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Interim Hearing on Treatment of People With AIDS

Senate Select Committee on AIDS

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TREATMENT OF PEOPLE WITH AIDS

CALIFORNIA LEGISLATURE
SENATE SELECT COMMITTEE ON AIDS
GARY K. HART, CHAIR



November 17, 1987
State Building
350 McAllister — Room 1155
San Francisco

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California Legislature
SENATE SELECT COMMITTEE ON AIDS
Senator Gary K. Hart, Chair

Interim Hearing On
Treatment of People with AIDS

State Building
350 McAllister, Room 1155
San Francisco, California
November 17, 1987
1:00 p.m. - 5:00 p.m.

88-4-124

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California Legislature

SENATE SELECT COMMITTEE ON AIDS



SENATOR GARY K. HART
CHAIRMAN

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CHAIRMAN GARY HART: I'm Senator Gary Hart from Santa Barbara and with me on my right is Senator Art Torres from Los Angeles. We're expecting Senator Milton Marks from San Francisco who was with us at San Francisco General Hospital. That's the reason why we're a little bit late.

I want to welcome everyone to the Senate Select Committee on AIDS hearing on "Treatment of People with AIDS." This Committee was formed about two months ago to help the California Senate respond in a coordinated, informed and hopefully thoughtful manner to the many important AIDS-related policy issues that we face as a state and indeed as a nation. So far, we have visited the AIDS unit at the California Medical Facility prison in Vacaville, held an overview hearing in Sacramento, and met privately with people with AIDS to learn what their lives are like and to hear their personal perspectives on AIDS issues. This Committee has also met jointly with the Senate Select Committee on Substance Abuse for a two-day hearing in San Francisco in this very building and also in Los Angeles on "AIDS and I.V. Drug Users."

Future Committee activities include a trip to the East Coast to learn about federal AIDS issues and to see how the East Coast is handling the AIDS problem. We will also be holding a hearing on December 18 in the Los Angeles area on "AIDS Prevention Strategies."

Today, we are devoting ourselves to AIDS treatment issues. We spent this morning at the AIDS wards in San Francisco General Hospital, talking with the physicians, nurses, volunteers, and patients who have made the "San Francisco model" of AIDS care famous throughout the country. Now we are here to learn from those people who deal with AIDS or with infected people in a variety of settings--not only the hospital, but also the doctor's office, the home, the hospice, the community service agency, and various emergency situations. We will also hear from a person with AIDS who is involved in the most promising treatment currently available (AZT), and from an attorney who helps people deal with employers or others who respond in a discriminatory manner to someone with the AIDS virus.

By the end of today, I expect this Committee will have learned about many aspects of medical, social, and personal treatment of people with AIDS.

I'm expecting the invited witnesses to finish their remarks by, hopefully, no later

than 4:30, leaving a half hour for comments from people in the audience who would like to make brief remarks, no more than 5 minutes, to the Committee. If you would like to participate in this opportunity toward the end of the hearing, please sign the sheet near the entrance. This hearing is being recorded, and the transcript should be available from the California Joint Publications Office in about 6 weeks. I also invite any of you who wish to submit written remarks for the hearing record to send them to my office.

I want to thank all of you for joining us here today. Before I call our first witness forward, Senator Torres, would you care to make any opening remarks? If not, Dr. Fred Armstrong who is President of the California Medical Association is our first witness. Thank you, Dr. Armstrong.

DR. FRED ARMSTRONG: Thank you, Senator Hart, Senator Torres. It is indeed my pleasure to tell you something about what the California Medical Association and the position of the State of California is doing about this AIDS epidemic. And I think I'll follow the outline which I've been given that I think emanated from your Committee.

The physicians' level of knowledge. This is difficult to determine. There was one article written and published in a public health bulletin or journal not too long ago, which surveyed physicians' knowledge of AIDS in the State of California. And the article was somewhat critical of physicians. Now I don't know if this really reflects the knowledge about AIDS or not. It's very difficult to do this, to find out.

I can only tell you that I have never seen so many educational sessions, so many publications, so many conferences on one disease in my professional lifetime as I've seen on AIDS for physicians. It's difficult to attend many hospital staff meetings, departmental scientific sessions without AIDS being one of the primary subjects for discussion. An awful lot of professional education is occurring at the present time, and will continue and will grow.

Now, if the level of physician understanding of AIDS is not what it should be, I think it will just take time. After all, most physicians have never treated, have never seen a patient with AIDS. I would say a very small percentage of physicians throughout the State have really ever seen a patient with AIDS. Those who live in areas like San Francisco or Los Angeles where it's much more common versus (inaudible due to background noise).

It is our position that a physician who refuses to care for an AIDS patient is not meeting the ethical standards of the profession. In fact, just last week the American Medical Association came up with an ethical position on this. And I think it was very well stated. The American Medical Association declared that a physician may not ethically refuse to treat a patient whose condition is within the physician's current realm of competence simply because the patient suffers from or carries AIDS. I know of

It's the epidemic of the century and has the potential for the greatest -- being the no single case where a patient _____ (noise) _____ treatment because the physician had refused care of the patient. There have been individual physicians who have said, who have said publicly, that they would not care for AIDS patients. There's an orthopedic surgeon here at San Francisco General who has said this. There's a cardiac surgeon in my area in Santa Clara County, who has said that he does not want to treat AIDS patients.

We think these physicians who have declared this are misguided, and we hope to convince them that it's not proper for them to refuse patients with AIDS. We feel very strongly about this, and throughout history physicians have always treated people during epidemics. In fact, with great mortality among physicians at times in the past with epidemics.

Current training programs. Oh my, I've brought so much material here. I don't think you want to be bored with all this material. Things which we do. Our various specialty organizations have AIDS conferences. At our annual session, CMA annual session in March, we have a conference lasting a whole day and a half just on AIDS. The California Society of Internal Medicine, I'm a member of that organization, had its scientific session this year on AIDS. And I could go on and on. American College of Surgeons met in San Francisco here about a month ago and had several sessions on AIDS. We see it in virtually all our sessions.

The literature, just to give you one example, here is a book from the Journal of American Medical Association. This is just articles and journals of the American Medical Association on AIDS up to two years ago. This was published two years ago. There are thousands and thousands of articles. California Medical Association, our Association's official journal, The Western Journal of Medicine, which covers eight states, but this is published by the California Medical Association, will have its December issue devoted entirely to AIDS, and we've had many, many articles printed there. Our magazine for communicating with our members, last month had its whole issue devoted to AIDS.

We belong to coalitions. Here's a coalition for AIDS education. We're the coordinating organization and this includes the American Red Cross, the California Conference of Local Health Officers, the California Association of AIDS Agencies, the California Nurses Association, the Department of Health Services. We participate in this and each of you has received a whole packet of information which we have published on AIDS.

So to make a very long story short as I should, we're deeply involved in this and our interest and concerns will continue to grow.

Now, communication of HIV antibody test results. I'd like to talk a little bit about legislation. I'm sure that's the main reason you're here. We are, as physicians, we're disturbed by the unnecessary politicization of the AIDS issue. It's a horrible disease.

greatest epidemic of all time. And yet it's been politicized far too much.

Now there's some reasons for that which I know all of you understand, and I understand too. It has to do with who the people are that have AIDS. Physicians are very, very sensitive about the rights, the dignity, the privacy of individuals. It's very important in our work. And so we understand the sensitivity of the AIDS issue and why it's been politicized so much. But we, the State of California and Legislature, have overreacted in certain areas in legislation, and we think that to deal with this epidemic that some of this is going to have to be altered.

For example, I cannot disclose the positivity of an AIDS antibody test to one of my colleagues without the written permission from the patient. In today's medicine we work in teams. An AIDS patient usually has several doctors taking care of him, and it is very difficult, far too restrictive for a physician to have to obtain the written permission every time he discloses this information to an AIDS patient.

Furthermore, we have to file the results of an AIDS antibody test someplace other than the usual place in a patient's chart. This is not the way to communicate in medicine. We have multiple physicians taking care of AIDS patients in our offices, too, and this we should not (background noise).

Just a month ago, I was on backup call from the emergency room in my hospital, went in to see a patient who had overdosed and who was about as comatose as anyone could ever be, and the nurses were terribly concerned that this man might have AIDS. They thought that he was gay because of the people who came with him, his closest friends, the one he lived with was a man. And I could not order any tests. There was a lot of blood involved because of the intratracheal tube in taking care of the patient. And the nurses and emergency doctor were quite involved in all this bloody affair. And yet we could not -- I could not order an antibody test, as far as I know. There may be a law, I've been told by one of our attorneys, there may be a law someplace in California law that states that in emergency situations, we can. I don't know if that's true or not. But I felt I could not protect the nurses in my own hospital. Fortunately, the patient survived and I asked him and he said, yes, I am gay. I said would you submit to an antibody test and he said, by all means. And we did it and it was negative, so it came out well.

Well, things have been far too restrictive and we'd like some of this changed, without -- without -- violating the dignity and privacy of the individuals who have it.

I met with the Los Angeles Times editorial board about two months ago. They had criticized one of our positions on the Agnos bill. We did not support it. We are not heavily opposed to it, but we did not support it because of some of the restrictions which were still there. After discussing this with them at some length, I think they saw our concern. And then I asked a question to the whole board, do you know of any

instances where confidentiality of patients information has been breached by physicians? Those who sat on the board, where they also have writers of health articles of the Los Angeles Times and everyone of them said, no, they know of no instance where that privacy, that confidentiality has been breached. The medical profession, then, has to be trusted with that. And I can assure you, we treat that trust very seriously and we're aiming to do everything we can to deal with this epidemic. And we do need your help.

CHAIRMAN HART: Senator Marks.

SENATOR MILTON MARKS: I'd like to ask you a question, recognizing that we owe a lot to the medical association. And we're very pleased that you are doing what you are doing and I think that your opposition to many of the Doolittle bills was well done and I appreciate it. But there have been complaints, some complaints as to the forcefulness of the position of the Medical Association. There were some people who have claimed that the Medical Association didn't take as active a role as they should have. Do you think those are justified?

DR. ARMSTRONG: Yeah, I suppose there's some merit to that criticism. Most of the bills -- what was it, 70--some bills that were introduced about AIDS during this past legislative session, somewhere around there -- and most of them were not very good bills in our opinion, in my opinion. And what we want to do is to make some scientific and social sense out of these bills. Now, because of what we were faced with as a professional organization, and also as a lobbying force in Sacramento, it's very difficult for us to deal with these because some parts of these bills, we agreed with. We agreed with several parts of Doolittle's bills after he amended them. I'm sorry that Senator Doolittle isn't here because I would like address him on some of these issues. And the same with the Agnos bill, AB 87, the omnibus bill. We agreed, finally, with virtually every provision in that bill, except one. And it should have been amended, in our opinion. And I think this next year you'll see, and I think you'll see the California Medical Association more upfront than ever. In fact, we are writing our own bill right now. In fact, maybe more than one, I'm not sure.

SENATOR MARKS: I think the point I'm trying to make, and I'm not critical of you, I say that the Medical Association has done an awful lot to oppose these bills, but I think you can do more. I really do. I think that some of the Doolittle bills were terrible. I don't think you did the full extent of what you could have done.

DR. ARMSTRONG: I can tell you that Senator Doolittle and some of our members who were very active in writing and supporting his bills, feel very much the opposite.

SENATOR MARKS: Every time I got up on the floor and I told him the Medical Association was opposed to the bill, he said the lobbyists were making so much money _____ therefore, _____ oppose _____. Didn't pay any attention at

all to the Medical Association or the Nurses Association or any other health professionals. He felt as a lawyer that he knew more.

DR. ARMSTRONG: Well, that's most unfortunate.

CHAIRMAN HART: Dr. Armstrong, I carried AB 87 for Senator, or Assemblyman, soon to be Mayor, Agnos for the Senate, and you said that the CMA was in support of that bill with one exception? What was the exception?

DR. ARMSTRONG: Yeah, I think -- well, you see, there's so many amendments at the last minute. The one -- there were two parts to it. One we did not -- I don't think we entered in any official discussion on. The one part was the disclosure of the AIDS antibody test. And finally, Assemblyman Agnos changed it or amended it, so that we could disclose it to each other, physicians to each other, and to health professionals who are taking care of patients. But that -- for that second _____, I disclosed it to one of my colleagues who especially takes care of an AIDS patient. He can then, he then could not disclose it to someone else without the patient's written permission.

CHAIRMAN HART: My understanding was that that language that was in the bill was written by CMA counsel, as the bill was debated on the floor of the Senate.

DR. ARMSTRONG: I really -- I'm not aware of that, Senator.

CHAIRMAN HART: Let me ask just two other questions. Is there an official CMA policy that has been adopted ...

DR. ARMSTRONG: Yes.

CHAIRMAN HART: ... on the responsibility of physicians to care for AIDS patients or to make appropriate referrals?

DR. ARMSTRONG: This -- responsibility of physicians taking care of AIDS patients?

CHAIRMAN HART: Yes.

DR. ARMSTRONG: The American Medical Association has done that last week, which I mentioned, and we've not adopted it because we haven't had an official session for doing that, but I'm sure we would adopt that same position.

CHAIRMAN HART: Okay. Last question I had was is there, from your standpoint, any problem or has there been any discussion within your organization, if a physician, a practicing physician has AIDS or tests HIV positive, their responsibilities or rights to divulge that information to their patients?

DR. ARMSTRONG: We have no official position on that. Our house delegates meet once a year, met last March and we adopted several AIDS policy positions and this was not one of them. I think you'll find us addressing that issue more and more as time goes on. It's a very difficult issue because many physicians could very well take care -- with AIDS -- with an AIDS antibody -- who are AIDS antibody positive -- certainly could continue to take care of patients, most patients, as an internist. And we know that it's

not a casual transmitted disease. If I had the antibody, there's no reason why I couldn't continue taking care of patients. I would be no risk to my patients.

Now, should some law be written that mandates my disclosure of that to all my patients? There was a pediatrician in Texas who was AIDS antibody positive. This became public information. His practice dropped down to zero and he had to leave town. Now he was at no risk to his patients whatever. So I am not speaking for the CMA when I say this, because we've not taken a position on this, but I think the confidentiality and the rights and privacy of physicians should be respected, too. Now, where it involves surgery, dentistry -- dentistry is another potential problem -- then I think we have to look much more carefully at it then, because there is exchange of small concentration, _____ surgery, often, inadvertently goes into surgeon's hand or it's possible. It's rare for the AIDS antibody to be transmitted this way because of the nature of the transmission base, but it is possible. Especially in certain kinds of surgeon, cardiac surgery. That would probably be the best ...

CHAIRMAN HART: So you'd say, your point is that, if I understand you correctly, that in certain medical specialties, if a cardiologist, for example, had AIDS, that in that situation it might be appropriate for some knowledge of that information to potential patients to be known ...

DR. ARMSTRONG: Probably.

CHAIRMAN HART: ... much more so than in other specialties.

DR. ARMSTRONG: Probably. We would advise the person, probably -- again, we have not taken a position on this -- probably, to not practice that part of his specialty. Now, that could very well destroy some doctors practices.

CHAIRMAN HART: I'm not sure the analogy works entirely, but if the medical community believes that sharing this information with other physicians is most appropriate, then there is somewhat argu -- some logic -- that if it should be shared with other physicians, then perhaps it ought to be shared with patients of a physician anyway.

DR. ARMSTRONG: Well, yeah, I think the analogy falls a little short, though, when we have multiple people taking care of one patient and we know that person's positive, I think it's _____.

CHAIRMAN HART: Do you have questions? Thank you very much, Doctor.

DR. ARMSTRONG: You're certainly welcome.

CHAIRMAN HART: Our next witness is Glen Coltharp. He's a member of the Board of Directors of the San Francisco AIDS Foundation. He's a volunteer with the Northern California AIDS Hotline. Have I pronounced your name correctly?

MR. GLEN COLTHARP: Excellent. Copies of my testimony. Good afternoon. As he said I'm a member of the Board of Directors of the San Francisco AIDS Foundation. I'm also a

person with AIDS.

I'm here today to discuss with you a particular treatment issue: How do we provide access to treatment information for health care providers who are just beginning to see people with AIDS-related illnesses?

As a volunteer on the San Francisco AIDS Foundation's hotline, I've answered hundreds of questions about treatments. As a person with AIDS (PWA), I've asked at least that many.

The San Francisco AIDS Foundation hotline receives 7-10,000 calls every month. Men and women, gay, bisexual, straight, mothers, fathers, sisters, brothers, friends, lovers, people of all colors and backgrounds call us for information. It is not uncommon for us to field questions about treatments for AIDS-related diseases.

For instance, we had the experience of a physician calling the hotline asking what drug they should prescribe for pneumocystis pneumonia (PCP) or Kaposi's sarcoma (KS) or other opportunistic infections. Often, these physicians are seeing a person with AIDS or AIDS-related complex (ARC) in their practices for the first time. They are usually -- although not always -- calling from rural areas of the State. And they do not know anything substantive about AIDS.

The Foundation also sponsors the People With Aids (PWA) and PWARC Switchboard. There we receive calls from people who are requesting detailed treatment information, much of it extremely sophisticated. For example: "What is the difference between the mechanism of action of ribavirin compared to AZT? Why does Acyclovir enhance the efficacy of AZT? What are the side effects?"

It is unreasonable for us to expect a general physician, particularly one in a rural area, to keep up-to-date on all of the recent information about AIDS-related treatments. The information changes daily. The morning headlines, the latest medical journal, or simply information heard through the grapevine often dictates the questions a physician is asked by his or her patients on any given day. How does a health care professional in Yolo County, for example, respond to the specifics of a New York Times article about a new French medication?

They do not.

At the same time, how can we expect a person with AIDS not to ask about the promising new treatment they hear about.

We cannot.

In the age of AIDS, information means hope and life. People must have access to the most current treatment information available. We can fund all the research units we want, set up all the laboratories money can buy, but if we cannot get the information to people who need it -- health care providers and people with AIDS or ARC -- we haven't

helped anyone.

Physicians need access to treatment information. So do people with AIDS and ARC and other HIV-related infection. All too often, the patient has more information about available therapies than the physician does.

Imagine your frustration if you went to your doctor to be treated for heart disease. You are not feeling well and you are frightened. You mention that you have heard of a new drug which would prevent you from having a second heart attack. And your doctor says, "I don't know anything about it. I've never heard of it. Find out everything you can."

What we've been forced to do is to rely on the experts at San Francisco General Hospital, at the National Institutes of Health, and at UC San Francisco, again and again for answers to our questions. With the growing demand, these good people will not last much longer if they are required to carry the sum total of all of our knowledge about AIDS for every physician in the State.

How can we take their knowledge and communicate it to others? How can we be certain that hotlines and public health clinics and physicians in outlying areas have access to the information they need to assist their patients in making intelligent decisions about their treatment?

Our experience in San Francisco is perhaps unique. Many people with AIDS or AIDS-related condition (ARC) have taken it upon themselves to become experts in their illnesses and about the available treatments.

When no one could provide the answers they sought, they went and found out the answers themselves. They asked questions of their providers and demanded answers or access to information. Fortunately, the medical community here has responded extremely well. And they've continued to do so to the best of their ability.

You may not find that same eagerness to respond in other parts of the State. In fact, you may not find the same eagerness to even ask the questions or to know what are the questions to ask.

So, we need to provide people with the wherewithal to make the best decisions they can. One of the best ways to accomplish this is to ensure that health care professionals have access to current treatment information.

It is an exceedingly difficult task. It will require commitment from the State to provide resources for education, training, staffing, etc. of health care providers and health care facilities and networks. But I think that it is the trend for the future in dealing with this epidemic.

As a final note, I want mention and I believe you'll hear more about this today, that this effort to provide information to both health care providers and their patients must

recognize the obstacles that fear and ignorance place in our way in the form of discrimination. Discrimination, whether based on a person's gender, sexual orientation, drug use history or economic status prevents health care professionals from delivering information and services adequately and discourages people from seeking that information and those services that they require.

As the Surgeon General Koop has said, "We are fighting a disease, not people. Those who are already afflicted are sick people and need our care as do all sick patients. The country must face the spread of AIDS while at the same time preserving our humanity and intimacy."

Thank you.

CHAIRMAN HART: Thank you very much. I want to, as a member of the Board of Directors of the AIDS Foundation, want to commend you and the Foundation for its outstanding work. It's really a very important resource, not only to the people here in San Francisco, but to people throughout the world and throughout the State of California.

One question I had, if you heard Dr. Armstrong's previous testimony, one of his points was, there's all this material that's out. You go to the conferences and everybody's talking about AIDS at the medical conferences, and yet sort of one of the key themes of your testimony is that a lot of the physicians don't know very much about this at all. They have to call the AIDS Foundation to get information. Do you view these two threads of testimony as being contradictory or inconsistent?

MR. COLTHAKP: No, I don't believe Dr. Armstrong was suggesting that a general physician in Yolo County -- just to use the same example -- goes to the annual AIDS conference every year. There is -- there are lots of physicians who perhaps never get that information except maybe through the California Medical Association if they belong or the Journal of the American Medical Association or some place like that. A lot of doctors don't believe they're seeing people who are HIV infected.

A recent controversy has developed over some statistics regarding the length of time women survive after they've been diagnosed. It seems to be much shorter. The fact of the matter is is that women often are diagnosed much further along in the course of their medical care because their physicians aren't expecting that what they have is AIDS. They don't -- they're not aware that this woman had a sexual partner three years ago who three years before that used I.V. drugs. And probably has no way to know that. The woman herself may not know it. So they're not looking for HIV infection and the diseases related to that. There might not be any reason for a gynecologist -- no reason he knows of -- to believe that this is something he needs to know about. He's much more interested in finding out the latest information on birth control and Pap smears and stuff that he sees on a daily basis. A lot of physicians don't have -- well, not just

physicians, health care providers in general -- don't have a clue that they're currently seeing people who are at risk. They may not know what all the risk categories are. They may not know that this person falls into one of them.

CHAIRMAN HART: Thank you very much for your testimony. Senator Torres.

SENATOR ART TORRES: What is the latest French treatment?

MR. COLTHARP: Um, I can't pronounce it. I actually -- the French are looking at some things that we've also looked at. They're looking at some things that we are currently looking at. There is a new study beginning in Paris, and well, it's beginning this month. And in fact, there are people from San Francisco who have gone to Paris, two people I know of, to be part of that study. It's an immune system enhancer that I had never heard of before, and I can't tell you what the name of it is now.

Generally speaking, the way that information becomes available is through, in San Francisco anyway, there's a very well established grapevine of people with AIDS, people most directly concerned with these things. We, of course, saw the phenomena of Rock Hudson; people locally, Bill Kraus for example, going to Paris to get treatments on a drug that was called HPI. That was not available here. People have gone to Mexico for ribavirin. And the reason I know about it is because a friend of mine did it. You don't read about a lot of that stuff in medical journals, newspapers, perhaps the gay press in San Francisco because of their obvious concern there. I wasn't referring to anything specific in that.

SENATOR TORRES: Thank you.

MR. COLTHARP: Thank you.

SENATOR MARKS: I think you're a very fine organization. Where do you get your funding?

MR. COLTHARP: We get funding from the State for specific services. Our hotline is partially funded by the State. We produce educational materials that are used throughout Northern California. We receive funding from private individuals and foundations. You know we're a nonprofit and we do the same constant song and dance that all nonprofits do, which is getting as much from the State, from the County, from the federal government as possible, and using the private funds that we can raise to supplement those programs. None has been completely paid for a single program.

So that's 30 percent of our funds come from something public, whether it's a municipality, State or ...

_____ : You don't get any public health funds, any government, State, _____?

MR. COLTHARP: Yes sir, we do. About 30 percent. 70 percent of our funds are from private donations. 30 percent are from a mix of different kinds of public funds that often are earmarked for specific kinds of program, production of certain pamphlets and

they won't pay for other kinds of pamphlets.

SENATOR MARKS: Fine. Thank you.

MR. COLTHARP: Thank you.

CHAIRMAN HART: Thank you very much.

Our next witness is Mary Foley with California Nurses Association.

MS. MARY FOLEY: Good afternoon. My name is Mary Foley and I'm an officer on the Board of Directors with the California Nurses Association. I'm also Chair of the Economic and General Welfare Cabinet of the American Nurses Association. In that position I play a leadership role developing policies regarding union activities nationwide. I'm a registered nurse who has cared for persons with antibody positive and persons who are symptomatic for Acquired Immune Deficiency Syndrome (AIDS).

As a staff nurse at Saint Francis Memorial Hospital in San Francisco, I cared for some of the first AIDS patients as early as 1981. I will speak today on behalf of the California Nurses Association about testing, confidentiality and work place exposures to AIDS and other infectious diseases such as Hepatitis B.

There are now nine confirmed cases in the United States in which health care workers have been infected with the AIDS virus as a result of occupational exposure. This is a matter of great concern to the California Nurses Association and our members. The health and safety of health care workers is one of our top priorities.

Our concerns are not new. Nurses have always been faced with extraordinary occupational hazards on the job. For example, Hepatitis B is another deadly disease which is transmitted by blood. Last year several thousand new cases of Hepatitis B were reported among health care workers. At least 200 deaths are expected annually as a result of these exposures.

As with Hepatitis B, AIDS can be prevented by observing AIDS exposure in the work place, can be prevented by observing proper infection control. In fact, proper infection control on the job is really the only reliable way to prevent the spread of infectious diseases in the work place.

In the interest of providing the best possible care of the patients, CNA supports measures which would permit disclosure of the HIV test results to health care workers. However, such disclosure does not automatically translate into protection for the nurse. Patients may not test positive for the HIV antibody from 6 weeks to 6 months after they become infectious.

The only way to prevent the spread of AIDS amongst health care workers is education and the use of proper infection control procedures.

I want to make it very clear that CNA does not believe that a nurse or any health care worker needs to know the results of the HIV test in order to protect themselves. Relying on test results to protect health care workers only provides a false and

misleading sense of reassurance to those who rely on them. Only the practice of good infection control measures with every single patient will protect nurses and other health care workers from occupational exposure to AIDS.

It is precisely for that reason that CNA last year applied for and received State grant money to implement an AIDS education and training project. This is an innovative program based on adult learning principles which effectively trains 759 health care professionals in the State, who then in turn train 18,000 other health care workers in the facts about AIDS, how to prevent the spread of AIDS and other infectious diseases in health care settings.

I will discuss this program in greater detail toward the end of my testimony.

The AIDS project has been so successful that to date 33 states, 9 foreign countries and the World Health Organization have requested technical assistance from the California Nurses Association. We are doing our part to face this epidemic responsibly and calmly. Simply relying on the normal process of professional education is not enough. We are facing an epidemic and knowledge and calm are in short supply. CNA is doing what must be done. We are training people, on the job, during working hours. We need to reach every health care worker in this State with this information. And we need to do it very quickly.

We need many more programs like CNA's AIDS project. We need the cooperation of health care institutions and governmental bodies. Sadly, some institutions have not been cooperative in releasing health care workers for this training. Some institutions have even actively prevented health care workers from observing the recommended infection control guidelines, and this must change. Examples of that include institutions that have barred the use of gloves, particularly blood banks in the use when people are exposed directly to blood. Also, there have been difficulties in securing the right kind of gloves, the right size gloves, or gloves in adequate numbers. And in fact, when we talk about needle boxes and the disposal of needles before they're being capped, we're of the understanding that there are institutions that are putting plastic bags inside the needle boxes so that the maintenance workers or whoever has to dispose of those plastic bags are still being exposed to the uncapped needles. That is not the intent of these precautions.

I'm also here today to recommend that the Legislature enact measures permitting health care workers involved in direct patient care to be informed of the HIV test result. Under existing law, a nurse, physician or health care worker can be informed of the results of the HIV test only with the written consent of the patient. And this consent must be obtained for each health care worker who is to be informed. As we know, this law only applies to the results of the HIV test. It does not apply to a diagnosis

of the disease itself. A doctor may tell a nurse or a second consulting physician if a patient has the disease of AIDS.

CHAIRMAN HART: Senator Torres has a question.

MS. FOLEY: Sure.

SENATOR TORRES: Ms. Foley, I'm very disturbed by what you've just told us in respect to preventing hospital workers from being protected. I want to make sure that this committee understands what you're saying today, and that is there are institutions now in California that are preventing health workers from being protected adequately?

MS. FOLEY: Yes, sir. I'm of that understanding. There are some blood banks that have prohibited their health care workers from wearing gloves in the process of drawing blood.

SENATOR TORRES: And, what in God's name, is the rationale for that type of activity?

MS. FOLEY: Well, I don't represent the blood banks, but it's my understanding that they're concerned about public relations campaign ...

SENATOR TORRES: They've been concerned about the public relations campaign for years. And part of the transfusions which have resulted in infection could have been prevented if they would have taken the time to provide for antibody testing ahead of time. Now we're still dealing with blood banks that are concerned about their public relations?

MS. FOLEY: I believe so, sir. In fact, I gave blood a couple of weeks ago and I was quite surprised to see that the workers were not wearing gloves.

SENATOR TORRES: And what blood banks are not following these procedures?

MS. FOLEY: I understand there was a blood bank in Sacramento. I utilized the Alameda County blood bank. I don't know the others. I'm sure my staff has some information on the details.

SENATOR TORRES: Are your members represented at these institutions?

MS. FOLEY: We have a few members in some of the Southern California blood banks. I don't know of -- particularly if we are involved in the local ones.

SENATOR TORRES: As an association, are you contemplating legal action against these institutions?

MS. FOLEY: Not at this time that I'm aware of. But I'm not sure what our role would be in responding to this.

SENATOR TORRES: Well, your role would be, that would require the Department of Health Services to issue emergency regulations that ought to be enforced on these blood banks across the State.

MS. FOLEY: I think you're absolutely right, sir.

SENATOR TORRES: Are you suggesting to this committee also, that there are other

public institutions, such as hospitals, that may be also in violation of those procedures?

MS. FOLEY: It would be very supportive of our efforts to provide inspection control procedures if any official bodies could support those activities.

SENATOR TORRES: And there are hospitals now that are not following those activities, similarly to the blood banks that you've indicated?

MS. FOLEY: We have -- that's right. That's right. Most hospitals have been extremely responsive to this issue. We have heard of some improper procedures and it's a very simple procedure to have a puncture-proof box where you dispose of the needle before it's capped. Never cap a needle again is the new technique. And we have been informed and I've heard of this on a national basis and it's been confirmed in the State, that there are some institutions that are putting plastic bags inside of the box. So therefore, I as a nurse may be able to put my needle in there and not cap it. But the maintenance worker or whoever is cleaning up those boxes, then has to remove the plastic interliner. And it's defeating the intent of the protection. And therefore, it may be exposing someone later on down the line and that's not the intent of any of the efforts. Everyone should be protected.

SENATOR TORRES: What about the sizes of gloves, you said are not adequately available?

MS. FOLEY: Well, women have smaller size than the standard 7 or 8 size hands that many production gloves are made for. And there have been periodic shortages of supplies of gloves, particularly the latex gloves which have been recommended, primarily because they fit quite well and they're considered an adequate barrier. During the summer there were periodic shortages of supplies and at times, you'll find that the proper sizes are not available. You make do with what you have. But the health care worker who doesn't have equipment that they feel they can use comfortably or safely, will probably not use that equipment. And we consider that a barrier to their using those gloves every single time they should.

SENATOR TORRES: Mr. Chairman, I urge you as the Chair of the committee, to communicate immediately with Mr. Kizer to find out just what hospitals and what blood banks are not following the correct safe procedures. And I think your leadership is already well known in this State. And that kind of admonition as soon as possible to the Department of Health would certainly be in the interest of all Californians, not the least of which are those workers that are potentially exposed to this virus.

(cross talking)

CHAIRMAN HART: ... some kind of audit perhaps of what actually is transpiring, get a better fix on ...

SENATOR MARKS: Have we passed any legislation which makes the practices of the blood banks or the hospitals necessary?

MS. FOLEY: Not that I know of, sir, no.

SENATOR MARKS: Was any of the legislation that Senator Doolittle instituted involved with this question?

MS. FOLEY: No, I don't believe so.

SENATOR MARKS: And your association was basically opposed to his bills? (Sorry, I've got a bad cold, so excuse me.)

MS. FOLEY: Generically, we did have difficulty with much of his legislation.

SENATOR MARKS: Every time I got up on the floor and I opposed his bills and I told him that the hospi -- the nurses were opposed to it, they paid no attention to you at all, or to me either.

MS. FOLEY: I know. We're very concerned with the details of many of those pieces of legislation. We did provide testimony throughout the year on the problems that we had with those pieces.

SENATOR MARKS: Thank you.

CHAIRMAN HART: Could I ask one other question? Following Senator Torres' line of questioning on gloves, your testimony also, if I heard you correctly, was that to get proper education often times I presume requires some kind of release time from normal responsibilities in order to get this training and you were saying that, in some instances, some hospitals were disallowing that kind of release time so people could not get it.

MS. FOLEY: That's right. I believe this is one of those on-the-job education opportunities and there were many people who found it necessary to use their own time. There are also many people ...

CHAIRMAN HART: Did the training that normally is received would be at the hospital rather than going to some community center?

MS. FOLEY: I was just going to say, some of our workshops have had the opportunity of having 2-3-400 nurses or other health care workers come and attend it. Those are effective, but only for those people who know they should come and listen. There are many more health care workers who don't necessarily know that they need to come listen to information on AIDS, or may not avail themselves, or may not have the opportunity to use the continuing education format.

So therefore, the best education is at the work place, on the site, on the job education; intensive; among all health care workers, everyone from the dietary worker, the maintenance worker, all the way up the ranks to the physician, the business office and personnel department. We have had these training programs and many of them have required on-the-job release time. And there's been some obstruction to that. On the

whole, there's been good cooperation. But we'd like to urge the institutions to cooperate even more fully with the activities.

I was discussing the HIV antibody test and our concern that the immediate health care team have access to this information. The reason for this is that we want to provide quality patient care. If a nurse who is doing discharge planning does not know that a person is positive for the virus, she cannot adequately plan for that patient's future care. If a nurse is caring for a cancer patient, she needs to know that that patient is antibody positive in order to deal with the unusual depression or other psychosocial problems and be alert for other unusual symptoms.

It is important for us to differentiate here that we do not want to have the knowledge so that nurses can discriminate against those people they provide care to. In fact, we have ethical standards and statements that indicate that we believe that all citizens have the right to health care without discrimination for lifestyle type of illness or their diagnosis.

The California Nurses Association was the first organization to recognize the need for health care workers to be informed of the results of the HIV test. In 1986, before any other organization had raised this issue, we sponsored AB 3667 and AB 3407 which broadened disclosure to include health care workers. Currently, we support AB 87 which also addresses this issue. Each of these bills contains essential provisions which must be tied to broadened disclosure: clear protections for persons who test positive for the HIV antibody against discrimination.

The medical record is a more public document than most of us like to think. It is available to the insurance company and through them often to the employers. Few nurses would support disclosure of the HIV test results knowing this might well result in their patients losing a job, housing, or health insurance.

This is not a new position for CNA. We strongly oppose discrimination against any individual on the basis of disease or any physical disability. This is our position in regard to cancer, heart disease and diabetes, as well as AIDS.

I would like to spend a few minutes talking about the program I mentioned earlier dealing with the education and training of health care workers. CNA has done extensive education among our members on proper infection control techniques. You will find in the package of information we have prepared for you, a letter addressed to all CNA members with a wallet-size laminated card attached. In September we sent these to every one of our members. The card reminds nurses that any patient can be infected with the HIV virus, even with no symptoms. It takes 6 weeks to 6 months after exposure for a person to develop HIV antibodies. Therefore, nurses must use precautions with blood and body fluids from all patients to protect themselves from exposure to HIV. These precautions

also protect against other infectious organisms. This card is designed to fit into a nurse's wallet or pocket, so that he or she can carry it at all times. In the absence of a clear national policy to deal with the AIDS epidemic, CNA is not waiting for others to lead the way. We are committed to educating our own members.

We have also made a commitment to educate as many California health care workers as possible. In 1986 and '87 we received a \$25,000 -- I'm sorry, \$250,000 grant from the Office of AIDS in the Department of Health Services to establish our AIDS education and training project. As I said, we trained over 700 health care workers, including dietitians, hospital administrators, and doctors, as well as nurses. In turn, 500 of these trainees returned to their facilities and trained an additional 18,000 members. This year we have a grant of \$350,000 from the Office of AIDS to train additional health care workers.

The CNA AIDS program has four primary goals. The most immediate goal is to increase health care providers knowledge about HIV infection. The second goal is to allay unwarranted fears about AIDS which prevent health care providers from giving adequate care to people with HIV infection. A third goal is to teach innovative strategies to enable trainers to effectively communicate with health care workers. The final goal of the program is to decentralize AIDS expertise to training experts in each health care setting, to reduce the necessity to continually turn to the already overburdened AIDS experts.

There are more than 200,000 nurses in California, 35,000 physicians and thousands of other health care workers, including dietitians, dentists, physical therapists, janitors and many others who could be potentially exposed to infectious material. We are proud to have begun the first program and to have educated these 18,000 health care workers in one year. But it is only the beginning.

Mandatory education is not the answer. There are health care workers who need the education not covered by requirements of Continuing Ed. That's why we recommend the work place education.

We were asked to provide the committee today with information on proper infection control techniques. As I noted earlier, health care workers must use precautions with body -- all blood and bodily fluids from all patients to protect themselves from exposure to the HIV virus, because patients can be infectious for 6 weeks to 6 months before they seroconvert in test positives. Nurses and other health care workers cannot rely on the results of the HIV test to protect themselves. Nor can anyone rely on a visual inspection to determine whether a patient is high risk. How can anyone tell if a patient received a blood transfusion between 1979 and 1985 just by looking at them?

Health care workers should wash their hands before and after all patient or specimen

contact. They must wear gloves for potential contact with blood or bodily fluids. They should wear additional protective garb including gowns, masks or protective eye wear when splatter is possible. Additionally, used syringes must immediately be placed uncapped in a nearby impermeable container. All linens, laboratory specimens and waste must be treated as if they are potentially infectious.

Health care workers must assume all patients are infectious. The same procedures that protect against exposure to the HIV virus also protect against transmission of other infectious organisms, including Hepatitis B. These time-honored infection control procedures are not new or radical. They can and do save lives. AIDS education should be the top priority for government, health care employees and professional associations.

I want to thank the committee for holding hearings today on this critically important subject. And I'll answer any additional questions.

CHAIRMAN HART: Anybody with questions? Thank you very much for your testimony.

Our next witness is Monte Clark, Project Director, AIDS Education for Emergency Workers.

MR. MONTE BLAIR: My name is Monte Blair.

CHAIRMAN HART: Blair, pardon me.

MR. BLAIR: I want to thank you, first of all, for the opportunity to come and to address you. As I -- as in my remarks, I want to point out that when we talk about emergency service workers, we're actually thinking not simply of fire fighters and ambulance service personnel, but also law enforcement officers who in the course of their work are called on to provide responses. For example, in a custody setting, a correctional officer will be expected to provide first aid. Or a law enforcement officer will appear on the scene and be the first one there and as a result, when we think of emergency service workers, I ask you to think of law enforcement, fire service and ambulance service personnel.

We know that the virus that causes AIDS is easily -- is not easily transmitted, excuse me. However, public safety workers are expected to respond to a myriad of situations and some of these will involve contact with blood. And we know that infected blood in contact with an open cut or lesion can lead to infection. As a result, we have folks all around the State who are concerned when they go out on calls and come in contact with the public.

The concerns focus on not going to be infected obviously, and they manifest themselves in many different ways: a desire to know who is infected, especially after to exposure has taken place. There are officers who feel that if they had been exposed, for example, to Hepatitis B, they can be told by a hospital. But they can't be told if the person has -- is a carrier of the virus that causes AIDS.

There's a desire in some cases, to be able to refuse contact with infected persons. In some cases there's a belief that we don't have a problem here. There's a concern that the personnel have for the health and safety of their family members that they come in contact with, blood for example, and they take it home on their clothing. They wonder what -- might that affect a family member.

There's a desire for information and training, and a desire for support.

Our experience in a project that I've directly been working now for almost two years tells us that effective education can address the majority of these concerns. In terms of what is being done, the work ranges from agencies that have been working at it for a number of years and other agencies that haven't done anything yet. We do know that the safety of personnel begins with AIDS education and the consistent following of universal blood and body fluid precautions by all individuals.

We know -- and I had a call just last week from somebody in the State of Ohio who told me some officers came upon an accident scene. An 8 year old child was involved, was injured. They waited for the arrival of equipment to assist them and the child died. Afterward they find out that the child was infected with a virus. The child was a hemophiliac. And as I spoke with the individual in the Ohio departmental services, they pointed out that they had a problem on their hands, because the officers had not been educated. They did not understand where the risk existed. And in fact, the situation they're facing was not one that placed them in a considerable risk.

CHAIRMAN HART: Senator Torres.

SENATOR TORRES: Mr. Blair, we heard testimony earlier by the California Nurses Association that there are certain blood banks in California that are not following safe procedures. What procedures are followed at Red Cross blood banks?

MR. BLAIR: I can't speak to Red Cross blood banks because I only focus on AIDS education as it relates to emergency workers. So I can't really tell you what goes on in the blood banks because I'm just a person in charge of this one responsibility and I was asked to come and speak just on that.

SENATOR TORRES: Well, what procedures are you recommending the State follow in respect to emergency workers then?

MR. BLAIR: The recommendations are that there be support for the education of public safety workers, and that there be funding for the educational programs and for the equipment and supplies that are needed. For example, Mr. Areias had a bill in the previous session that led to -- we got -- pocket masks and training for law enforcement officers. But law enforcement officers make up only a portion of the public safety community. And in addition, it's more likely that we would have someone with cuts or lesions on their hands who would come in contact with a person that's bleeding than that we would have exposure that would put us at risk in giving artificial respiration.

So to involve, in the decision making process, folks from the public safety community. I know that last year the Office of AIDS in generating its Request For Proposal did not include input from anybody in the public safety community before that RFP was generated. And there are a lot of people in the law enforcement, fire service and ambulance service community who are very interested and committed to having the right things happen.

SENATOR TORRES: Education, equipment. What else?

MR. BLAIR: That's essentially the focus there. That's the most important part of it because we know that the vast majority of the concerns can be addressed in that way.

SENATOR TORRES: And that's what you're advocating from the Red Cross?

MR. BLAIR: Yes, sir.

SENATOR TORRES: Thank you, Mr. Blair.

MR. BLAIR: May I continue? Thank you.

As I said, I asked you to include public safety workers in your discussion and issues that affect them, and we appreciate the opportunity to come before you today and speak about this. It's important also to remember that there are organizations that are established and resources that are established. For example, the California Fire Chiefs Association as an EMS (Emergency Medical Services) section which developed communicable disease guidelines a few years ago and modified them to include AIDS, and is working to distribute those statewide. So there is not a need to go reinvent the wheel in some cases.

We have some organizations, for example, in law enforcement, the Commission on Peace Officers Standards and Training which is part of the Department of Justice and we work closely with them to set up training programs for law enforcement officers around the State. We have a similar arrangement with the Board of Corrections and their standards and training correction program for custody personnel and probation personnel.

There is no such agency or resource for fire service and ambulance service personnel. So when we talk about funding programs, we need to make certain that folks who have to -- who need that information can actually have access to it. And often times we're talking about agencies where if we want to have someone trained, you've got to pull them off from their shift and that can pose some problems in funding for those kinds of things that are important.

We have in the course of our project, when we train folks, we take an experienced officer from law enforcement required service and we have been them teamed up with a health educator or health care professional who knows something about AIDS and they go in together and train other trainers. And we've used the pyramid system and we think it's working fairly well.

We've also produced this guidebook which I brought copies for you "Emergency Workers

and the AIDS Epidemic" and we're finding that it's very popular and very well received.

All of this has been developed by working closely with folks from law enforcement and fire service and ambulance service personnel, AIDS education agencies, etc., and I think we're successful, but you know, we're just beginning to hit the problem.

Any questions?

CHAIRMAN HART: I wanted to ask, you mentioned equipment. And could you elaborate a little bit on that. What sort of equipment? I thought you said the most important thing are gloves, more than maybe some other types of equipment that relates to respiration kinds of issues.

MR. BLAIR: I think the most important thing, first of all, is the education itself, because we know that there are agencies where the individuals have been issued pocket masks, but they haven't been told how and when to use them. Or for example, most pocket masks only work on an adult and they don't work on a child. And if you haven't trained an officer how to use a mask, they may respond to a situation and not be able to use it effectively. So the education ends up being really important every time.

When we talk about equipment, we know that there are situations where it would be appropriate for an officer to use the gloves, or a firefighter or paramedic to use gloves, and so to educate them and have that available so they can use them. I know agencies over the past year, I've seen more agencies that are now issuing gloves to their personnel. Down in Southern California an agency last week, I was told by an officer, they put on gloves every time they arrest. Personally, I don't think that's necessary, but if they think that makes them feel more comfortable, then you know, and the agency's willing to spend the funds, great. But I think that the pocket mask is appropriate because there are some situations, no evidence to date that the virus is transmitted through giving artificial respiration, but it's theoretically possible. And that's where we want to put the emphasis.

In terms of the gloves, in terms of wearing proper equipment, there are officers who go in on an autopsy. I was just talking to an officer last week with the department down in Southern California where they were involved in an autopsy and as they cut into the skull, the blood spurted out six feet and hit an officer in the face and he got blood in his eyes and in his mouth. Again, if they had been educated properly, the officer would have been equipped and protected because that is something that may happen in that kind of a setting.

CHAIRMAN HART: So in terms of, for example, the mask, what would be your recommendations on who should have those masks? Are we talking -- would you recommend that there be certain protocols that every certain kind of fire fighter or police officer have those masks on their body to be used when they want to?

MR. BLAIR: Right. Public safety workers that are expected in the course of their work to provide assistance, respiratory assistance and are trained to provide it, should be trained on the use of pocket masks or other auxiliary breathing devices and be issued those devices.

We've just, for example, been working with the California Department of Forestry and we've recommended following the guidelines that come down from the Public Health Service that they have available the pocket masks. And people that we train say, okay, what's the agency going to do? Is it going to issue pocket masks now? And so the policies have come down from Public Health Service saying that it should be there. Relating to the gloves, the same issue comes up. They have them available. I know agencies that are, for example, equipping their officers with gloves and are carrying them in a little baggie in their back pocket. And if they come into a situation where they believe that it's likely they're going into contact with blood, then they can glove up and use them. But to know how to take them off. Yesterday I was told of a case where an officer finished handling a situation and took his gloves off by pulling them off with his teeth.

So you can see how it's both a need for the education, when to use them, how to use them, how to take them off, how to dispose of them, as well as having the equipment available.

CHAIRMAN HART: Do you have any sense of what percentage of fire fighters or law enforcement officials in the State carry this equipment or have access to this equipment?

MR. BLAIR: I don't. It's really inconsistent. For example, I'll go back again to the Department of Forestry. I know that in some regions, the Chief has issued the equipment and it is not a departmental-wide policy, so it depends on the individual. In Long Beach, for example, they're issuing pocket masks and gloves to everyone, and they are carrying them. In other agencies they're not doing that yet. I don't know. I'm trying to get a feeling for that, but I don't know yet.

CHAIRMAN HART: Thank you very much.

MR. BLAIR: Thank you.

CHAIRMAN HART: The next witness is Susan Haber, California Association of Public Hospitals.

MS. SUSAN HABER: My name is Susan Haber. I'm the Director of Research for the California Association of Public Hospitals. I'm testifying on behalf of our member hospitals which represent roughly 90 percent of the county hospital beds in California. I am pleased to have this opportunity to speak to you this afternoon about treatment of persons of AIDS, especially as it relates to county hospitals. While county hospitals are not the only providers of care to persons with AIDS, we have played a major role, for several reasons which I'll address during the course of my testimony. We also anticipate that our role will be expanding.

While California Association of Public Hospitals has not yet undertaken any original data collection about AIDS and our analysis of this issue is in the early stages, our organization is in the process of forming an AIDS Task Force. And we're cooperating with the Institute for Health Policy Studies at the University of California in San Francisco on the studies of the cost of AIDS. And we hope that in the future we'll be able to provide you with even better information than we have today.

Today what I'd like to do is share with you findings for California hospitals from a national survey that was conducted of major public and private teaching hospitals. This survey was conducted by the National Association of Public Hospitals (NAPH) and the Association of American Medical Colleges Council of Teaching Hospitals (COTH). The survey looked at the patient profile of persons with AIDS and the utilization and financing of services -- inpatient services to these people in 1985.

I'd also like to give you some idea about perspective on what trends we see in the future in terms of what the patient profile is going to look like of persons with AIDS and hospitals, and utilization and costs and financing of inpatient services. And then finally I'd like to just say a few words about non-inpatient -- non-acute services, both their utilization, the need for them, and the financing of these services.

I'll highlight very briefly the findings of this survey, but I'll keep my remarks on data to a minimum. But I do have written testimony that I'd be happy to share with members of the committee, so you can get some more detail at a later point.

Twenty California hospitals responded to this survey, and of them, 65 percent were public hospitals. These hospitals provided services to roughly half of the people in California that were reported by the CDC to have been diagnosed with AIDS in 1985. So they got a pretty good picture of what was the situation for the utilization and financing of services in that year.

This study found, as have others, that persons with AIDS in California use less inpatient care than they do elsewhere in the country. Their length of stay per admission was 20 percent shorter than the national average and the persons with AIDS in California were hospitalized for 28 percent fewer days than the national average. This translated into lower hospital costs. Specifically, the costs in California were 24 percent lower per admission than the national average and 26 percent lower per year.

Despite the relatively lower costs in California in that year, it still translated into an expenditure in 1985 of \$32 million, in just these 20 hospitals alone. Undoubtedly, the figures are much higher at this point, given the increase in size of patient population. I'd also like to mention -- remind you that these figures reflect the cost of inpatient -- acute inpatient care only. And there were unknown amounts back in that year on outpatient and non-acute services.

The hospitals in the survey were also asked to estimate their costs for these

services and the reimbursement that they received for these services. The hospitals estimated that they were losing roughly \$160 a day in caring for persons with AIDS in 1985. And again, I think there's reason to expect that the losses have increased since then.

I also should point out that San Francisco contributed heavily to the data in this survey and that the lower costs and utilization that were seen for California as a whole in this survey may be skewed by experience in San Francisco where there's a well developed network of community based services that had made it possible to discharge patients earlier and have reduced hospital care costs. The statewide averages probably masked broad differences in experience between institutions and communities within the State. And outside of San Francisco there may be many communities where costs and utilization look much more like they do in the rest of the nation.

The other reason that California may be seeing differences in its cost and utilization is that the patient profile that we saw in this survey was very different than that from the rest of the nation. In this survey, 81 percent of the patients were in a homosexual risk group and 79 percent were Caucasian. Whereas the national results show that I.V. drug abuse-related cases were five times the share they were in California and Caucasians were only 42 percent of the patient population.

It's expected that in the coming years in California, the AIDS patient population -- well, AIDS will increasingly become a minority problem and a drug use related illness. If this is the case, in California costs and utilization may also begin to look more like the rest of the nation.

The changes in the patient profile that California may expect to see also have implications for the reimbursement for inpatient care. The patients in this survey, at least for county hospital patients, were relatively well insured. One quarter of them had private insurance. However, half of them relied on Medi-Cal for the payment of their services and 20 percent of them were uninsured altogether. As more of the patients with AIDS who are served in hospitals are in the I.V. drug-related risk groups, we expect to see a smaller share of private paying patients and more uninsured patients. This also means that probably more patients are going to be cared for in county hospitals than in private hospitals, and we've seen it in the past.

Again, what this means is the cost of care for persons with AIDS could seriously strain the financial liability in county hospitals, many of which are already in precarious health. They will see greater proportions of the persons with AIDS in California, and the people they will see will probably be more costly patients than they've been in the past, if the reimbursement for services will be less adequate than it's been in the past.

Having spoken at some length about inpatient care, I'd like to say a few words about non-acute care services. I've less to say about this both because information is less available and because there are fewer services available. The need for alternative services to acute inpatient care is already apparent, particularly with new treatment methods that are increasing the longevity of persons with AIDS and with changes in the patient profile, persons with AIDS -- so that persons with AIDS will come from groups that will have fewer existing community support systems. The need for developing these services will only become greater. San Francisco has demonstrated that we can decrease the use of costly inpatient care if alternative services are available. Non-acute services are often not only more efficient forms of services, but often more humane treatment settings.

Among the types of services that are needed are subacute care services, skilled nursing facility services, hospice services, home health, adult day health, outpatient services, homemaker services, mental health services and drug treatment services. For some people, a need as simple as housing is also critical.

While San Francisco is further along than most other counties in the State in developing a continuum of care outside of inpatient services, alternatives are beginning to develop elsewhere. Several counties have established dedicated outpatient clinics for serving persons with AIDS in their county hospitals. San Mateo County is operating a free-standing Skilled Nursing Facility for persons with AIDS. Counties, we expect, will play a key role in providing non-acute care services as providers of care, coordinators of community services and payors for services.

Although the need for services at alternative levels of care is widely recognized, financing could pose an insurmountable barrier to their existence. Programs currently in operation rely heavily on government and foundation grants, private donations, and community volunteer work for their support. San Francisco has estimated that 45 percent of the funding for non-acute care services provided there, come from either county -- come from county general funds and 20 percent come from private contributions. It is my understanding that San Francisco has really only been able to support this level of funding from its general funds because of the budget surplus it's had in the past. And in the future, if it's going to continue that level of funding, it's going to mean that it's going to have to cut services in other areas. It's obvious that a stable source of funding is going to be as needed if non-acute care services are to be developed and maintained.

California has recently applied for a Medicaid community and home-based -- home and community-based care waiver for persons with AIDS. And this does provide promise for improving the financing picture. However, the waiver will not cover the full spectrum of needed services and it's not yet clear what the current level of reimbursement will

actually cover the costs of providing these services, and those people feel that the likelihood is that they will not.

To come full circle, I would like to point out that even if we have a fully developed spectrum of services in place in California and stable funding for these services is available, inpatient care will continue to be an important part of that spectrum. California's public hospitals have played an essential role in the treatment of persons with AIDS. And we expect that our role will continue to increase in the future. Given the potential magnitude of the impact of the problem on our institutions, the direction that AIDS policy takes in California is of grave importance to the California Association of Public Hospitals and its members. We look forward to assisting you in developing compassionate and responsible policies in California and will provide you with whatever information we can in that effort.

CHAIRMAN HART: Any questions? Thank you, Ms. Haber, for a very comprehensive overview.

Our next witness is Sally Wright, California Association of Hospitals and Health Systems.

MS. SALLY WRIGHT: Good afternoon, Senator Hart and members of the committee. I'm Sally Wright, Legislative Advocate representing the California Association of Hospitals and Health Systems (CAHHS). Joining me in our testimony today is Ms. Christine Cahill, Epidemiologist/Infection Control Coordinator for Seton Medical Center in Daly City. So on behalf of CAHHS and the Hospital Councils of Northern California, Southern California, Central California and San Diego and Imperial Counties, we appreciate the opportunity to appear before you to address important issues associated with AIDS. The development of AIDS policy in California is an important concern of the State's 532 general acute care hospitals which provide care for over 25 percent of persons with AIDS in the nation.

Today we will address the following issues:

1. Health care worker safety - preventing the transmission of HIV in the work place.
2. Testing of patients for HIV.
3. Protocols for testing employees exposed to HIV.
4. Access to AIDS care and continued services.
5. Funding for AIDS treatment.

On August 21 of this year, the Center for Disease Control (CDC) issued recommendations for Prevention of HIV Transmission in Health Care Settings. Prior to these recommendations, CDC advised hospitals to follow infection control procedures commonly used for patients with Hepatitis B when contact was made with blood or body fluids of patients known to have AIDS or HIV antibodies.

I would like to point out that those recommendations originated here in San Francisco from San Francisco General when they first started dealing with the epidemic. They worked closely with CDC and at that time just working directly with patients who were known to have been exposed, the recommendations were to take existing protocols for Hepatitis B, and those were issued nationwide.

But, today we are now using or implementing what's known as "universal precautions" which we no longer limit to a diagnosed case. And in fact, every patient entering the hospital is considered potentially infectious. Since the HIV/Hepatitis B status of patients is often unknown to health care workers at the time of admission, "universal precautions" is a sound and sure method of protecting both health care workers and patients from transmission of HIV, Hepatitis B, and other nosocomial infections.

Before we describe the type of precautions implemented, it is essential to review the real risk to health care workers of acquiring HIV infection in the hospital setting.

According to CDC, as of June 1987, there were only 12 documented cases of health care workers having contracted HIV infection after a known needlestick or other contamination exposure to an HIV infected patient's blood. Although recent exposures at San Francisco General Hospital and Sutter Memorial Hospital in Sacramento bring the total to 14. Four of the original 12 were part of a group of 1,432 health care workers studied who had sustained exposure to blood or body fluids from an infected patient. The remaining 1,428 health care workers were not infected. There have been an additional 33 health care workers who have developed AIDS without any identifiable risk factor. In these 33 cases, HIV infection was likely acquired outside of the health care setting. It is important to note that last year 200 U.S. health care workers throughout the nation died from Hepatitis B, a disease which is much more virulent in transmission than AIDS, and one that can be prevented through an available vaccine and universal precautions.

Earlier the committee -- it was questioned as to what was happening in regulatory, and I would like to, before I move on, just address that. The Occupational Safety and Health Administration (OSHA) at the federal level has proposed regulations for health care employers on their responsibility to protect workers exposed to both Hepatitis B and the AIDS viruses. And those proposed regs were distributed nationwide on November 9, and the public comment period is going on at this point. We are bringing OSHA out for our members. On December 14 and 15 we will be conducting seminars throughout the State on infection control practices. So we do support the use of "universal precautions" in every California hospital and we are going to be conducting those seminars.

I would like to take just a second before I go on and have Christine Cahill, Epidemiologist and Infection Control Coordinator from Seton Medical Center describe some of the "universal precautions."

MS. CHRISTINE CAHILL: Thank you, Sally. First of all, I'd like everybody to know

that these guidelines will only be effective if health care workers choose to follow the guidelines. And the second point I'd like to make is that there will be instances when health care workers will be exposed to blood and body fluids, even though their intention is to follow the infection control guidelines, but because of the emergency of the procedure, these guidelines may not be followed.

First of all, we advocate hand washing as an essential component of infection control before and after contact with patients and immediately following unprotected contact with blood and body fluids or mucous membrane. If the skin is intact and there's blood and body fluids, even if it's contaminated with HIV virus or HBG virus, the chances of getting an infection are very minimal and practically close to nothing.

We advocate the wearing of gloves for contact with blood and body fluids or when touching surfaces that might be contaminated with these fluids. And such examples might be suctioning of the respiratory tract, emptying of bed pans or drainage bags. Health care workers with exudative lesions or weeping dermatitis should avoid contact with blood and body fluids when gloves are not worn.

Gowns or plastic aprons are indicated for soiling. If it is anticipated that clothing will be soiled.

Masks, protective eye wear, including face shields in emergency situations in which there might be blood sprayed into your face or other body fluids, should be worn. Examples of these would be a trauma patient coming in with a profusely bleeding wound, surgical and dental procedures and wound irrigations. Ventilatory assist devices such as Ambu bags or mouth shields should be readily available to all patient care treatment areas and the need for mouth-to-mouth resuscitation should be minimized or eliminated.

Sharps should be handled in a manner which will prevent accidental cuts or punctures. We advocate putting sharp disposal units in every patient's room. Exposure to blood and body fluids by needlestick or by mucosal splash, or contamination of open skin wounds should be reported immediately to Personnel, Health, and provisions made for testing of the patient and testing of the employee for HIV and HBG should be taken.

Laboratory specimens should be handled as if they were all potentially contaminated, in such a matter as to prevent leakage or soiling of any hands during transport period.

Pregnant health care workers should strictly adhere to body fluid precautions as outlined. Pregnant health care workers are not known to be at any higher risk of contracting HIV infection than nonpregnant health care workers.

And as I said, HIV testing should be offered to health care workers who have been exposed to all blood and body fluids when the exposure is reported.

MS. WRIGHT: Also, I would like Ms. Cahill to perhaps tell the committee the procedures which we use in hospitals for testing of health care workers who have been

exposed.

CHAIRMAN HART: Before she gets to that.

SENATOR TORRES: The operative word I've been hearing today is "should". Why isn't the word "must" being used?

MS. CAHILL: The discretion at this point is left to the health care worker as to the assessment of the interaction between the health care worker and the patient.

SENATOR TORRES: Isn't the hospital concerned about liability questions regarding their ...

MS. CAHILL: Oh, very.

SENATOR TORRES: Then why aren't they required to do that across the board?

MS. CAHILL: They're required -- the assessment between the nurse and the patient -- if the nurse goes into the patient's room and is not anticipated to have contact with the patient's blood or body fluids, then we say, don't -- you don't have to wear any gloves, for instance. If there is going to be hand contact, hands on contact with blood or body fluid, then we say that you must put on gloves. You should put on gloves.

SENATOR TORRES: Now we've heard today from the Nurses Association that there are some problems with that.

MS. CAHILL: There are instances that -- for instance, starting peripheral I.V.'s. It's a very delicate process and nurses feel that sometimes they don't have the sensation that they need with the gloves on to palpate the vein. And missing the vein, of course, you know, requires sticking the patient three or four times, which is a very painful thing for the patient. And actually, if the health care worker is careful, there is very little chance that that blood will get onto the hand, even while starting a peripheral I.V.

SENATOR TORRES: So the concerns of the Nurses Association are not substantial then?

MS. CAHILL: Oh, yes, they are substantial.

SENATOR TORRES: Then what are the hospitals doing about it?

MS. WRIGHT: First of all, I would like to point out that I receive numerous calls throughout the week from administrators who share those very concerns. The majority of -- to my knowledge every hospital in the State is now implementing "universal precautions", but the concerns that I've received from the administrators are "I have mutiny on my staff; my phlebotomist refused to wear gloves; is that going to" -- you know, because -- the same identical reasons that Christine just pointed out. They insist that they are able to draw blood without having blood -- without coming in contact with the patient's blood. And by wearing gloves, they are in fact, there are numerous sticks taking place. And then the question is, so what should our policy be? And they are concerned, Senator Torres, from a liability concern. The CDC has not, in their

recommendation, gone that far. They've simply said, when it is anticipated that there will be contact with blood and bodily fluids. So it's really a matter of common sense in the workplace.

SENATOR TORRES: So we shouldn't be worried then as a committee or a legislator?

MS. WRIGHT: I think that we should be worried if there are incidents where health care workers are being prohibited from following such precautions. I know for a fact that what's happening today in the field, we are -- supplies are made available to them, training takes place on a weekly and monthly basis throughout the hospital through our infection control units and epidemiologist units. And OSHA's regulations are going to be very interesting because for the first time hospitals will to have monitor and discipline their employees who would not otherwise -- or would choose not to, for instance, not to wear gloves.

MS. CAHILL: I would just like to make one point, Senators, that the wearing of the gloves when doing some of these critical procedures may enhance the chances of needlestick pre -- needlesticks, and that's one of the things that we do want to try to prevent is the needlestick which is probably the worst type of injury that a health care worker could get.

CHAIRMAN HART: Help me with that. Why is wearing gloves likely in some situations to increase the prospects of a needlestick?

MS. CAHILL: Well, I think that you heard testimony that we don't have the proper supply of gloves that we really need to have to implement these body fluid precautions or "universal precautions" adequately. And there is a shortage of gloves. And now we're using just about anything that we can get our hands on that the health care workers can use to protect their hands. The gloves may not fit adequately and therefore they, in performing the procedure, you have the chances of sticking the needle right through the glove and into your finger because you just don't have adequate control.

CHAIRMAN HART: Is that a fairly common problem of not having proper size gloves? Is it not only the size of the glove, but the kind of material of the glove?

MS. CAHILL: Yes. There is an extreme shortage of vinyl -- I'm sorry, of latex gloves.

MS. WRIGHT: Would you like to go on with testing of patients and employees?

MS. CAHILL: Because of body fluid precautions, we have taken -- at our hospital at least, and I think in most hospitals -- have taken the stand that all employees who are exposed or who report an exposure to blood and body fluids need to be offered the HIV testing and we have implemented that protocol. Our protocol is, in fact, to request the patient to give his consent for HIV testing and if the patient is -- and also to test baseline the employee. If the patient is negative at the time, we will just follow the

employee clinically and not subject the employee to safe sex guidelines, all of the other things. If the patient refuses to be tested, then we must instruct the employee to follow safe sex guidelines, to be tested frequently at frequent intervals for six months to a year, and to report any febrile illnesses to the employee health service. And we have also instituted a protocol for testing unconscious and mentally incompetent patients.

MS. WRIGHT: We'd like to briefly touch on the issue of testing of patients prior to entering the hospital and what our industry position would be on that.

The California Association of Hospitals and Health Systems supports the CDC recommendations regarding testing of patients and health care workers for HIV.

And those recommendations are limited and I would like to point out that previous CDC recommendations have emphasized the value of HIV serologic testing of patients for: 1) management of parenteral or mucous-membrane exposures of health care workers, 2) patient diagnosis and management, 3) counseling and serologic testing to prevent and control HIV transmission in the community. In addition, more recent recommendations have stated that hospitals, in conjunction with State and local health departments, should periodically determine the prevalence of HIV infection among patients from age groups at highest risk of infection. Senator Seymour carried a bill last session (Ed: SB 942, Chapter 1391, Statutes of 1987) which now allows us to do that anonymously, and we do have hospitals in this State that are participating with the National Institute of Health on such a study.

Adherence to universal blood and body fluid precautions recommended for the care of all patients will minimize the risk of transmission of HIV and other blood-borne pathogens from patients to health care workers. The utility of routine serologic testing of patients, and the good of that is at this point unknown. Results of such testing may not be available in emergency or outpatient settings. We need to point out that the turn around time for the test, even when it's conducted in a health care facility, begins at 24 hours and can go up to 48 hours. So obviously with trauma patients an enormous amount of our patient load is emergency. We would not be testing patients or refusing treatment based on whether or not they were positive.

So we have to have personnel in some hospitals that have advocated testing of patients in settings in which exposure of health care workers to large amounts of blood may be anticipated. Specific patients for whom testing has been advocated include those undergoing major operative procedures and those undergoing treatment in critical-care units, especially if they have conditions involving uncontrolled bleeding. If it's in a situation where it's elective surgery, the patient knows weeks in advance, we feel as an Association, that it's up to the attending physician and the individual patient, and of

course when testing does take place it has to be done through protocols that include:

- * Obtaining consent for testing.
- * Informing patients of test results.
- * Providing counseling for seropositive patients by properly trained persons in the hospital.
- * Assuring that confidentiality safeguards are in place to limit knowledge of test results.
- * Assuring that identification of infected patients will not result in denial of needed care or provision of suboptimal care.

I'll skip over the Health Care Worker Testing, which Christine has covered, and Management of Infected Health Care Workers. If you look through the testimony which we've submitted we've also covered Management of Exposures.

I would like to make one comment on access to service and continuity of care and our position. Our Association believes that no individual should be denied needed services. If appropriate services are not readily available at a hospital, the hospital should make every reasonable effort to make arrangements for, or assist the patient in arranging the service within the constraints of the patient's health care coverage, experimental drug protocols, and community resources.

Community resources is a very difficult problem that we're facing here in California. We are constantly hearing from our discharge planning departments throughout the State that there's very -- that the services are very limited and patients are staying in the hospitals longer than they need to. So we're extremely supportive of the State looking at and supporting hospice, home health care and residential care.

As for funding, I think that the previous testimony did a lot of background coverage there, but you can also refer to our written statement.

And we believe that hospitals represent an important community resource for accurate information regarding AIDS. We support a uniform approach to education and patient treatment protocols. All those who work in hospitals -- physicians, volunteers, employees providing direct or indirect patient care, administrative and management staff -- have an important role to play in educating their friends, neighbors and family about AIDS and its prevention.

Earlier it was mentioned that the CNA project that it was difficult for health care workers to leave the site and undergo the training that they are conducting throughout the State. As an Association we've been extremely supportive of their project. In fact, just today our second mailing went out to every hospital throughout the State along with the schedule informing them of where the sites -- many of the sites are hospitals -- where the training will be taking place. I would like to point out that we provide

training in every single one of our hospitals through our infection control units and our epidemiology units. That's a normal part of the hospital function and a responsibility by law. So we are doing that.

CHAIRMAN HART: Let me ask, we've gone over a lot of material here. Hard time digesting all of it.

MS. WRIGHT: I know. It is a lot.

CHAIRMAN HART: As I understand your written testimony as it relates to health care workers that may have been infected with the HIV virus, your recommendation is that once that's been determined, that there then be a case by case review as to whether or not it's appropriate for that health care worker to continue in their position. Is that accurate?

MS. WRIGHT: That's correct and it would depend upon where they were employed in the health care setting. For instance, in a situation where a health care worker who is antibody positive is working in invasive procedures or in surgery. We actually had a hospital in Southern California last year where five O.R. techs were antibody positive and each one of them was transferred into other areas in that same facility, not because they were a threat to the patients, but because of the exposure. When you're antibody positive, your immune system is very vulnerable and when you're exposed to various diseases you're only going to become more ill. That's the reason for transfer. We have very little medical evidence -- both through the National Institute of Health and the Centers for Disease Control -- of a patient contacting AIDS from an employee at this point.

CHAIRMAN HART: So have there been cases in California that you're aware of through your hospitals where someone has been identified as being HIV positive and has been removed, not so much for their own protection, but possible risk to the patient?

MS. WRIGHT: Not to my knowledge. It's for their own protection. And that's the position at this point. I know of no reason -- I know of no situation where the health care worker was removed because of concern for the patient.

CHAIRMAN HART: All right. Thank you very much.

Next witness is Ted Benjamin, Institute for Health and Aging from UCSF Medical School. Is Dr. Benjamin here?

Next, Brian Cross, AIDS Coordinator, Alameda County.

MR. BRIAN CROSS: Thank you. Thank you for inviting me this afternoon. Alameda County is a county of high prevalence of the AIDS virus as well as a county of high numbers of persons diagnosed with AIDS. Right now we have approximately 500 persons who have been diagnosed. We're the fourth largest concentration of cases in the State.

We offer a comprehensive network of services which is in part based on the San

Francisco model. I emphasize "in part" based on that model. I have some material here which goes into some detail about the services and how people can access service.

I'd rather spend the time just briefly going over that service system and also talk about some of the problems involved with offering services, direct services to persons with AIDS and the persons around them.

We have dedicated inpatient acute-level services at the County hospital as well as dedicated subacute-level inpatient services, also at the County hospital. We have two -- we have one open and one soon-to-be-opened -- dedicated outpatient clinics at each County hospital and we have a number of dedicated outpatient clinics at private hospitals in the County.

Our experience is different than that described by the person representing the Public Hospital Association in that, maybe because our numbers started increasing later in the epidemic when people were eligible for MediCal, presumptively. We have a number of people who become diagnosed at private facilities and often end up at public facilities as their resources diminish and they become sicker. Our concern is that the County hospitals -- I think the representative from the Public Hospital Association is very accurate -- the County hospitals and County services will be called upon to deal with sicker persons and persons with greater level of need than those presenting probably at private facilities.

Once again we have an array of medically-related services, including screening and anonymous test sites. We offer psychosocial support services similar to those offered by the Shanti program in San Francisco as well as comprehensive in-home nursing care, hospice care, in-home attendant care. And once again, I have a fairly good description of that which I'll pass out later.

My concern is that the San Francisco model is based on a very high level of volunteerism. We have a large gay male population and even larger lesbian population in the County of Alameda. However, relative to the population base, it isn't as great as those populations in the San Francisco area. And in general, those populations have been where a large number of the volunteers relative to AIDS services have come.

We are trying to outreach to churches right now to identify volunteers to assist the psychosocial services providers as practical support volunteers and telephone switchboard operators, those kinds of things, speakers for speaker's bureaus. But we realize that volunteer-related services become fairly culturally identified as middle-class and predominantly white services. In order to volunteer you need to have a job. And moreover, you need to have a job which permits you to take an afternoon off. If you're attempting to relate to a person and help that person live and help that person die, you need to have some flexibility in your life, and you also need to have an income so that

you can indeed provide those services.

So we're real concerned that a continued belief or reliance on volunteerism as a major source of support for the person with AIDS is a bit naive. And I urge the Legislature to consider that possibility. And not only is it naive, it's really shortsighted, in that it just deals with a particular segment of the population, particularly middle-class persons.

Right now a lot of the services provided to people with AIDS, as previous speakers have mentioned, are based on volunteerism. They're based on demonstration grants. They're based on one-time gifts from private foundations, and so forth. We need to move away from that kind of a model of service delivery to one that is based on entitlement programs, one that is based on real strong and secure sources of funds.

We're encouraged also by the recent decision to ask for a waiver from MediCal for community based in-home services. We are very concerned, however, that we continue to underfund these services, continue to underfund them for persons with AIDS through MediCal. A point in fact: the actual rates provided, some of those proposed by MediCal will cover like 1/3 to 1/2 of the actual cost, and would cause people to remain warehoused in large, basically County-run hospitals.

We also need to begin to identify mainline organizations to provide services relative to AIDS. We've found how difficult it has been in Alameda County to deal with well meaning in-home nursing providers, to help them understand that some of the needs that people with AIDS have are different than their usual clientele, and how to get over that. This is after, of course, dealing with the whole array of issues, of denial, and so forth. After you get through that, you get into how are these people similar and how are these people different. The point in fact, we need to move away from ghettoization (that's my word) of services to persons with AIDS and realize that persons with AIDS are more like everybody else than they are unlike them, and therefore are entitled to mainline community services in health, mental health, social services, and so forth. And I think that's going to take money, simply put.

So I'm recommending that you consider ways of establishing, not only an adequate, but a stable funding base through entitlement programs or other resources. The concern I had, for example, is the federal government has recently funded AZT which is a treatment for -- antiviral treatment for the HIV virus, and in point of fact, has paid for the actual pills. They have, however, not paid for the administering of those pills, or any of the other costs related to it. So Alameda County is going to do that. It's going to cost Alameda County a lot of money to provide that service and we're willing to do that.

But counties are, you know, stretched already. And to presume that local government is a final solution to the monetary problems is also naive.

Finally, (not finally, just before finally) the kinds of things I've been talking about: adequate funding, end of ghettoization, are based on some things that the State -- based on the attitude of anti-discrimination. I'm proud to say that the majority of anti-discrimination ordinances in this State are municipalities in Alameda County. Three of our four largest cities -- Fremont, Berkeley and Oakland, and the County itself, all have anti-discrimination ordinances on the issue of HIV positivity and diagnosis of AIDS or ARC. I encourage the Senate to consider statewide anti-discrimination ordinances so we can begin to let people with AIDS and ARC and people who are HIV positive know that we mean it when we're talking about protecting them against the unnecessary and unwarranted invasion in their privacy or rights. And I think unless we identify as a community, as many communities in my County have done, that we are committed to that, then we're going to have a very difficult time getting widespread community support for many of the things suggested this afternoon.

I think the role that the State Office of AIDS is an important matter for the Legislature to consider. We're very encouraged by the fact that there has been a recent change in administration. I should speak personally. I'm really encouraged that there's been a recent change of administration at the State Office of Aids because of one particular issue. Up to this point, in my mind, the State Office of AIDS has been reluctant to be the funder of Direct Services Programs. The Roberti 1251 (Ed: SB 1251, Chapter 767, Statutes of 1985) money, which came through 3 or 4 years ago and has been renewed, was a program of direct services of in-home care with a cost of care component. That was interpreted by the state bureaucrats as a cost of care study or a set of cost of care studies. We participate in that.

What I'm trying to point out that we need direct services funds also coming through the State Office of AIDS. And I'm encouraged that perhaps with the new leadership in that office, it'll be able to see that more clearly.

Finally, I encourage you to look at basically the funding of these services because I think unless we begin to deal with the actual (noise) of indigenous supportive services at the local level, and empower local health departments -- county health departments to become the coordinator of those services, the monitor of those services, and the evaluator of those services. If we do those kinds of things, I think we go a long way. My boss, the health officer, is responsible for the control of the spread of this infection in Alameda County. He also should have at his disposal the ability to deal with that control in prevention activities, in other educational activities, in treatment of persons with the diagnosis in the treatment of people with HIV positive.

Thank you.

CHAIRMAN HART: Thank you. Let me ask a couple of questions. How many AIDS patients do you have in Alameda County currently?

MR. CROSS: At the end of last month we had 488 persons with the diagnosis. I suspect there's a little over 500 as of today.

CHAIRMAN HART: And is the proportion of people who have the disease comparing say, gay men with I.V. drug use -- is it ...?

MR. CROSS: There's a slight fluctuation having to do with some issues, but basically the patient profile is very similar to that of the City of San Francisco. Our concern, however, is that our population at risk is much different. We have large numbers of gay men. There's no question about that in Alameda County. We also have very large numbers of persons who use I.V. drugs, estimated conservatively at 25,000 to 30,000 persons this week in Alameda County are shooting up and sharing the works. So we're real concerned about the spread of the virus to other populations. But right now, those 488 cases, which is kind of a signature of what the epidemic was maybe four or five years ago, Yes. Four or five years in Alameda County the epidemic was similar to what it was four or five years ago in San Francisco. But we're concerned that, as time goes on, things have changed.

CHAIRMAN HART: You mentioned -- and maybe you're not in a position to respond to this -- but one of the things that we heard earlier today, and you've mentioned, and other people have mentioned, is the level of funding and how important that is in the treatment of people. There is a concern that's sometimes expressed and maybe sometimes not expressed in Sacramento that we're falling all over ourselves to deal with AIDS, and we're forgetting about a lot of other sick people. And is it appropriate to -- I mean in the best of all worlds, we would want to increase funding for all ill people -- if we single out a particular disease such as AIDS for special funding, that potentially presents some real problems when it ...? Can you comment on that at all?

MR. CROSS: Sure. If I can back up a minute to say something which I missed, and I think it ties in very importantly here.

AIDS has not created any new problems. AIDS, however, has exacerbated every problem we had before the onset of this virus. A point in fact, we had a Health and Human Services system which did not adequately provide for people in need, long before this virus came along. When you overlay that, an epidemic of this proportion, and the consequences of this epidemic regarding persons -- the effect on the work force and the effects on the tax base, you've got a problem on your hands. I don't think people with AIDS are asking -- or the people around them -- are asking for any special treatment. I think they're asking for access to the service delivery system that's there, and their fair share of that. Sometimes, their needs will be different than other people's needs. Somebody may choose to die at home -- to live and to die at home, and therefore will need more attendant care than perhaps somebody in another circumstance of a terminal illness. We're saying that just like that person, that other person whose special needs may be met

because we're used to dealing with older people in a hospice situation, this person's special needs should be met, too.

We're also pointing out that if you begin to deal with community based programs and programs that keep people at home, you're going to cut the actual cost substantially. And a point in fact, one of the -- if there are benefits of this epidemic, one of the benefits of this epidemic may be to teach us how to care for people humanely and cost efficiently.

So I'm not sure we're asking for a lot more money. I think we're asking people to respond to the fact that we're in an epidemic. And like everything else about this disease, the first wave of this disease is one of denial. I think that there are folks, certainly maybe not many folks in this room, but there are folks, both in Sacramento and in Washington, D.C., who are still in that denial and who are not willing to deal with the fact that we are in the mist of the public health crisis of this century.

CHAIRMAN HART: Thank you very much.

MR. CROSS: Thank you.

Our next witness is Diane Wara ...

MS. DUKE: Maybe you should get Ted Benjamin here. He was the one you tried to do last time. He's just coming up.

CHAIRMAN HART: Oh, I'm sorry. Okay, Dr. Benjamin, sorry. I called you earlier and you were not here, so I assumed you had not come in.

Dr. Benjamin is with the Institute for Health and Aging, UCSF Medical School. Dr. Benjamin.

DR. TED BENJAMIN: I'm actually representing two organized research units at UCSF, the Institute for Health Policy Studies in the School of Medicine, and the Institute for Health and Aging in the School of Nursing. I welcome this opportunity to review with you some of what we've learned about the cost of AIDS and what some of the issues are in the study of present and future costs associated with this epidemic.

The cost of AIDS to persons with AIDS, to hospitals, physicians, and agencies providing care, to communities, to third party payers and others, has caused growing concern. Legislators have raised a number of questions related to cost, coverage and financing of care for persons with AIDS.

The economic costs of any disease are both direct and indirect. The major component of direct costs is the care of patients in and out of the hospital, including physicians, services, drugs, nursing and home health care, and others. Indirect costs reflect the economic loss to society, generally measured by lost wages due to sickness and early death. Direct costs are high if hospital and nursing home care loom large in patient treatment. Indirect costs are high if illness and death occur in young people at the

peak of their earning power. Both of these circumstances are characteristic of AIDS.

The direct cost of AIDS include two major components. Personal medical care in and out of the hospital; and non-personal costs including infection control, screening, testing, monitoring, and so forth.

Estimates of the direct cost of AIDS, that is the cost of treating persons with AIDS, from diagnosis to death, have varied enormously. Some recent estimates have ranged from as high as \$200,000 in lifetime costs, to as low as \$25,000 per person with AIDS.

To date only a limited number of studies regarding the direct cost of AIDS have been published. The first report in 1983 estimated the cost at \$50,000 to \$100,000 per patient, but gave no basis for this estimate and no detailed breakdown. The second, published in 1985 estimated the average lifetime hospital cost to be \$42,000 per patient but was limited to 16 patients only.

The most frequently cited AIDS cost figure in the U.S. is an estimate with a lifetime direct cost of the first 100,000 -- I'm sorry -- of the first 10,000 patients with AIDS reported in the U.S. These estimates were made by Hardy and her colleagues at the Centers for Disease Control in 1985. They estimated lifetime hospital costs of these patients at just under \$1.5 billion or \$147,000 per AIDS patients. This estimate was based on an assumption of a lifetime use of 167 hospital days, 5 1/2 months in the hospital, an average survival time of 392 days or about 13 months, and average charges of about \$880 per day in the hospital. This was based on one hospital in Atlanta and 35 patients. To their credit, Hardy and her CDC colleagues stressed that, "These figures are admittedly estimates, since data were available from only a few sources." Subsequent research has shown that their estimates were indeed very high.

The most detailed study to date was directed by Anne Scitovsky of the Palo Alto Medical Foundation and the Institute for Health Policy Studies at UCSF, and was published in 1986. This study found that the average cost per 450 admissions to San Francisco General during 1984 was \$9,000 per patient admission, that is about \$775 a day for just under 12 days. For those patients who died in 1984 and received all services at General, the average lifetime inpatient cost was \$27,500 and a total of just under 35 days were spent in the hospital.

These figures are only about 1/5 of the original CDC estimate by Hardy, which incidentally is still widely quoted in the press.

The single largest factor explaining the difference is the total number of hospital days used by patients with AIDS from diagnosis to death, 35 days in the case of the San Francisco General sample, compared with 168 in the CDC study. Part of this difference in turn is due to the shorter survival time from diagnosis to death of persons with AIDS shown by our San Francisco General data compared with those estimates by Hardy. When our

data are adjusted to reflect the longer survival period, we find a median survival of 1 1/2 months and a lifetime cost of \$41,500. When the higher average hospital cost used by Hardy are used instead of the cost at General, the average lifetime cost per patient increases to about \$46,000, still less than 1/3 of the original CDC estimates.

A somewhat higher figure of \$67,300 for lifetime hospital cost per case in San Francisco was reported by the California Department of Health Services. The difference is probably due to the fact that DHS recorded costs from the time of first symptoms while we recorded costs from the time of firm diagnosis.

A recent report from Rochester, New York reports annual costs even lower than our findings in San Francisco. Based on 64 AIDS cases, the annual cost of AIDS care in Rochester were about \$26,000 including inpatient, outpatient and community care. Other estimates from Southern California recently are \$25,000, from Alabama-\$40,000, and from a larger study in Boston just over \$50,000 in lifetime total costs of care.

Placing a price tag on the direct cost of illness is just the first step in measuring the total financial burden on society. But direct costs are often the only one cited by hospital administrators and others. There is a significant indirect cost when large numbers of productive members of society become ill and die, and society is robbed of their potential social contribution. Although the number of AIDS deaths has been relatively small when compared to the nation's current leading causes of death, the indirect costs are high because of the relative youthfulness of AIDS victims. According to the CDC, 90 percent of all persons in the U.S. are between ages 20 and 49.

Scitovsky and Rice of UCSF had estimated the indirect costs of AIDS nationally to be \$3.9 billion in 1985, \$7 billion in 1986 and just under \$56 billion in 1991. Again, the reason for the high indirect cost, and especially the high mortality cost, is the fact that most persons with AIDS are young.

Finally, I'd like to talk about some of the factors which help us understand variations in the cost of treatment across states and communities. Comparisons of the costs of treatment of persons with AIDS across states and localities reveals that the critical factor in costs of care per persons with AIDS is the length of inpatient hospital stays and the use of intensive care. Studies in California reveal that the average length of hospital stay in San Francisco dropped to 10.8 days in the first quarter of 1986 from a high of 18.2 days for the first cases treated in 1982.

Data from other states and communities reveal wide variations in average length of hospital stays. Studies done in seven major cities outside of California reveal lengths of stay ranging from 29 1/2 days in Philadelphia, to 12 1/2 days in Minneapolis with Boston, Miami, New York, Chicago and other cities arrayed in between, roughly from 15 to 25 days.

In virtually all parts of the country, the average length of stay in hospitals has been declining. I noted the decline in San Francisco from about 18 days to about 11 days. In a continuation of a study in Massachusetts of five hospitals and 215 persons with AIDS, George Seage and his colleagues found that over the past two years the mean cost per case has decreased from \$50,000 to \$37,000 due to shorter length of inpatient hospital care, as well as a decrease in the average number of hospitalizations per patients. Similar decline has been found in Parkland Hospital in Dallas, Texas where the average length of stay dropped from 22 to 12 days.

Differences in methodology, research methodology, case mix, risk groups involved, treatment protocols, and availability of non-hospital care facilities in community-based volunteer support account in part for the wide disparity in hospital use and thus in estimates of cost. Moreover, current estimates may not be a good benchmark for future projections of the cost of AIDS treatment for several reasons.

First, patterns of care and thus costs may undergo change over relatively short periods of time. Many earlier cost estimates, as we've suggested here and other speakers have suggested, were based upon lengthy hospitalizations with little use of comprehensive outpatient services which were not in place in most communities. Subsequent studies, however, have found significant reductions in inpatient use in many communities. In some places a great deal of attention is being given to shifting inpatient to outpatient and home settings which may further reduce costs. As the shift is available, home and community services are developed and extended. Further cost reductions may also result.

Second, patterns of care vary widely across communities due to variations in the availability of non-hospital services in the community that permit persons to reduce hospital stays. As various people have suggested, relative costs tend to be lower in San Francisco where a wide variety of community support services are available.

Third, patient mix varies across time and place, and this can have a significant impact on utilization and cost. The socioeconomic background of the patient can affect utilization patterns, as well as the presenting diagnosis. For example, I.V. drug users tend to present with pneumocystis which is more expensive to treat and results in longer hospital stays when compared with Kaposi's sarcoma, which tends to be less expensive on average to treat.

Cost projections based on current data are further complicated by several other factors. The costs of ARC care are virtually unknown, but probably represent a substantial drain on public and private resources. The future seroconversion and transmission rates are unknown, making projections about future numbers of AIDS and ARC cases and cost estimates inherently uncertain. Incidence patterns will continue to change with an expected increase in the proportion of total cases related to I.V. drug use, as you've said, including a proportionate increase in pediatric cases and thus a

change in the future case mix.

The availability of AZT and possibly other drugs that prove to be safe and effective in the treatment of AIDS and ARC could increase patient utilization of medical services and possibly increase longevity, all of which may increase costs. However, if more effective drugs are discovered, costs may decline because of reduced inpatient hospital care.

The cost of central nervous system complications are still virtually unknown, but potentially significant. The strength of volunteer networks, as Brian Cross suggested, which seems to have significantly reduced costs in many communities, may be waning, which could profoundly affect future care patterns and costs.

Earlier diagnosis of AIDS in the future due to better medical knowledge or revised CDC definition could result in higher estimates for cost of care, either because care patterns may change, or the measurement process may become better attuned to the true level of expenditures for AIDS care.

I would like to close by just commenting that the State of California has provided some significant leadership in supporting research on service provision and expenditures associated with AIDS. I share Brian's view that demonstration programs and research are no substitute for serious continuing funding of service programs. At the same time, we at UCSF welcome the opportunity to work with the State on these issues. Thank you.

CHAIRMAN HART: Doctor, let me ask, would you have any recommendations to myself and others at the State level that are interested in this issue of what steps we might take to reduce the costs without adversely effecting quality of care? Is there anything that stands out in your mind that the State can and should be doing in that regard?

DR. BENJAMIN: I share the view of some of the other -- some of the rest of those who have testified about the significance of home and community based support services and I would suggest that -- I have a background in Aging and in Aging the approach has also been demonstration programs and a halting acknowledgement of the significance of home and community based services, but a lot of concern about what is sometimes referred to as the woodwork effect that public programs will drive out voluntary effort and will reduce the effort made by families and other informal caregivers in the home and the community.

I would suggest in the area of AIDS that heroic efforts have been made in communities like San Francisco to mobilize volunteers to provide the kind of sustained -- what is sometimes called nonskilled care, but which is in fact skilled, but non-medical care, the kind of personal care and attendant care that the persons who don't require skilled nursing care, but require attention and assistance in living in the community require.

I would suggest that a system of long-term care is what California needs and that it's highlighted by the AIDS experience, but it's not part -- back to your earlier

question -- it's not at all limited to the AIDS population, and that there are -- in fact, there's a growing interest among those working with the elderly in the experience with AIDS because many of the same issues related to reducing the use of institutional care and sustaining people in meaningful and humane ways in the community arise in that some policy discussion involving those who work with the elderly and those who work with AIDS would produce perhaps some creative thinking about sustained reasonable funding for home and community based services.

CHAIRMAN HART: Thank you very much.

Now, Dr. Wara, Professor of Immunology at UCSF Medical School and Member of the American Academy of Pediatrics.

DR. DIANE WARA: Thank you very much for inviting me to testify this afternoon. I'm here to represent children, and specifically children with AIDS. I'm a Professor of Pediatrics at UCSF. My research interest is immunology. And I've been taking care of children with AIDS in retrospect since 1979, in more significant numbers since 1980. Both people who work with me and myself have been handling blood samples clearly since 1979 of children with AIDS. And again, I'm here to represent the Academy of Pediatrics this afternoon, but I have spent some time phoning my colleagues on the East Coast, as well as my colleagues in Los Angeles, who care for children with AIDS in order for me to be able to give you some more unified suggestions.

Unfortunately, we all believe that pediatric AIDS is an increasing medical issue in California. In contrast to the epidemiology scene on the East Coast, whereby part of the majority of children with AIDS acquire their HIV infection prenatally, that is their mothers are antibody positive and are infected. In contrast to that group, on the West Coast, approximately 50 percent of new pediatric AIDS patients, that is patients that I'm seeing this month, have acquired their infection because of the past receipt of contaminated blood products. This 50 percent figure is true both for the San Francisco Bay Area and for greater Los Angeles, in stark contrast to what's currently being seen on the East Coast.

The predictions for the numbers of pediatric patients for the future are very difficult to make, and I've spent some time trying to come up with that for you. I'll tell you why it's difficult. There will be an end to the transfusion-related patients. Or at least there will be a great diminution in them because blood banks are now screening, as you know, blood products for HIV -- blood donors for seropositivity for their status. But unfortunately, the incubation period between the receipt of a contaminated transfusion and clinical illness is prolonged in children, and at least at the present time this incubation period is extended to 6 years. That means practically that the new patient, the new child with AIDS that I'm seeing today, received his or her

contaminated blood transfusion in 1981. That gives us some years to go before we're going to see a decline in transfusion-related pediatric AIDS. And unfortunately, again, in the State of California, around half of the children that we're seeing have transfusion as their major risk factor.

The second large group of children are those that are born to HIV antibody positive mothers. And again, this group appears to be increasing, both on the East Coast and on the West Coast, as well as in the middle of the country. This disease does not respect geographic barriers. The estimated percent of antibody positive women in high risk groups in Los Angeles and in San Francisco varies considerably, and numbers range between 4 percent and 10 percent. This large range reflects the lack of a good study. There is a very good prevalence study that's going on now at the San Francisco General Hospital in which all women who go into the obstetrics clinic are being, of course, asked if they may be tested for antibody positivity, and they are being tested. But the results of that study are very preliminary. They clearly reflect higher percentage of seropositivity among women who are at risk. But again, we have no idea what that -- what the percentage of actual women of child bearing age who are antibody positive in San Francisco and Los Angeles is going to come out to be. So that prevalence study is under way. Somewhere between ...

CHAIRMAN HART: Doctor, your comment was that the estimates vary from 4 percent to 10 percent of women who are ..

DR. WARA: Who are of child bearing age, and so are attending an obstetrics clinic. The reason that those percentages vary, we believe, is because of the group of women surveyed. In other words, if one carries out this survey at the San Francisco General Hospital among a high risk population, then the percentage of women who are seropositive is probably going to be higher than among middle class, upper middle class private hospital in Los Angeles.

And so until we have a better assessment of the percentage of women who are seropositive and are of child bearing age, it's difficult to extrapolate and to give you a prediction of the number of children who will be born in this State with AIDS. That's the reason for needing decent studies of seropositivity among women of child bearing age. At least a reason, not the only reason.

_____ takes the women who are seropositive, one has to know how many infants born to this group of women will actually develop AIDS. And those numbers vary, too. The highest number is 35 percent and that number is derived from a study in Florida, in which infants born to mothers who had previously had an infected child, who were looked at -- were looked at prospectively and marked as to whether they developed AIDS or not. The flaw in that study, from my point of view and most pediatric immunologists point of

view, is that women who give birth once to a child with AIDS may, for a reason that we don't yet know, have a higher risk of transmitting HIV to their fetuses and their babies. And so that number may be falsely skewed in an upwards direction.

Our own estimate, which is a reflection of a study which we just began about 18 months ago, is that the percentage of infants born to antibody positive women will be around 20 percent rather than 33 percent that's previously been reported.

MS. KATHRYN DUKE: I'm sorry. We heard Dr. Grossman speaking this morning and I think he was giving us some slightly different estimates.

CHAIRMAN HART: Substantially different estimates.

MS. DUKE: Higher.

CHAIRMAN HART: Saying 60 percent, 40 percent, roughly 50 percent is the average.

DR. WARA: It's hard for me to contradict Dr. Grossman because he's an associate of mine. On the other hand, the study that's being carried out is one that I'm directly responsible for. So I don't know where Dr. Grossman derived his data. I can tell you that the original Florida data, 33 1/3 percent, precisely 1/3 of infants born to a group of antibody positive women who had previously given birth to infected children, other subsequent children, 1/3 eventually developed AIDS. And from a biological interest though, which is perhaps very important in terms of prevalence, there were normal pregnancies interspersed.

In other words, a mother could transmit HIV to one baby, and then have one or two babies which were completely normal, and then have another baby who eventually developed AIDS. So there's something about the process of pregnancy, the biology of pregnancy that has to do with transmission of the virus that we don't yet understand.

And again, in our own study which is about now -- exactly 18 months on -- approximately 20 percent of infants born to HIV positive women have -- are infected with the HIV virus.

CHAIRMAN HART: Could you -- I didn't have a chance to show my ignorance with Dr. Grossman today. Maybe you can help me with this one. If I recall Dr. Grossman's comments, he was saying that when a baby is born, you're not able to tell whether or not they indeed have the AIDS virus and sometimes it takes years -- or no, I think he said eight or nine months before you can actually -- if you wanted to give a test. Could you explain that to me? Why is it that when a baby is born, it has something to do with these antibodies? And I don't understand that very well.

DR. WARA: Well, the way we test -- the way we screen for AIDS, both in California and nationally, is to look for antibody -- to the HIV virus. And we do that in a screening method by using ELISA and then we confirm that by Western Blot and immunofluorescence. Since this antibody that we're looking for crosses the placenta, so

passes from the mother to the baby at about 32 weeks gestation, the baby is born with an antibody repertoire, a library, that reflects the mother's infection, not the baby's.

CHAIRMAN HART: So the antibodies that are there may not be in response to the virus being there. They're just passed from the mother?

DR. WARA: That's right. They're just passive. And so in the study that we're doing right now, we're looking and following prospectively babies and mothers -- babies who were born to mothers who are antibody positive. And in the case of this particular study, the mothers are all intravenous drug users. We're studying these babies from the time they're born, out through two years of age. And what we're finding is what we actually predicted, and that is that about 80 percent of the babies, who initially are antibody positive because their moms are positive, lose that antibody positivity. But that's the reason why one can't tell.

The Academy of Pediatrics has issued a guideline, and the CDC has an identical guideline, that we should not use antibody positivity in infants as a criteria for diagnosing AIDS until a child is 15 months old, because that's when they lose their maternal antibody. There's an alternative method, though. It's an expensive method. It's one that we're using in this particular study. The method we're using is to identify the virus. So Jay Levy is looking at lymphocytes from all of these children, every three months, to detect actual virus in their system. And once we find virus, that implies infection. That's what the infection is all about. Antibody is a response to that virus. And that's where my 20 percent figure comes from. It comes from identification of the virus in these babies and/or following them out to age 15 months and finding that they've lost their antibody and we can't find virus. That means to me that they're not infected. We may have to wait longer before I can say that with as much satisfaction as I'd like.

Okay, I wanted to give you some sense of the increasing magnitude of the problem that's facing us in San Francisco. Last year at Moffitt Hospital at UCSF, we had two infants who died of pediatric AIDS and four who were identified as antibody positive. And this is a fairly large referral population. We see children from all over Northern California. The boundary for the referral base is usually estimated north of Santa Barbara. Children south of Santa Barbara are referred to major medical centers of Los Angeles.

This year, since July 1st, we've had six infants who have died, and these infants that either I or my associates had personally cared for, and 22 who have been identified as antibody positive and infected. That's clearly more than a doubling of this patient population. 2 to 6 and 4 to 22 is very worrisome to those of us who practice pediatrics in Northern California. I think that this increase in the patient population reflects

both an increase in patient numbers -- a real increase, but also an increase in the referring position of awareness. That is, as pediatricians in Northern California learn more about what the clinical landmarks are for pediatric AIDS, they're referring these children and so we're seeing them and we're diagnosing them. But I don't think that number necessarily reflects an enormous increase in -- it's a significant increase, but not as large as the numbers look in the pediatrics AIDS population in Northern California.

CHAIRMAN HART: Doctor, if you identify an infant that has the HIV virus, is there a greater or lesser likelihood that they will develop full blown AIDS? In an adult, is the time period from -- is a time period from which they are first identified as having the virus to getting the disease greater or lesser than it would be for an adult?

DR. WARA: Well, our group was one of the first that thought that the time period was shorter for infants. In other words, a newborn who was infected, we thought had an incubation period of around 8 or 9 months then. And the published data and our information agrees, is that well over half of these babies had died by the time they were 14 months old. And we thought that that reflected infection in utero. In other words, these babies were being infected while they were fetuses. Their immune systems were less mature and so the whole disease syndrome is squashed together, if you will.

What's a little bothersome about that, and what I do not understand, is why the incubation period for blood transfusion induced AIDS in these children is so long. The blood transfusions that these children are receiving are almost all during the first week of life, so their immune systems are still very immature. And I would have anticipated biologically that they would have gotten sick within a couple of years. And in fact, we thought we were coming out of the woods. And now we're seeing, as I said, significant numbers of 5, 6, 7 year old children who received their contaminated blood transfusions during the first week of life. And that's worrisome.

And so I don't know the answer to your question, is what I'm saying. Until this recent event, I could state with some -- being reasonably assured that the incubation period was much less, much shorter in children. I now know that it's not for all children.

There's specific problems unique to children with AIDS, which I feel strongly have to be addressed before we are found or faced with a caring of large numbers of these patients. San Francisco has, as you have heard all day today, been at the forefront of taking care of and providing not only medically humane care, but financially responsible care for adults with AIDS. And I hope we're not going to see enormously increased numbers of children with AIDS. But those of us working in San Francisco and Los Angeles think that we are. And we'd like to be able to say the same thing in 3 or 4 years about

the care that we're able to provide for these kids.

So there are a number of things that are unique to children, that I want to point out to you, because they're very different from adults. First, the confidentiality law, very worrisome to pediatricians. We feel, and this is a fairly unanimous feeling, that the State law was designed -- and I'm going to read this because it's important that the wording be correct -- "to maintain confidentiality of antibody status for adults", okay? You need to understand that parents may refuse testing for their infants because of implications to themselves. That makes sense. That is, an antibody positive newborn implies that the mother is antibody positive. So that's the first -- the first piece of this.

The second, and I think more, or at least equally important piece, is that children are not of an age to be responsible for their own medical care. They're not consenting adults. And in other circumstances, if as a physician, I disagree strongly with a parent's decision regarding the medical care for their child, I go to court about that. For instance, if a Jehovah Witness refuses a blood transfusion for a child, and if that child doesn't get the blood transfusion, the child could die, then I go to court and I get a court order to give that blood transfusion because the child is not making the decision, and in our society the parents -- a parent does not have the right to contribute to the medical demise of their child.

I think the same thing is happening within this with AIDS. It's important, as a pediatrician, that I know whether a child is antibody positive or not, because it impacts significantly on the kind of care that's necessary for that child. If the child is antibody positive and has AIDS, then the child should receive special treatment for possible pneumocystis, for instance.

There are also other medical precautions that should be taken, and therefore, at least I personally recommend that the existing law be changed to allow testing of children without parental permission, but following their notification.

I also feel that a child's antibody status should be given to those with a need to know, such as the private pediatrician -- and this is reiterating what others have said today -- such as the private pediatrician. Basically the law needs to be changed, at least with regards to children.

Next issue. I think that we need to prepare to provide multi-disciplinary care for children with AIDS. And we have in this State, California Children's Service, which is a superb organization. California Children's Service, or CCS, have available models for multi-disciplinary services for other diseases such as spina bifida, neurological diseases, rheumatologic disorders. Pediatric AIDS group, in other words, physicians and nurses and paramedical personnel who are going to take care of these children, require

input from an immunologist, someone who is educated in infectious disease, and finally neurology, because I have to point out to you that when infants are infected early on in life, they have HIV infection of their brain at the time that their brain is growing. Therefore, the percentage of children that we're seeing with severe neurological impediment, that is delay in development, exceeds 50 percent at the time that we document that they're antibody positive and are infected. So help from a neurologist, a developmental neurologist is important in the care of these children.

In addition, we clearly need psychosocial input to help with family and financial support. And we need to resolve school placement, and I'll get to that in fact next. Children with AIDS -- and this is the viewpoint of both the Academy and the Center for Disease Control -- who are healthy should go to school. It's just that simple. If they're healthy, if they're neurologically capable, they should be in school. Placement should be confidential. At least as confidential as possible. Children should be placed in small classrooms, so that they are not exposed to large numbers of other children with infectious disease. Others have made the same point today, that we want to protect the individual with AIDS. I want to protect the child with AIDS and so I would prefer to have a child with AIDS in a classroom with 20 children rather than a classroom with 40. The teachers of those classrooms have to have input from individuals representing the child's medical needs, their psychosocial needs in the school system. And it would be advantageous to have school admission policies for children in place in large cities throughout California before (underlined) a child of school age needs school placement. We found in San Francisco -- and Dr. Grossman chairs the Mayor's Task Force on Pediatric AIDS, and I'm a member of that Task Force -- we found it extraordinarily efficient, and I feel we've provided good care and good placement for our children, to have had our school policy, in place, one year before we were confronted with a child of school age with AIDS. We really bypassed community hysteria, because we didn't have to, we didn't have to deal with an event as it happened. We had things planned.

Because they're planned in the city and they're working well, I would encourage school systems throughout the State to use the educational resources in this city, at least to find out how we've done it, how it works, how we meet and decide where a child should be placed. It's worked well. We haven't had any hullabaloo in the media at all.

Okay, an additional problem of concern to pediatricians caring for children with AIDS on the West Coast is the lack of designated treatment trial centers for children. This is very, it's important to us. It's more important to children and their families. To date, our patients and their families have had to move to Bethesda, Maryland for long periods of time, up to two to three months, in order to participate in antiviral trials. That is, all AZT administered to children under age 13 years has been given at Bethesda.

As new antivirals become available, it's certainly my strong feeling and I'd love to have the support of other individuals, that pediatric treatment areas have got to be established on the West Coast, at least one and preferably two, one in Northern California and one in Southern California. The current state of events is unacceptable because many families are unable to participate in these trials. They don't have the psychosocial support or the money to move to Bethesda, Maryland for two to three months. And therefore, _____ experimental _____ deny their children and that's just plain wrong. Therefore, West Coast treatment centers for experimental agents really need to be established, and they need to be established now, before our numbers of patients escalate.

Finally, as a pediatrician and again representing the Academy, I'm concerned about the education of our adolescents. And I haven't heard that mentioned yet this afternoon. I feel strongly that a suggested core curriculum concerning transmission of HIV should be developed at the State level and be made available to all school districts. I also feel strongly that the recommended age for initiation of education should come down from the State level. We have recommendations in San Francisco, but they're not necessarily the recommendations in Alameda County or anywhere else throughout the State. The recommended age level in San Francisco is 5th grade. And there is a core curriculum. It's small, it's too brief, but at least it's in place in San Francisco. And as a pediatrician I have to emphasize education, especially education of adolescents.

In sum, I think we have the opportunity to have in place a medical and psychosocial framework within which to care for children with AIDS in California before our patient population grows any larger. But we really have to do these things now instead of waiting until we're faced with 50 children in a hospital, which is what's going on in the East Coast.

So I thank you very much for asking me to testify. Any questions?

CHAIRMAN HART: Thank you, Doctor. We appreciate your willingness to come and share your concerns with us. A couple of questions I had. In your comments about the San Francisco placement of children in the school system, we heard again briefly about this morning, and you said it's important to have this in place so you can avoid some of the community hysteria. As I understood the way it works here in San Francisco, I mean, you just set up a committee and the committee decides. Is it something more than that? It seems to me that the way it was described, it's really key, who is on that committee. What would you like to see take place in Santa Barbara and Laguna Beach and Escondido?

DR. WARA: Well, what happened here was that Mayor Feinstein asked Dr. Grossman to chair a committee to look at all issues surrounding mothers and infants with AIDS. And that committee first met, to the best of my recollection, about 18 months ago. One of

the recommendations that came out of that committee is that any child of school age in the city with AIDS would be placed, and they would be placed by a group which consisted of the child's pediatrician. If that pediatrician was someone who was considered an expert in the care of children with AIDS, then no additional physician needed to be present. Otherwise, the recommendation was made that an additional physician be present who had some expertise in caring for children with AIDS. The third person that is always present is the head of the school system for that age. In other words, if we're placing someone in the 2nd grade, then the superintendent for the lower schools is present. If it's the middle school, then it's the superintendent for the middle schools. Finally, we have a representative of social services who is always present at these meetings and is extraordinarily useful in terms of input to how we can optimize the child's environment in other ways. So this group meets and discusses the individual child and looks at available educational opportunities for that child. For instance, if the child is a biter, if they bite, it's inappropriate that they go to school and so they need a home teacher. If they need a home teacher, that home teacher has to be willing, in some cases, to go into the housing project that the child lives in. In some cases, that's not possible. The school can't imagine recruiting a teacher to go into the housing project. And so one of the jobs is to change where the child lives. It's a very squirrely route to get to where the child can go to school.

CHAIRMAN HART: Help me a little bit. Why can't you find someone to go into the housing project? Safety of the person?

DR. WARA: Now, I've asked that. Yes, safety of the person. I asked that exact question and I was told safety of the person. I was told that among the teachers who provide at-home education, it is unusual to force a teacher to educate a student. Rather, there's sort of, again, a meeting between the requirements for the student and what the teachers would like to do, and that some of the housing projects in San Francisco in fact are probably not safe for teachers to go into.

Now, the reason I think that this group works well is that the Mayor endorsed it, the Board of Education endorsed the concept, and all of this happened before the issue was ever an issue. So it happened before we were asked to place a child.

CHAIRMAN HART: I guess, you know, there's a thousand school districts in the State, and San Francisco, having the first wave of cases, it might be appropriate, quite appropriate to set that up here, but in every other community in the State at this point when there are very few cases, I'm not sure that's going to work.

DR. WARA: Well, I certainly think it's appropriate in Los Angeles. I can tell you that this summer when I had a child was referred to me from Northern California, in order to get that child into school, it took two days of my time, flying up to the community in

Northern California to meet with the school board. I can do that to a limited extent. But it can't go on forever. And I would like to see communities address this issue ahead of time instead of at a time when it becomes an emergency. And there is something unique about this.

CHAIRMAN HART: I had one other question. Again, we heard this morning and I'd be interested in your comments about foster parent care. If you have a situation where the mother of an AIDS infant or child may be deceased or may be incapacitated or whatever, the issue of taking care of these children, could you -- you didn't comment on that at all, and I'd be interested if you have any comments.

DR. WARA: Sure. Placement of children who are known to have AIDS or who are known to have been born to a mother who is antibody positive is difficult. In the State of California, foster mothers who agree to take care of these children, as I understand it, are placed -- are paid a bonus. I'm not certain that that's a terribly good incentive. In our experience, we've had better success placing these children in groups with -- and this won't work indefinitely, by the way -- but with women who are particularly interested in taking care of children with special diseases, special problems. For instance, there is a woman's monastery up north of Mendocino where three of our patients are being cared for. It's a particularly unusual group of women who elected to provide foster care for infants with AIDS. I don't think we're going to find very many groups like this, but if they're around, it's certainly a wonderful opportunity for these children to grow up in as near normal an environment as they can.

I guess one issue is finding foster parents.

Another issue is that foster parents properly wish to know the antibody status of the babies that they're going to take care of. That gets back to the law again. Though if the infant is given up, then you can get a State order -- a court order rather -- to test the baby.

The final issue is assuring that infants who go into foster care situations have ongoing medical care. And sometimes that's difficult. For instance, it's difficult for us to see on a continuing manner the babies who are living north of Mendocino. Yet the balance is proper. Their situation is better there than it would be in San Francisco in a large foster care setting.

Are there any specific questions, though, of the foster care issue?

CHAIRMAN HART: Well, I guess the issue of reimbursement was one, and you commented that the business of some kind of bonus ...

DR. WARA: I think you have to pay. I'm not sure it's always going to work. That's the -- it'd be nice if I could say that it would always work because I frankly think that would be the easiest, in the long run, the least expensive route of keeping these kids

out of the hospitals. Visiting the pediatric AIDS wards in New York it's really a terrifying experience. There are boarder babies in those hospitals who are there only because they cannot find foster families to take care of them. And that's the kind of thing you need to prevent in California.

CHAIRMAN HART: Thank you very much.

DR. WARA: Thank you.

Our next witness is Constance Little, Executive Director of Visiting Nurse Association of San Mateo; Member, Board of Directors, California Association for Health Services at Home.

MS. CONSTANCE LITTLE: I'd like to be the eleventh person to thank you for the chance to testify, and also thank the foregoing speakers for giving my testimony. However, I am here representing California Association for Health Services at Home and we have member agencies of over 200 health home agencies across the State. I'm primarily directing my remarks toward the AIDS patients who are covered by the State and MediCal program.

Theoretically, AIDS MediCal patients qualify for the same full range of home health services as patients with other payment sources. Nursing, physical, occupational and speech therapies, home health aide and social work can be provided in the patient's home.

In reality, because of the low MediCal reimbursement rate and higher cost because AIDS patients take more time per visit, AIDS patients on MediCal have less access to needed care.

As AIDS patients survive longer, they are far more likely to do so in poverty. In San Mateo County, our first AIDS home care patients had good comprehensive health care coverage. Now the patients that we get with AIDS are more ill, more frequently on MediCal, and in need of more services.

An especially needed service is attendant care. Personal care attendants are often the crucial link in maintaining a terminal AIDS patient at home. While it may be possible to get a few hours of chore service a week, if the need is for 24 hour or even 8 hour/day care service, the service is just not available. One exception to this, and an encouraging one that has been mentioned, is the demonstration project for home care for AIDS patients that's through the Department of Health Services. And we do have that demonstration project in San Mateo County. It's providing a very valuable service.

There's no coverage for dietary counseling, which is a major need of gravely ill patients. Social worker visits that are crucial to help the AIDS patient and caregiver locate other needed services is rarely authorized.

Further, care is concentrated among voluntary agencies such as Visiting Nurse Association, so that nonprofits may be subsidizing care that should be cared for by the State. Access is also limited by the MediCal system itself, which requires prior

authorization and is rarely authorized at the needed frequency.

In short, there is no coherent, organized home care system for AIDS MediCal patients.

A patient of the San Mateo VNA who suffers from AIDS needs intravenous fluids to avoid becoming dehydrated. He is very ill and suffers from debilitating fluid loss. His caregiver works 2 jobs and cannot be available so that I.V. fluids may be given. It may be necessary to hospitalize this patient for I.V.'s because he's a MediCal patient and can't get enough care at home.

MediCal is not even penny-wise and certainly pound-foolish to limit home care -- a humane and infinitely less expensive alternative to hospitalization for AIDS patients.

Thank you.

CHAIRMAN HART: Could have asked this of a number of the witnesses. I don't know if you're in a position to respond, and I'm someone who is chairing this committee that does not have a great deal of expertise in the health care area. You're mentioning penny-wise and pound-foolish. Why is it that the medical bureaucracy does not respond to these kinds of concerns and have the network and the reimbursement for home care, variety of ways?

MS. LITTLE: Well, I think our current MediCal system traces back to the reforms that Reagan did as Governor here, reorganized and quote, "improved" the system. But what the State tries to do is limit their expenditure in that area, and they limit it by limiting what they will pay. And whatever your costs are to provide the service, the State will pay you less. And the less gets less each year. So I think that the -- as I say, theoretically, the service is there, in point of fact because the reimbursement rate is so low, the access is limited.

CHAIRMAN HART: The idea that if you don't take care of someone in their home you're going to have to take care of them in the hospital which is much more expensive. I guess the response is, well, they ultimately may be in the hospital, but if you provide this service in the home, there are going to be so many more people who will take advantage of it. Is that the point? Someone made reference earlier to woodworking, I guess, that families and friends, if the service can be provided for, then fewer friends and families are going to volunteer.

MS. LITTLE: That's never been our experience. Families and friends who are available do not abandon a patient because a hired professional can do the service. What in point happens is that most people would rather be at home if they could, in whatever circumstances. And the support that is given by the health care provider is just to underscore what is already being done by families and friends. And families and friends, I feel, want to care for their loved ones at home if they possibly can. And what they need is more help.

CHAIRMAN HART: Okay. Thank you.

Next witness is Ann Hughes, Acting Director of Coming Home Hospice.

Appreciate the witnesses who are coming on later here for their patience in getting to you.

MS. ANN HUGHES: Good afternoon. I think I'll probably no doubt will echo everyone's remarks previously. I represent not only the views of Coming Home Hospice, but also the AIDS Home Care and Hospice Program which is another part of the programs of Visiting Nurses and Hospice of San Francisco.

Really, since mid-1982, Visiting Nurses and Hospice of San Francisco have cared for more than 1200 persons with AIDS at home. Of these 1200 persons, 1000 have been cared for in the AIDS Home Care and Hospice Program. Of that 1000, 70 have resided at Coming Home Hospice.

Coming Home Hospice is a residential care facility we administer that opened in March of 1987. And in the short period of time since it opened, it's provided, I think, one more step in the continuum of services here, that I'm sure you've heard time and time again today.

I would like to spend a moment to talk about the home care, the AIDS Home Care and Hospice Program because those same services are provided at Coming Home Hospice. Just because the AIDS Home Care and Hospice Program is organized around the philosophy of care that is common to hospice care, it is based on a multi-disciplinary approach of care. And that, I'm sure, is another theme that's been recurrent today.

Nurses, social workers, attendants, volunteers, physicians, all provide much services to these clients and all are essentially needed. Nurses provide -- not only serving as case managers and coordinators of care, but they provide health monitoring. They provide education, as a previous speaker has identified. They may administer medications. They may, also then, be preparing the families and clients as they are near death.

Most of the clients in our program have died at home, 90 percent of that 1000 that I've spoken about. To a large extent, that's occurred because we have had for the last four years a large city contract that has allowed us to provide the needed attendant care, that the previous speaker's just alluded to. We can provide, depending on the reimbursement available, we can provide up to 24 hour care at home and that clearly has prevented institutionalization.

The instances where clients are hospitalized, for the most part, have to do with the client's ambivalence about their goals of care, that is they may choose that they want this particular infection treated aggressively and that cannot be managed at home. Or for other reasons, their symptoms cannot be managed at home. But for the most part people are able to stay at home.

Coming Home Hospice provides 24 hour care. It is staffed with attendants and

licensed vocational nurses 24 hours of the day. However, it's a very limited resource. It has 15 beds. And it clearly does not meet all of the needs. We have usually a very long waiting list.

I guess I would just like to make another remark about reimbursement or just echo what the other speakers have said because I think that's really a key here. We have 60 percent of the clients in our program are MediCal clients. Recently I think we've experienced some of the more stringent application of MediCal requirements in the refunding of home care and hospice services, and this is really a change, it seemed in the last few years, that we hadn't encountered before. And understandably, I think we can all respond to the need to have cost savings. But in this population, even one unnecessary day of hospital care could pay for 7 to 10 days of home care, and that's providing attendant care, nursing, social work, and all the other support. So I think it's really an essential cost-saving measure to reimburse home care and hospice services.

The other component that we have identified is the need, certainly with chronically and terminally ill patients with AIDS, the need for 24 hour nurse availability, on-call service. I think this service is another aspect of the program that really prevents unnecessary hospitalizations. If a nurse is able to make a visit at 3:00 in the morning to deal with a symptom, this sort of intervention can prevent an emergency room visit and an unnecessary hospitalization.

The other topic that I was asked to address was, to what extent has our program provided training for other home care and hospice providers around the State? And the final topic was, to what degree was our program importable to other areas in the State? The training efforts that we've undertaken of visiting nurses and hospice have included the development of a training manual that was funded in part by the Robert Wood Johnson Foundation, but also by Caremark of America. This 200 page training manual has been distributed to over 140 persons within the State, from as far north as Redding and in the south to San Diego. The manual provides a lot of educational resources in training methods for providers around the State. We've also participated in a variety of advisory boards and committees.

And we've had probably about 100 visitors to the program and to Coming Home Hospice. You're all invited to visit any of the clients we serve in the Home or Coming Home Hospice. I think it provides a real understanding of what the needs of clients are.

Finally, with regard to the issue of to what degree we can sort of export our multi-disciplinary team. I think the team concept is essential. And as the previous speaker has alluded, all of the services provided are really critical in keeping someone out of the hospital and providing cost effective care.

In light of that I think that certainly, as I'm sure has been echoed throughout the

day, there are other models and other patient populations that really give us a lot of information of similar needs and similar service plans that we can use in the state.

CHAIRMAN HART: Thank you very much.

MS. HUGHES: You're welcome.

CHAIRMAN HART: Next witness is Norm Nickens, J.D., AIDS Discrimination Representative, San Francisco Human Rights Commission.

MR. NICKENS: Good afternoon, Senator Hart, members of the committee. Again, I'm Norm Nickens from the San Francisco Human Rights Commission. I'm responsible for AIDS-related activities of the Commission.

The Commission has been involved in AIDS-related activities almost since the beginning of the epidemic in San Francisco. The first patients with AIDS were diagnosed in San Francisco in the summer of 1981. The Commission received our first complaint of AIDS-based discrimination in the summer of 1982; in '82-'83 we investigated two complaints of the AIDS-based discrimination; in '83-'84 we investigated eight; in '84-'85 -- 20 complaints; in '85-'86 -- 65; for '86-'87 we're estimating over 100 complaints of AIDS-based discrimination.

Traditionally, the Commission has been involved in complaints involving race and sex discrimination. AIDS has some similarity and some dissimilarity as to race and sex discrimination. The similarity is that we look at people with AIDS in the United States and 45,000 people have been diagnosed with AIDS. If you break those figures down a little bit: 25 percent of people with AIDS in the United States are Black; 14 percent are Latino; 2 percent are Asian, Native American and other minority. Breaking these figures down a little more with the women with AIDS: 56 percent are Black; 20 percent Latino.

You've heard some discussion of AIDS in pediatric cases. Of AIDS in pediatric cases below the age of 13, over 80 percent are Black or Latino. In AIDS cases among school mates in correctional facilities, over 80 percent are Black or Latino.

At the same time, there's a dissimilarity amongst AIDS cases in that the average life span for a person with AIDS in San Francisco, from the time of diagnosis to the time of death is approximately 13 months. There is a time urgency in these cases, such that we can't handle them in the same way as race and sex cases. AIDS has had a disproportionate impact on minority communities, though. When we hear of someone being discriminated against on the basis of AIDS, when we hear of someone losing their job, losing their house, losing access to insurance or medical care, or when we hear of lack of facilities for children with AIDS-pediatric cases, remember that there may be another element involved as well.

Just in summarizing the legal environment realm of discrimination against people with

AIDS. At the federal level, the Rehabilitation Act of '73 provides some limited protections to people with physical disabilities, including AIDS. We have Secretary Bowen, the Director of Health and Human Services, who recently stated that anti-discrimination protections for people with AIDS are a state and local concern. Given the fact that his agency is the federal agency responsible for federal protections, I think that sums up the federal commitment to enforcing anti-discrimination protections.

At the state level, approximately 43 states have statutes that prohibit discrimination on basis of disability. California has a statute that seems to offer some protection. Again, enforcement is minimal to nonexistent. I'll give you a typical case. The first case to work its way through the entire system, Chadbourne vs. Raytheon Corporation. It involved an individual who had AIDS, who filed a complaint through the Department of Fair Employment and Housing in April of 1984. The individual who filed the complaint died in January of 1985. The Department issued a preliminary ruling in June of 1986 stating that they did not have jurisdiction. The Commission issued their ruling in February of 1987, stating they did have jurisdiction, more than 2 1/2 years after the individual involved had died.

A more recent example, I had an individual who came into my office two weeks ago. He was referred to me by the Oakland Office of the Department of Fair Employment and Housing. And I asked him why did he come to my office. We have no jurisdiction over matters that happen outside the City and County of San Francisco. He said, well, I tried filing with the State Department of Fair Employment and Housing. But I went in and I started explaining my case to the intake worker. And she said, well, I'm real glad you have ARC and not AIDS. If you had AIDS, I'd be afraid to handle this complaint. He said, well, don't you have jurisdiction over AIDS complaints. She said, we do, but I'm afraid of people who have AIDS. I'd be afraid to sit here and handle the paper work. That's why I'm glad you have ARC. He explained to her what ARC meant and that was the end of the intake. They referred him to my office.

To give you an idea of the type of cases we see in San Francisco ...

CHAIRMAN HART: Hold it, just -- this is with the State Commission?

MR. NICKENS: This is the State Department of Fair Employment and Housing.

CHAIRMAN HART: State Department. And when you -- this happened two weeks ago when you had this kind of information, will you ...?

MR. NICKENS: We will be in contact with the local office. Again, the problem is enforcement. There are very few, if any people, in the State Department of Fair Employment and Housing who have been trained to handle AIDS discrimination complaints. And those complaints are simply lost in their caseload.

CHAIRMAN HART: What percentage of the cases do the state agency get that are AIDS?

Is it a very small percentage?

MR. NICKENS: Very, very small because it's my understanding people are hesitant to go in there even to bother to file a complaint. That complaint will never see the light of day. I would suggest if you ask them what is their average length of time for investigating a complaint, the figure we've heard tossed around is about 2 years. And given the average life span of people with AIDS, that tells you something about their problems.

To give you an idea of the type of cases that we see in San Francisco, a sample case, I had a woman who came into my office last summer. Her husband was hospitalized on Saturday and he was diagnosed with AIDS on the following Saturday. She went into work the first thing Monday morning to notify her employer that her husband had AIDS and that she would need time off to visit him in the hospital and take care of her family. The employer's response was, "I want you to have an HIV antibody test and bring me the results. I want you to be tested every 6 months for the next 5 years and bring me the results. Get off the property while you're thinking about it, and if it's not acceptable, you're fired." It was his immediate response. She came into my office and I spent about 2 hours calming her down. And I contacted the employer who yelled at me on the phone for 5 minutes saying we had no right to tell him what he could do with his employees. I politely asked him the name of his law firm, got a hold of them and read them the riot act, citing the Rehabilitation Act of '73. The employer is a federal contractor also covered under local AIDS ordinance of San Francisco.

San Francisco has an ordinance that was adopted in December of 1985, as a result of lack of enforcement at the federal and state levels. San Francisco, as some other California municipalities, has adopted a local ordinance that specifically prohibits discrimination against people with AIDS, AIDS-related conditions and those perceived to have AIDS or AIDS-related conditions.

We were able to resolve this complaint under our ordinance. The resolution in this case consisted of working out a "reasonable accommodation" arrangement. The "reasonable accommodation" being the employee was allowed to visit her husband in the hospital and not lose her job. It sounds simple. It took us two weeks to negotiate with this employer.

In San Francisco we have seen a steady increase in AIDS-related employment discrimination complaints from 1982 to 1987. Beginning about, I'd say, early 1987, we started seeing a decline in AIDS-related discrimination complaints in San Francisco. We've seen a slight increase in complaints against health care providers in medical facilities, but we're still seeing a decline in employment-related discrimination complaints. And we attribute that to a number of things:

(1) the past enforcement efforts by the Commission and other groups in San Francisco, under the San Francisco ordinance, and

(2) education in the work place, in regard to AIDS and AIDS-related conditions.

A number of large employers in the Bay Area, including Wells Fargo, Bank of America, Levi Strauss, Crocker, etc., have adopted AIDS in the workplace policies and treat AIDS like any other long-term or catastrophic illness, and a number of these companies have instituted specific AIDS in the workplace training policies.

As a result of that, we've seen a decline in AIDS-related employee complaints against large employers. The bulk of the employment complaints that we're handling now are against smaller employers with 25 employees or less.

So education does work and the ordinances do work. And the ordinances, the local ordinances do more than just protect the civil rights of people with AIDS. The San Francisco Anti-discrimination Ordinance is an essential part in the City's AIDS education prevention strategy. Without adequate, enforceable anti-discrimination protections, and confidentiality protections, individuals with AIDS or at risk for AIDS would be hesitant to take the steps they need to take to protect their health and the health of others.

One last example. I had an individual recently who asked his employer for time off to go to one of the city's anonymous test facilities to be tested. He was concerned about his health. He had taken the advice that he had gotten from the Department of Public Health, going in and being tested. The employer said, sure, no problem, take the afternoon off. He went in, he was tested, and came back to work. And the employer said, well, what were your results? The employee responded: Well, first of all, I was tested today and won't get the results until later, and second, I don't think that's information that I should give to you. He was fired on the spot. That's exactly what our ordinance is designed to prevent. We were able to resolve that complaint and the individual received a settlement check last week.

CHAIRMAN HART: That's not bad. Thank you. When you're dealing with employers, can you generalize about what you feel are the reasons for taking action against employees? Is it personal fear that they're going to get the disease? Is it primarily concern that their workers are not going to be able to do their job? Is it fear that there's going to be hysteria among the other workers in productivity? In other words, is it more productivity or is it health-related concerns or is it just meanness?

MR. NICKENS: I've seen all three, but to generalize, we treat every problem as if it were -- every case that comes to us as if it were an education problem. Very often there is misinformation and apprehension about transmissibility of AIDS. The case I cited of the individual who was requested to have an HIV test, she was involved in clerical position. And when we sat down and spoke to the employer, I asked him why he had asked for an HIV test. He said, well, she's in a clerical position and other people use her

typewriter, other people use her calculator, other people use the same drinking fountain, other people use the same doorknobs. We were able to educate that particular employer about AIDS and how AIDS is transmissible and how it is not transmissible. He was also concerned about the reaction of other employees. We spoke to the other employees and they were concerned. They were concerned that one of their fellow employees had a husband who had a long-term chronic, possibly fatal illness, and they wanted to know how they could be supportive. They were not concerned in the way that the employer automatically assumed that they would be concerned.

I think education is a problem, and we encourage employers to go in and do the education before they have the need to. Doing the education after you've had something happen in the workplace is not the most appropriate and not the best time to do education. It should be done before anything happens, before an individual comes down with AIDS or has a relative or family member who has AIDS.

I certainly have to say also that we have seen classic examples of discrimination where individuals have been discriminated against solely on the basis of the fact that their antibody status or perception of their antibody status can only be compared to other forms of discrimination.

CHAIRMAN HART: Thank you very much.

We have a sign-in sheet here and some people may have signed in just to be present. Other people signed in and want to testify. Is there anyone here who would like to testify at this point in time?

MS. CHRISTINE CAHILL: Senator, I'm Chris Cahill from Seton Medical Center and I testified earlier on use of body fluid precautions of health care workers. I work for an acute care center that has a skilled nursing component, and I have been doing some consulting on freestanding skilled nursing facilities. And there's two problems that are identified with the skilled nursing facilities:

- (1) the lack of trained infection controlled practitioners to implement body fluid precautions, and
- (2) lack of money to buy the sufficient protective devices that these health care facilities -- or skilled nursing facilities need.

When you consider that a patient who is incontinent of urine and feces, who's 80 years old and who may have had blood transfusions prior to being admitted to a facility may utilize one box of gloves, which is 100 gloves of which 50 -- of which would -- 50 times of caring for that patient, you'd use -- you could do 50 times, the box of gloves costs \$12 a piece, and if you have a facility that had 100 skilled nursing patients, of which maybe 80 percent of them are incontinent, and you times that, you know, 12 times 80 a day, that could add up to a lot of money. And so one of the most frequent problems

that had been addressed to me is that we just don't have the money to implement that precaution.

CHAIRMAN HART: Thank you, Miss Cahill.

That concludes our hearing and I want to thank everyone who testified. Once again we will be reviewing the testimony and based upon this review, we're optimistic that legislation will be introduced as a result of this hearing. It will take many different forms, and that will occur when the Legislature reconvenes in January. With that, this committee stands in adjournment.

