? How do you find yourself taking the moment to reflect on your experience?

**JW:** That's a problem, it really is. And actually, I am

happy that I am going to ease into the new job. The clinic that I am going to be directing isn't opening for six months, so I am going to be doing some other things with the organization, which I think will allow me some reflection; time just to sort of look at what we've been doing. In addition, [Clinic 42 social worker] Colleen Baynes and the clinic chaplain, Jim [Cassidy], are going to write about the values that underlie decision making as death approaches.

But really it is a chance for us, for me, from my perspective, to consolidate my experience of the last eight to ten years doing this kind of work. Just to look back at what are we doing here, and what does this mean, and what is it about, and what are our values. That's hard to come by in the day-to-day. I am fortunate to have that opportunity now.

**FN:** You have talked about the emotional part of working in AIDS, and some about the intellectual challenge. Can you tell me more about that? Is this writing project part of that aspect for you?

**JW:** In this case the writing is more emotional than intellectual--we don't really care if anybody ever reads it, I don't think. It's mostly a personal experience. But in terms of the intellectual challenge, yes, I find that very exciting. AIDS has made me a much better physician cognitively. To be able to deal with complicated problems and to deal with multiple aspects at the same time and to be comprehensive and thorough--that is the main intellectual or cognitive challenge. But it is also satisfying just to keep up on what's new and sort of stretch my brain power that way.

**FN:** How do you find felicity in your life? Happiness? What gives you that?

**JW:** What a great question. I'm really happy right now.

**FN:** Why?

**JW:** Well, one of the obvious things is that I'm happy because I don't have any pressure right now. [Laughs]. I was just thinking about that this morning, as a matter of fact. Right now I am unemployed and about to undertake a great adventure and explore and have fun, and there is really no pressure right now for these next few weeks.

But there are different things that contribute to happiness. I think in general it's feeling. What really makes me happy are those occasions when I have that feeling of sort of "Aahhh...this is okay, this is enough." And then I don't always have that for sure.

**FN:** What makes you say "aahhh"?

**JW:** There are several parts to that. One is rewarding relationships, a real connection. A real understanding, being understood. Being appreciated, I guess, applies also to the professional aspects. To see a product of my efforts. Just plain having fun. Adventuring.

**FN:** You were talking about your anger. Some of the frustrations you explained in terms of a societal level--your sense that people don't see the complexity of this disease or its impact. What is your vision of America? When you think about this country, what do you feel, see?

**JW:** Huge dichotomies. There is incredible freedom and incredible narrow-minded judgment about people's personal behavior. On one hand there is a great compassion. AIDS is a perfect example of that. And a generosity of spirit and a willingness to give time and caring. And on the converse there's--I don't know if indifference is what it is, really--but there is a very intense disapproval that is very hurtful and injurious.

**FN:** How do you fit into America? How do you think you impact the country?

**JW:** Actually, I feel somewhat patriotic. And part of my move has to do with patriotism. I feel like I am going to be addressing one of the most serious problems in the country and that makes me feel really good. That's not my main reason for doing it, but it's sort of a side reason. And it is interesting to think about.

You know when President Clinton gave the state of the Union address and had a black police officer from the Bronx stand up and honored him for making his neighborhood safer? And the entire federal government rose to their feet--the Supreme Court and the Congress and Cabinet--and began applauding him? I just thought, "You know, this is what I want to be doing," in a small way.

I'll tell you that during my process of leaving here, there have been a lot of expressions of gratitude. That has had a very interesting effect on me. I think that I have always, I guess, been a high achiever. I have high standards for myself. It is hard to please myself. I have never really known what was enough, in terms of personal and professional accomplishment. Those expressions of appreciation have sort of shown me that doing good is enough in itself. It doesn't have to be splashy. Just doing good is enough. It's all.

**FN:** It sounds as though your leave-taking in part has helped you understand your role here.

**JW:** It has been very enlightening.

**FN:** Did you doubt that?

**JW:** Not necessarily, no. I think people are inclined to say things as part of a goodbye that they wouldn't have, even a month ago. The irritations or frustrations about aspects of their care that they have been unsatisfied with have sort of melted away at the end. So I just got to hear the good parts! [Laughs].

**FN:** How would you describe your activism? Do you see yourself as an activist?

**JW:** Yes, definitely, definitely. But it's mostly by doing, by being in the trenches. I am not so much a political activist, not because I am against that; I think it is very important. It is just that mine takes the form of direct service.

**FN:** Talk to me a little more about patriotism. I don't know if I have ever heard that term used in the context of AIDS. Maybe for you it has to do with the change in [presidential] administrations.

**JW:** [Laughs]. That's interesting. Because even though I am very disappointed with some of the things that Clinton has done in general, I still find him inspiring, which is a great quality in a president. I don't remember ever being inspired by a president before. But it is not patriotism in the sense of being greater than anyone. I really object to that kind of patriotism, that "We're the best, we're number one, we're

a great country." We are a country. We are a country with some great qualities, and we are a country with some real serious shortcomings. But it is my country, and I feel that I can make a contribution. Not just to my community, but in the broader sense.

What I am going to be doing, I think, is helping build a community in an area where there aren't communities, or there certainly aren't functioning, effective ones. Because I think to be the neighborhood doctor is to be a pillar of the community, and it's going to make a difference.

**FN:** What do you fear most?

**JW:** Other than gunshot wounds and tuberculosis? [Laughs].

**FN:** [Laughs]. Those are two good things, those would be on my list.

**JW:** I fear obstacles to doing the work, having to do with egos and people who are in a position to control the operation, whether that happens or not. This really says more about my need for control, I think.

**FN:** Well, as a patriot, what do you fear?

**JW:** [Pause] Indifference. I fear a return to a government that really doesn't care and won't allocate resources and provide inspiration. It means a lot to me that our government puts value on the kind of thing that I am going to be doing. Whereas in the previous administrations, I didn't feel that. That would be discouraging. That would be very discouraging.

**FN:** It doesn't sound like you are scared of death.

**JW:** No, I'm not fearing it personally.

**FN:** What do you hope for?

**JW:** For a sense of caring that can grow. It is there. I look forward to the sort of little niduses of it, the little focuses of it, to expand and grow, and for more people to get inspired and want to do their part. Not just for their close-knit community, but in the broader sense.

**FN:** What about AIDS? What do you hope for your patients?

**JW:** You know, this is really sad to say, but I have kind of given up hope that in the immediate future there will be any major breakthrough. Realistically speaking, what I am hoping for is that people who are uninfected will stay uninfected. And that the people who are infected--most of whom, not all, will decline and die--can find a way to have as long a life as possible. And that they will be able to make good and clear decisions about themselves, and to have support at the end. So that it is really not so much about a cure, it's about the process of dealing with it, including prevention. Maybe I have cut short the possibilities for a cure or a vaccine. But I just don't see it on the horizon.

**FN:** How do you think this time in our lives will be remembered?

**JW:** [Pause]. Well, by whom? I really still believe that most of the country is not very compassionate about the well-being or plight of people who are infected by HIV. So I guess I don't imagine there is going to be a poignant remembrance of the tragedy of it by society as a whole. I think that the populations that are affected will certainly remember huge losses. But also a focusing on certain values, on care giving.

**FN:** So a time of loss and also a time of...

**JW:** There is a reward that comes out of it, definitely, in terms of values.

**FN:** And for you personally?

**JW:** Well, there will always be a sadness about people I have loved who have died. Also a sense of how it sort of deepened me and others, in terms of the whole range of issues--a feeling of loss, grief, caring, going beyond yourself, relating at a very different level-- that I would not have otherwise.

**FN:** How would you like to be remembered?

**JW:** I think as someone who made a difference in people's lives.

**FN:** It strikes me that so much of the things you've talked about have been very personal, but also very focused on the individual. People's perception of your work here includes things like being the founder of MAP, and MAP is a community. Yet you now seem to really define yourself by the one-on-one.

**JW:** Yes, I do. That's an interesting observation. I hadn't even known that. I have pulled back somewhat from my community-wide involvements. For a variety of reasons, I guess. I find the one-on-one more rewarding. There have been some bruises along the way, too. Our community is not always kind to its own members. I will be doing some community-wide work where I am going, but I never want that to take precedent over the direct patient care. That is still the greatest, number one, rewarding thing. So the other stuff I am interested in only as it promotes a program that will affect individuals.

**FN:** It sounds much more a combination of your community and personal commitments.

**JW:** Yeah, I feel pretty integrated that way. It is neat. I hope I can keep it up.

**FN:** Is there anything else you wanted to say?

**JW:** I have a very deep sense of gratitude to the other caregivers that I have gotten to know and work with, and who have provided opportunities for my personal growth. They have really enriched my life with kindness and humor. There are some really great people out there. We are fortunate.