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Interim Hearing on "AIDS: Implications for Health, Treatment and Long-Term Care"

Senate Committee on Health and Human Services

CALIFORNIA LEGISLATURE

SENATE COMMITTEE ON
HEALTH AND HUMAN SERVICES

SENATOR DIANE WATSON, CHAIRPERSON

Interim hearing on

"AIDS: Implications for Health, Treatment and Long-Term Care"

STATE OFFICE BUILDING
AUDITORIUM, ROOM 1138
107 SOUTH BROADWAY
LOS ANGELES, CALIFORNIA
MONDAY, DECEMBER 16, 1985
1:00 P.M.

HEARING

SENATE COMMITTEE

on

HEALTH AND HUMAN SERVICES

In the Matter of:

"AIDS: Implications for Health, Treatment and Long-Term Care"

STATE OFFICE BUILDING

AUDITORIUM, ROOM 1138

107 SOUTH BROADWAY

LOS ANGELES, CALIFORNIA

Monday, December 16, 1985

1:00 P.M.

COMMITTEE ADDRESS

STATE CAPITOL
ROOM 2191
(916) 445-5965

CONSULTANTS

JIM LOTT
JANE UITTI
JOYCE ISERI
JOHN MILLER

GERI LADUKE
COMMITTEE SECRETARY

California Legislature

Senate Committee

on

Health and Human Services

"AIDS: Implications for Health, Treatment and Long-Term Care"

107 S. Broadway
Auditorium
Room 1138
Los Angeles
1:00 pm - 4:00 pm

December 16, 1985

A G E N D A

Cliff Morrison	California Hospital Association
Anthony J. Abbate	Hospital Council of Southern California
Leslie Dutton	American Association of Women Voters
Robert Lindsay	California School Boards Association
Carolyn S. Harris	Inland Counties Health Systems Agency
Paul Bonebery	Mobilization Against AIDS
Dean A. Doolittle-Sandmire	People with AIDS Related Complex Caucus
Dave Gooding	Association of California Life Insurance Companies Task Force on AIDS
A.J. MacDonald	Wisdom Clubs of America
Donald G. Gorman	Documentation of AIDS Issues and Research Foundation, Inc.
Steve Russell	AIDS Related Complex/AIDS Vigil
Hal Frank, Ph.D.	San Diego AIDS Project
Porter Warren	Florence Nightingale Nursing Service Aid for AIDS Patients
Corinne Sanchez	El Proyecto Barrio, Inc., and Southern California Program Directors

OVER --

Margaret Kelly	Blue Cross of California
Sue Sedaka	The Visiting Nurse Association of Los Angeles, Inc.
G.W. Levi Kamel, Ph.D.	Hemophilia Council of California
Norma Watson, R.N.	Foreign Nurse Defense Fund

Individual Testimony:

Dr. Ross Eckert

MEMBERS PRESENT

Chairperson Diane Watson
Senator Paul Carpenter
Senator Herschel Rosenthal
Senator Dan McCorquodale

STAFF PRESENT

Jane Uitti, Consultant
Geri LaDuke, Committee Secretary
Ruth Liberman, Senate Fellow

PUBLIC

Cliff Morrison, California Hospital Association
Anthony J. Abbate, Hospital Council of Southern California
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Brent Barnhart, Blue Cross of California
Sue Sedaka, The Visiting Nurse Association of Los Angeles, Inc.

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CHAIRPERSON WATSON: Good afternoon.

I'd like to welcome all of you to the Senate Health and Human Service Hearing on AIDS, the long-term treatment issue.

We're meeting this afternoon to accomplish several objectives related to the spread of AIDS in the State of California. First, we will be getting an update from the providers, from managers, and service groups that are involved with AIDS patients on a day-to-day basis on the best way to care for patients who have this dreaded disease. Second, we'd like to get an understanding of the types of problems related to AIDS that face us by the end of 1985, four years after this deadly disease first became recognized as a separate diagnosable illness.

As of October 31st of this year, the Department of Health Services reported 3,378 cases of AIDS in the State of California. Of these, 1,438 have died. The statewide AIDS advisory committee estimates that there 16,800 persons in California with AIDS-Related conditions, and they expect this number to double to 33,000 by next July. They estimate the average cost of the care for an AIDS patient to be $114,000.

AIDS symptoms have so far been diagnosed in over 12,000 people in the United States alone, killing half of them. Government health officials predict a total of 40,000 AIDS cases nationwide by the end of 1986, with an increasing proportion ending in death.

The number of cases doubles, approximately, every

nine months. California's overall AIDS case fatality rate is slightly more than 41 percent. The corresponding national figure is 50 percent. However, according to the Senate Office of Research, the pattern of case fatality rates suggests that unless dramatic strides are made in the current state of scientific knowledge for a medical treatment for AIDS, almost everyone diagnosed as having the disease will die within several years of initial diagnosis.

Some of the issues we will be addressing are critical, centering around the best ways to prevent transmission of the disease among the public, in schools, and in health care settings. We will hear about the areas that need research, and we'll discuss implications of the laws protecting testing donated blood that we passed last year. Some of the problems we face are financial, including ways that the private and public sector pays for health care and supportive services.

Some of our problems are educational. We must make sure that the public knows how the disease is spread to the best of our knowledge, and just as importantly, how it is not likely to be spread so that we don't limit individual freedom without carefully considered public policy rationale based upon conclusive medical evidence.

We have a long and informative agenda this afternoon including presentations from hospitals, schools, health providers, AIDS outreach organizations, insurance companies, and groups concerned with preventing the spread of AIDS. The Department of Health Service is also with us today

to answer any clinical or problematic questions the Committee might have, or maybe people in the audience.

Of key importance to this Committee is whether the state is spending its limited resources in the best way to provide patient treatment and follow-up, public education, and public health prevention. We, as legislators, want to develop the best mix of public policy and public funding to put a stop to the growth of AIDS in California, and hope that by our actions, the rest of the country will be so informed.

So, I'm asking that those who are making--excuse me. Those who are making presentations be brief, try not to repeat if you can. We do have a long agenda. We will like to hear from everyone. My policy is to let everyone have the time allotted to speak, but please understand we're starting about 40 minutes late, and we want to hear from you, but try to make your comments brief.

I will first call on Cliff Morrison representing the California Hospital Association.

MR. MORRISON: Thank you, Senator Watson, for allowing me to come and do my presentation today.

My name is Cliff Morrison. I am assistant director of nursing at San Francisco General Hospital and AIDS coordinator in that facility. I established the first inpatient care unit for treatment of persons with AIDS in July of 1983 at San Francisco General Hospital.

I'm here today on behalf of the California Hospital Association, and I'm asked to talk about the hospital as

a treatment setting for persons with AIDS. The need for specialized programs for the treatment of persons with AIDS exist because of the complex set of issues surrounding the disease. These issues are complex because we have allowed them to be. We have been afraid to deal with the issues up front, and we're now paying for it.

AIDS is forcing issues to the surface that have been issues for probably two or three decades in health care. Some of those issues being patient's rights, education, involvment of patients in decision-making concerning their own care, and the right to life issues. Rather than resist it, we should be eager to take on this fight, to learn from it, because I think that it's important for us to realize that good things always come from bad.

AIDS is the Number 1 health priority in our country today, and it's been an issue now for approximately five years. We have been slow to catch on in dealing with the problems. As a patient said to me just recently, or actually a couple of years ago, "Do we have to wait until every family in America has been touched by AIDS before we do something about it?"

Well, in San Francisco, we're already dealing with that. We've reached a point in our city where almost everyone has been touched by AIDS is one way or another. Must we wait until the entire country reaches that point, meaning that everyone will be directly affected by AIDS because they will know someone, either a relative, a friend, a roommate, or a co-worker, but someone that each one of

knows directly will come down with AIDS, and at that point we will all be a lot more concerned. Must we wait until that time?

What are the issues that are causing so much difficulty for us to deal with AIDS? Some of the issues could be the illness itself, but after having five years' experience in dealing with it, we now know a lot about AIDS. We've isolated the virus, and we know how it's transmitted. We know that AIDS is a sexually transmitted disease, and we know that the general public and health care workers are not at risk for contracting the illness.

Other issues that are even more complex than the illness itself, are the issues of sexuality. We've all been educated and raised in a society that does not deal with issues around sexuality very well at all. We tend to talk about sex, but we joke about it. We never really deal with issues around sexuality in a very objective way. It's only been recently, over the past few years, that professional schools for health care providers have been including classes in sexuality in their curriculums.

Probably the biggest issue concerning care of the person with AIDS is the issues around death and dying. This is really the issue. We all, again, live in a society, and we're educated in a society that tends to deny death. We're very youth oriented, very materialistic society. I had a patient who said to me, about a year ago, "I am not as afraid of death as I am of what you will do to me in the process of dying."

Now, is the time for us to examine our feelings, and look at this hysteria.

Health care providers, as professionals, have an obligation and a commitment to be informed and to serve as role models within our institutions and within our communities. We cannot afford to be hysterical. Everyone else will be looking to us for leadership and guidance. We must know what we're doing.

It's important for us to look at how we can develop programs within our existing system, so that we don't actually reinvent the wheel. The most important aspect for us has to be planning. I personally consider myself a planner and an educator more than anything else. Without proper planning, we can't accomplish almost any--almost anything that we set out to do.

In the hospital and in the community, planning has to be the first step, and it must involve all levels within the community and the government itself. In the City of San Francisco, we've been very fortunate, because our city government has been extremely active. The mayor of San Francisco, from the beginning, has taken a very positive stand and has worked with San Francisco General, the Department of Public Health, and with the community to solve our problems.

Not to say that our program has not had problems, and not to say that our program is perfect. We do have some difficulties, but we are probably the best planned and best coordinated system anywhere in the United States

today. It's extremely important for us to coordinate our services, not to duplicate them. There are many agencies and organizations that are available in our communities to assist us, such as the California Hospital Association. They have the resources. They have expertise when it comes to planning and to coordination of services. We should utilize them.

It's important for us, whenever we're looking at planning, to look at coordination, and when we look at coordination we have to think about the fact that we actually have to cooperate with each other, and even more importantly than that, we have to communicate with each other.

An area that is just beginning to receive a lot of attention is the area of education. How else are we going to be able to deal with these complex set of issues? Education has to be a three-pronged situation. The first area has to be for patients themselves. Patients need to be educated about their illness. They need to be educated to the level that they can understand, and they need to be involved in their own care.

Education for health care providers: Education for health care providers in the past has not been done very well. In San Francisco General Hospital, we have actually done more education than any other hospital in the United States, and we've still had our problems. The reason why is that institutions are still having difficulty grasping the fact that educational programs have to planned,

coordinated and ongoing. You cannot do educational programs in a reactive manner. You cannot wait until you have your first AIDS patient. You cannot react to headlines in the newspaper. It is important to have well-planned and coordinated educational programs.

At San Francisco General, our program is a multi-disciplinary program. It is well-coordinated. Our patients are educated and they're involved in the decision-making around their illness. When they're admitted, and they're usually admitted into the inpatient area for an opportunistic infection, the treatment is patient centered. We strive to foster independence, rather than to make our patients dependent on us. That's a mistake that we've made for a long time in health care. We tend to make patients very dependent upon us.

Our goal is to get the patient out of the hospital as soon as possible and functioning at his highest level of wellness. The focus has to be on quality of life.

The Medical Special Care Unit at San Francisco General, which is the unit for AIDS known as 5B, is a 12-bed unit. We're in the process now of expanding that to a 20-bed unit. We have an average daily census at San Francisco General Hospital of 24 AIDS patients.

I don't advocate special programs for special groups. I never have. I advocate for good, quality health care for all people. When I was asked to coordinate and set up an inpatient unit at San Francisco General, I did so because I was in a situation to do that. I have always

felt, and I've always hoped that what we're doing now with our Medical Special Care Unit at San Francisco General is what we could be doing with all of our patients.

The reason why that program was set up and why it's a model program, is because these patients simply were not receiving the quality of care that they were entitled. We began to set up 5B, because we had a need to centralize our resources and to develop expertise. The Medical Special Care Unit is not so much an isolation unit as it is a specialized unit for care with the focus on the patient.

Physicians, nurses, counselors, social workers, and other volunteers focus on education and care. Discharge planning--the discharge planning effort begins immediately, even before the patient comes into the unit itself. The focus, again, is to get the patient out of the acute care setting as soon as possible. These patients do not want to be in the hospital. They will cooperate with us in getting out as soon as possible.

Acute care units in hospitals are needed to be the center of this process because we already have the experience, and we have the resources there to do proper discharge planning.

Leadership in institutions is extremely critical at this point in time. Administrative and management personnel in our institutions today, and particularly in California, must pull their heads out of the sand and deal with these issues up front.

We contact community agencies directly at San

Francisco. They come to us. They work with us in our discharge planning process.

Our focus, again, is on the quality of life for the individual, and we try not to reinforce guilt. We are not here to punish people. We are here to care for them. Our patients are terminally ill. They need our compassion, and they need our understanding. We are not to be biased, and we're not to be judgmental. That is not the role of a health care provider.

Because of our planning and because of our coordination, we are able to contain costs in our hospital. San Francisco General has the shortest length of stay for people with AIDS anywhere in the United States today. It's 11.4 days, as compared to 31 days elsewhere in the United States. It costs us approximately one-fourth as much to treat a patient with a diagnosis of AIDS at San Francisco General Hospital as it does in institutions elsewhere in the United States.

Our patients still live an average of 18 months after diagnosis in San Francisco. We are meeting the needs of the patients, and we are meeting the needs of the community, and we're providing a high level of quality care in the process. Our inpatient unit has been extremely successful because of the way we recruited our staff and because of the way that we have been able to retain them. The Medical Special Care Unit at San Francisco General Hospital has no attrition rate, meaning that the staff that is there has been there since the beginning, and they do not leave.

I was told two years ago that I would never be able to recruit them and never be able to keep them.

We treat mostly opportunistic infections as acute medical emergencies. Fifty percent of our patients that come into our unit have pneumocystis carinii pneumonia. The remainder come in with a combination of Kaposi's sarcoma with pneumocystis carinii pneumonia and other opportunistic infections. What we're beginning to see now are particularly neurological complications along with many of the other opportunistic infections.

5B is a model that could be used for any group of patients, and I hope that when we look at it that we can look at it carefully and from that standpoint, that we're not doing something special for one group.

We need to be able to maintain the level at which we are presently providing services in our institutions. In San Francisco that's going to be the major challenge for us over the next two to three years. We have to develop more resources in our community. Our community has been very responsive. Our agencies have been extremely responsive. We work very closely with agencies such as the AIDS Foundation which assists us tremendously in public education. We're very fortunate in San Francisco to have the Shanti Project which works very closely with our patients and the community to provide peer counseling and at the same time provide practical support and residence programs.

We're also very fortunate to have organizations such as Visiting Nurse Association and particularly Hospice

of San Francisco. It is imperative that we begin to look at these kinds of community services and to look at funding them more appropriately.

Volunteer programs have assisted us tremendously in San Francisco. Many of our volunteer programs are able to donate needed equipment to our outpatient department and to our inpatient unit. We do not get federal funds for our inpatient unit at San Francisco General Hospital, so we have to rely on local funds and what we can get from the community itself.

We need to develop more resources for skilled nursing care. We need to have more resources for hospice care.

Psychosocial support needs to be assessed at every level in the care of these patients.

In conclusion, I would like to say to you that I believe that AIDS is a test. I believe that it is a test for us as civilized people and as a society and particularly for those of us in health care. AIDS will test our ability to show compassion, our understanding, and above all our humanity. I believe that we will meet this challenge, and I hope that we will pass that test.

Thank you very much.

CHAIRPERSON WATSON: Thank you.

Mr. Morrison, you mentioned in your testimony that San Francisco County keeps patients in around 11.7 days as compared to--

MR. MORRISON: 11.4, yes, ma'am

CHAIRPERSON WATSON: 11.4. What--why? I mean, how is it that you're able to cut your time down when others have not been able to?

MR. MORRISON: Discharge planning. Coordinating services and discharge planning, multi-disciplinary approach to dealing with patients. From the moment that they come into our institution, we focus on including the patient in their own care. Educating the patient, letting the patient know from the beginning that the focus is going to be to get them out of the hospital and into the community, which is exactly where the patient wants to be.

It's a very humane way to treat someone. We can provide very high quality care in doing that, and we're meeting the needs both of the patient and the community, and maintaining cost at the same time.

CHAIRPERSON WATSON: Thank you.

MR. MORRISON: Thank you.

CHAIRPERSON WATSON: Appreciate that explanation.

Anthony J. Abbate with the Hospital Council of Southern California.

MR. ABBATE: Thank you.

Chairperson Watson, members of the Senate Committee on Health and Human Services, I am Anthony J. Abbate, senior vice-president of the Hospital Council of Southern California. I'm speaking today also in behalf of the California Hospital Association. I have with me Arthur Sponseller, our vice-president of Human Resources and staff specialist on AIDS and AIDS education.

My testimony will be directed specifically at the aspect of the impending AIDS crisis that involves the ability of the health care delivery system to manage the patient care needs that will confront it. I will be speaking to three specific aspects of our concern: Number 1, the education of health care workers regarding AIDs; Number 2, adequate funding of care for the AIDS patient; and Number 3, availability of private insurance.

To put the discussion perpective, we feel we're facing a situation that in terms of human life is many time more devastating to large areas of the United States than the recent earthquakes were to Mexico City. While Los Angeles County has experienced 1,100 cases of AIDS to date, it is conservatively estimated that in Los Angeles County there are now 135,000 people infected with the AIDS virus, and that over 13,000 of these will develop AIDS in the next two to five years.

Almost as many AIDS cases in one community as there have been in the entire country to date. San Francisco reports the total of 1581 cases of AIDS as of December 5th, with 830 deaths. Over the past 30 days, 13 new cases have been reported in San Francisco, and there have been 11 deaths.

In terms of the individuals, the people involved, these patients are in the prime of their life. They're averaging 34 years of age. They are in an age group least likely to use health services, and yet in their remaining life expectancy of a little more than one year, they will

hospitalized two to three times with an average length of stay in Los Angeles of 17.3 days compared to an average of 6.3.

How is the health system to cope with this tremendous additional patient load and also with the concerns of its staff for their personal safety?

The first point I wish to address, the education and training of health workers is our highest priority. Number 1, because of the time constraint on us. There is so little time, and the problem of AIDS in the operational aspects of our hospitals, is so great.

Health care professional are very special and caring people, but they are also human. The AIDS virus, we know, cannot be transmitted to another person by casual contact; however, the consequences to accidental transmission are so severe as to cultivate deep personal concerns and warrant extraordinary precautions.

We must provide up-to-date information, training, and support to the individuals responsible for providing patient care to AIDS victims. Because the task of reach over 77,000 hospital workers in the Los Angeles area, alone, is so large, we are proposing a pilot "Train the Trainer" project. There is no way in most of the communities in which we're going to deal with this crisis that all care can be centered in one or two institutions. We must provide training. We must provide support to a large number of individuals in numerous organizations.

Through our proposed project, we would develop

a lesson plan and manual for training two or three people in every affected hospital in the Southern California area. These plans will address the facts of AIDS and AIDS patient care.

These trained individuals would then return to their hospitals equipped with teaching aids and manuals that would be used to train all other employees. They would become trainers in their own institutions. They would become resource persons for fact, for information, and for counseling at times of crisis on the part of the critical staff providing the care.

In addition to effectively reducing the chance of panic and impeded patient services from misinformation, these people would become responsible for being sources of new information as this is developed and as the science and the technology advances.

Once developed and tested, our plan is to make this available to all other areas in the state; however, we're impeded at this point. We have not been able to fund the Phase 1 of this project. We need approximately $231,000 to begin this in the Southern California area.

In addition, this proposal alone demonstrates that the funds allocated to health care worker education in SB 1251, which as we all know is $250,000 statewide or less that $.50 per hospital worker, is not adequate.

Also, on a related subject, if we are to provide quality patient care for AIDS patients, health care workers must receive accurate and timely information. While we

support the intent of recent legislation which preserves the rights of individuals that test positive to exposure of the AIDS virus, we need to eliminate current confusion by hospital personnel regarding the application of these new laws.

Public education regarding the prevention of AIDS, as well as up-to-date information concerning AIDS, is another service that hospitals can provide. We will not be addressing this however in this discussion. We will be happy to discuss it further with the Committee at some other time.

The second major point in our presentation is the funding of health care for the AIDS patients. The need for adequate funding is obviously essential. The length of stay in hospitals of an AIDS patient is, as I mentioned before, 17.3 days in Los Angeles, 12 days in San Francisco, about two and half to three times the average of a patient's stay of other patients.

The cost of hospitalization in Los Angeles is $16,652, which is three times greater than the average patient. In San Francisco the average total cost of care amount to $74,000, and uncollectibles--uncollectibles, the monies we don't have to make our payrolls and to pay our vendors amount to $5,214 per patient stay, 3.4 times greater than the average.

Now, a loss $5,214 per hospitalization up against 976 patients, the number we included in our survey, can be absorbed, not without some damage to the system, not

without some damage to care to other patients, but it can be absorbed. Five thousand two hundred fourteen dollars in lost revenue up against our cost on 13,000 patients cannot be absorbed.

The health care system as we know it will not survive that level of onslaught. Hospitals will either have to reduce the level of service provided to all patients in order to fund the AIDS service, or transfer the AIDS patient to already overburdened governmental facilities.

The per diem rate limitation, negotiated under the Medi-Cal Selective Contracting Program, are not adequate to cover the intensity of services required to treat AIDS. Even in the most efficient hospital, there is a sustantial shortfall per patient and we can't make it up in volume.

The higher length of stays make the capitation programs very, very dangerous in terms of the AIDS patient. When these programs were put together, AIDS was not taken into consideration. As an example, the underwriting data which is now available to bidders under the state's pilot Expanded Choice Project to capitate Medi-Cal does not reflect the higher than average future obligation of these plans for AIDS hospitalizations per enrollee, intensity of service, or length of stay.

Exceptional Medi-Cal per diem and capitation rates that adequately cover AIDS costs must be provided now.

The third point, and very briefly, is our concerns that there be available private insurance for persons with

AIDS. We oppose any legislation which would permit third party payors to selectively screen from coverage eligibility or benefits, persons with AIDS or persons who test positive to the AIDS virus.

In conclusion, if this was a Mexico City sized earthquake disaster that struck our metropolitan centers at the same time, we as a nation would immediately do what we had to do to preserve our society. Well, we are aware of AIDS. We do know the numbers, and in some instances, we're taking impressive steps. However, it's imperative that we act now. It's imperative that we look to education and training programs, that we plan for the future of funding of this health care system that we're so blessed, and lastly that we assure the persons with AIDS have access to health insurance.

Chairperson Watson, members of the Committee, in the hospital field we'll do our best, but we need your help and we need the help of the State of California.

Thank you for the opportunity of presenting these ideas.

CHAIRPERSON WATSON: Thank you very much.

Senator McCorquodale?

SENATOR McCORQUODALE: You speak about the issue of insurance, private coverage. Is that a thought-out position versus government funding for this, or would it make any difference to you which--the concern I have about the private insurance, first of all, if you try to insure against something that has a high and a fairly fixed cost

for it, you're going to find that insurance is going to be expensive. Frankly, if I--when I look at the things that I can have some control afterwards over, I want to have insurance. If somebody is going to steal my car, I want another car. So, I want to have car insurance that would cover it. But if I'm--at this point, when you get an illness in which, at this point, there's no chance of recovery, am I going to be that concerned about the insurance coverage that would have it, because I can go back on--there always is a county hospital that will take me somewhere.

Would it make more sense that we simply provide a mechanism that government pays to cover the health cost and leave some flexibility as to whether it's a private or the public facility that is covered? It seems to me that if you simply say that you're going to do it through private insurance, private insurance companies are going to not want to have the coverage. Therefore, they will say, "Fine, we'll do that, but your premium for this year is $14, 927, and that's what we're going to charge you.

Would it make more sense, though, to have that funded as a responsibility of government?

MR. ABBATE: Yes, thank you, Senator.

To begin with your question. We have thought our way through this one. We can't say that we have come to the final conclusions in our thinking, but just to share a little of this with you.

The numbers we're dealing with suggest that over a five year period of time, the care of AIDS is going to

require over $3.5 billion, and we looked at several alternative scenarios as to how this can be best handled,including the proposal at the federal government, and we've discussed this with the Waxman Committee and are discussing it with the federal government that a type of a hemodialysis-renal disease system be set up. However, it appears clearly that all elements of our society, the private insurance, state and federal levels are going to have to become involve to their degree of involvement in this.

There will normally be people who will routinely fall outside of insurance coverage. What we're looking to is where insurance is a--is provided to other people that it also be provided to individuals who may or--may potentially have AIDS. It's a nondiscriminatory situation, and even looking at that, looking at the numbers, this is only going to be a portion of the amount of health care that will have to be funded for AIDS patients.

SENATOR McCORQUODALE: That's why it seems like maybe if you had something that said, "All insurance policies would have to cover AIDS," would have some limit on--on the AIDS-related cost connected with that, and then a recognition that government would pick up the cost over that, because it seems to me that you could--if you had all of the health plans required to cover AIDS, then you may only increase all of the health plans in the country by $10 a year or something to cover that--whatever costs the insurance companies may have.

If you go to the point of having a specific cost

connected with that, I think we had polio insurance during the polio time, and it was--but they all had, if I remember correctly, most all of those policies had limits on them as to what they would cover, but it--it's the concept of how you go about best covering people for those types of things that are easily covered and then for the uniqueness of AIDS, that--you know, if it keeps doubling, at some point, I suppose, and then everybody at some point, half the people in the country have AIDS, we know in the next nine months the other half will have AIDS, and the insurance companies at that point will want $114,000, I suppose, as the policy per year for nine months.

It seems like you aren't dealing with something that can easily be determined on an actuarial basis and that until we have a better understanding of cost and how cost may be controlled or not controlled, as in your testimony and the previous speaker's testimony. There evidently are a lot of different cost related to--in some areas it's treated for less cost than other areas.

MR. ABBATE: The bottom line, as we see it on this, is that it's going to take a partnership of the insurance companies and the government. I'm a bit out of my element on this. You're going to have some speakers later on that I'm sure can do better--can better respond to the actuarial approaches that the insurance companies will need to pursue. Our evidence--or our studies indicate that insurance companies will need to live up to their obligations to the people in the community, however.

CHAIRPERSON WATSON: We appreciate your testimony. Thank you for the information.

MR. ABBATE: Thank you.

CHAIRPERSON WATSON: I'd like to introduce someone who's joining us up here at the table, former Assemblywoman Leona Agley who is with us, and welcome back. This is not unfamiliar to you.

ASSEMBLYWOMAN AGLEY: Thank you.

CHAIRPERSON WATSON: The problems continue on. We appreciate you coming and joining us.

Leslie Dutton representing the American Association of Women Voters.

MS. DUTTON: Senator Watson, members of the Committee.

The American Association of Women Voters is a--was formed in 1984 as an educational organization. It's nonprofit. We're not in any way related to the League of Women Voters or the American Association of University Women. We're the NOW organization.

We're involved in research and education and concerned with the dissemination of accurate, impartial, and non-political information, and we make that available to other organizations or anyone who want access to the research that we've compiled.

I might say that our organization is one of only two consumer organizations here today that are not representing "high risk" group for AIDS. We're here to participate in the segment of the hearing addressing the issue of prevention of AIDS.

The prime purpose for us being here today is to request a Senate investigation of the blood collecting industry in California regarding their false and misleading practices in providing blood and blood products to health care consumers. As evidence, I am going to submit a statement from June Moeser of San Diego whose personal experience with deceptive blood bank practices demonstrates a "public be dammed" attitude in the blood industry.

Also, due to the limited time, and the unfortunate circumstance that we're not able to go into great detail, we're submitting a statement from Stephen Smith, of the Dental Information and Services Corporation of Michigan pertaining to the problems related with AIDS transmission in the dental office. Mr. Smith's written testimony does demonstrate that 50 percent of the American population will visit their family dentist next year and could be exposed to the AIDS virus due to faulty dental equipment which collects the body fluids known to transmit AIDS.

My oral testimony today will be limited to the blood safety issue, and I won't be giving it all, but I'll by submitting a great deal more for the written record.

Our organization was drawn to the AIDS--to the issue of blood safety and AIDS because of the controversy surrounding the antibody testing program which surfaced earlier this year when some public health officials raised objections to licensing the antibody test claiming it was too inaccurate to be useful.

The issue of blood safety is one which is of great

interest to women, because it's women who help their family members make health care decisions about treatment, and it's women who have a unique commodity which can provide protection against the spread of the deadly AIDS virus through blood transfusions and blood products. Statistics reflect that women's blood is far safer from AIDS and even hepatitis than male blood. Therefore the chances of transmitting these deadly viruses via transfusion will be severely reduced if female blood was available.

Ever since the AIDS disease became reportable, in 1981, the Center for Disease Control has maintained that 94 percent of all AIDS cases are males. In California the figure is 98 percent, and yet the Food and Drug Administration tells us that the nation's blood collectors, and California, report only one-third of their blood donors are females. This is a distressful statistic, and one should--which should have been changed a long time ago.

We do not see any public appeals or campaigns by the Red Cross or the blood collecting industry to make an appeal to women to become blood donors. Certainly they should use their vast public relations resources to urge the women of America to come forward. Traditional donor recruitment procedures have used peer pressure in male dominated industries to set up blood-mobile drives, and it's that peer pressure which exacerbates the AIDS transmission problem, because those individuals who are standing in the blood-mobile line are reluctant to reveal that they may be "high risk" due to discrimation and problems with

insurance and so forth.

I want to point out to you the necessity for the investigation of the blood collecting industry is based on the misleading and deceitful contradictions that are being made by the blood collecting industry and our public health officials.

The first contradiction that I'd like to point out just to took place last week at a public--at a press conference held by the Los Angeles-Orange County Red Cross, where the director of the area Blood Bank made the statement that the AIDS antibody test was almost fail-safe and that every unit of blood is tested for the virus. Well, we all know that there's no test for the virus, no mass-produced test, and we also know that it's been established that not all affected individuals develop antibodies to the virus. This is only one example where the public is given erroneous information rather than the truth.

The second, is Secretary Heckler and Center for Disease Control Chief George Mason on down through state's public health officials, have assured the public that the AIDS test is the answer to our prayers. Dr. Mason even said that you're chances are one in a million, when knowing full well that in "high risk" areas the chances are more like 1 in 5,000 or 1 in 8,000.

The Journal of American Medical Association printed an article recently about the calibration of the AIDS antibody test and how it was necessary to calibrate the tests to keep the false positives to a minimum, and they also had

to be careful because that would then sacrifice the false negatives. We're concerned, because we know that at the FDA level right now there are discussions going on about redefining what is a positive test, and what we want to know is, where's the priority going to be? Are they going to keep the false positives to a minimum so they don't have to have to discard so much blood, or are they going to keep the false negatives to a minimum to protect the blood safe?

I would like to offer a quote that was put forth before the sub-committee of the U.S. Senate by Dr. Alfred Katz, the vice-president of the National American Red Cross when he was referring to the AIDS antibody test on September 26th at a hearing on funding. Dr. Katz said:

> "First of all, it's imperative that an even more sensitive screening test be developed for whole blood and its components. While measurement of an antibody response to HTLV-III is a major step towards making the blood supply safer, it has both theoretical and practical defects. It is essential that we develop a test that directly identifies infectivity. It must be more sensitive and more specific than the tests yet implemented, and we need an confirmatory test.

He went on to conclude that"

> "The long incubation period of HTLV-III, the AIDS virus, means that we will not be absolutely certain that a test is satisfactory for several years after it's introduced."

Now, Dr. Katz' testimony was signifigant a few weeks ago, because for the first time the Red Cross admitted that the screening test for antibodies is not perfect at screening blood. He pointed out the incubation period prevents us from knowing whether it will be satisfactory for many years. In the meantime, the public relations departments of the blood collecting industry, and our public health officials, continue to tell us that the blood supply is safe when the antibody test is only a few months old, hardly the years required to ascertain its effectiveness.

And then Dr. Myron Exxex of the Harvard School Public Health said that the supply--the blood supply, excuse me. Assertions that the blood supply are safe is grossly exaggerated. Dr. Essex, along with Dr. Gallo from the National Cancer Institute, published a study a year ago in December which found that a number of people did not develop antibodies even though they carried the virus. So, the blood supply is not safe as the public is being told.

The sixth contradiction, on the blood supply safety, is the blood industries claim that it was safe prior to the use of the antibody test. However, in the New England Journal of Medicine on August 8th, the Red Cross published an article the results of a study from Atlanta, that said the 92 percent of all blood donors who tested positive for the antibodies were males, and these were regular blood donors who did not see themselves as being members of "high risk" groups, even though the FDA, the Red Cross,

and our public health officials all had revised the guidelines to screen out "high risk" individuals.

The seventh most flagrant example of the intentional deceit by the blood collecting industry is the well-publicized blood-mobile drive in January 1985 this year, at the Gay and Lesbian Community Center in Garden Grove. The fact that such a blood drive was even scheduled is indicative of how the donor self-screening guidelines, issued by the FDA and the public health, did not work. This blood drive was initiated by the LA-Orange County Red Cross. Our organization protested, and it was consequently cancelled.

Recent polls indicate--Newsweek Magazine polls, as a matter of fact--that the public's faith in the blood collecting industry is down. Twenty one percent of the national sample said they'd been refusing elective surgery because of the fear of AIDS transmission, and it certainly appears from the contradictions in the blood collecting industry and from our public health officials that the fear is well-founded.

We have been offering, any hospital, any blood bank, any regional blood facility, that would label their units "male" and "female," we have offered to go out into the community surrounding these facilities and make an appeal to women to come forward as blood donors. To date, we've not received any assistance or any willingness on the part of the hospitals, and we believe this reason is because of the monopoly in which the blood collecting industry works. We've been told by some of the hospital administrators

and the blood band directors that we've met with that they could not work with us because they had agreements with the Red Cross, and because they were afraid that it would jeopardize their special services and special blood products from the Red Cross or from the regional blood supplier.

We are so concerned about this practice of monopoly, and also a letter that was sent out from the American Red Cross to all the hospitals in LA-Orange County which said that if they bought from lower-priced competitor--if they bought blood supplies from a lower-priced competitor it would jeopardize the Red Cross's ability to deliver these other products. The implication here was of implied threat. We are so concerned about this, and the fact that the public is not being told the truth and not adequately protected, that we have asked the Attorney General for an opinion in regards to this type of activity as being a possible violation of the anti-trust laws.

Finally, I'd just like to say that our organization is sponsoring a public policy workshop on "Safer Blood Products" next year. We will be addressing such topics as, Who bears the liability of blood borne infections? and also, How can we make blood safer? We are anxiously looking forward to many prominent people coming from all over the country and even the world to participate in this. It's long overdue for the public to hear the truth.

We had the distinct honor of being invited to address the American Blood Commission in Arlington, Virginia last Thursday. Their response to our findings and to our

proposals was very interesting. We found that some of the people in the physician community are very concerned, and we hope that the public health officials and the State Senate will take heed to this great problem, and we urge you to read the documents from Mrs. Moeser about the blood banking practices and the problems created there, and launch an investigation, and see that the consumers who are--who have to have emergency blood transfusions and who have no other choice in order to save their life are protected.

Thank you.

CHAIRPERSON WATSON: All right, thank you.

Are there any questions?

Robert Lindsay, California School Boards Association.

MR. LINDSAY: Thank you, Senator Watson and members of the Committee.

I'm Bob Lindsay representing SCBA, California School Boards Association, and currently president of the Centralia School District, board of trustees--

CHAIRPERSON WATSON: Could you move that mike right in front of you, please?

MR. LINDSAY: Right.

CHAIRPERSON WATSON: Right in front of you.

MR. LINDSAY: How's that? Better?

Okay.

And I'm currently president of the Centralia School District in Buena Park, California in Orange County.

This afternoon I'd like to express some concerns and ask for your consideration of several basic principles

held by the California School Boards Association or CSBA. One of our principal concerns in public schools is the high-visibility of this very low-incident disease as it affects our classrooms, and the resulting hysteria created within the school community. Even the singling out of this disease gives it much more publicity than the actual occurrence rate would normally demand. Schools would much prefer to treat AIDS as we do other communicable diseases, or infectious diseases, by treating with all-due consideration to the contagion of the disease and the specifics of how the disease is transmitted being the determining factors in how students, employees, and others are either educated or allowed to remain in the system or work in the system.

However, because of the unusual concern by the public, CSBA has expressed several principles and informed its membership of recommendations, or recommended ways, to deal with the impact of AIDS.

One, we are dedicated to the principles of local control. Let each board take the responsibility to either allow the victim of AIDS to remain in the classroom or to decided to provide alternatives options of educating the individual and remove the individual from the classroom. This allows each community to take into consideration the realities of each district; for example, the class sizes, busing requirements, facilities available, medical or nurse's availability, and all of the other multitude of variables that differentiate each school site and school district from each other. Special cost factors can become prohibitive

in one district, whereas it is of small consequence in another district. Local determination, then, has always been one of our most important hallmarks and concerns in this issue.

Two, information was another very important issue that we've considered as far as the AIDS situation. Just as information is most important to a group such as this in making decisions, school districts require good information in every situation as it applies to infectious or communicable diseases, and we need the best and most reliable information that can be provided.

Districts need it for several reasons. One, to provide the staff and community with the facts and to desensitize the fear that now exists. Two, to be able to develop the best procedures and how to care for the person with AIDS to ensure that the minimum risk to all involved, including the persons having the disease. Three, CSBA, in conjunction with the Association of California School Administrators, the Public Health community, medical and legal advisors in the State Department of Education are currently working to provide the best information that is currently available concerning infectious diseases and their implications.

We have provided a video cassette which is available to all districts and administrators, and it is a panel presentation involving the people that I've just indicated: administrators, public health community, medical and legal advice, etcetera. It endeavors to provide a background to school districts, both boards and administrators, involved with the use--the

control and treatment of infectious diseases and discuss the facts surrounding the public schools and implications of infectious diseases upon the education of our kids.

This video presentation was produced in November and was presented at our SCBA at our annual conference this past weekend. Also, as a part of this past weekend, CSBA resoundly passed the new policy giving direction to our organization and stating our strong resolve for retaining local determination or local control in all matters associated with infectious diseases and specifically with AIDS.

I thank you for your concern, and I wish to express my concern that we do have better information wherever we can possibly get it, and that we do have the privilege of making our own determination.

CHAIRPERSON WATSON: I gather from what you're saying, that right now the policy is one that is made on the local level?

MR. LINDSAY: That's correct.

CHAIRPERSON WATSON: And do you have any idea what some districts are doing in terms of the child with AIDS in school?

MR. LINDSAY: In some instances, such as the Carmel Valley School District, and the superintendent is one of the panel members on our video cassette--that particular instance is one that they have tried to keep--or they're endeavoring to keep the child out of the classroom and provide home teaching and other methods of educating that child.

Others have determined that they would like to have the children in their classrooms. However, there are--they have none, and whether or not that policy will change as they actually realize having someone in their community, remains to be seen.

CHAIRPERSON WATSON: In Carmel Valley, do they keep the child with the active case out, or that child that has the potential?

MR. LINDSAY: That child--the one that has been identified in that particular situation, and has resulted in a lawsuit trying to have the child remain in the classroom, is out of the classroom at this point in time.

Did I answer your question?

CHAIRPERSON WATSON: Well, I was just wondering, is that a child with an active case?

MR. LINDSAY: Yes, it is.

CHAIRPERSON WATSON: Okay.

MR. LINDSAY: And there is another instance in Saddleback Unified in Orange County where the child is trying to become enrolled in that school district, and to date, that child is--while may enrolled--is not in an active classroom.

CHAIRPERSON WATSON: I see.

MR. LINDSAY: So, we do have the situation that it's low incidence. We do not have that much history or what's happening. As you're well aware, the schools are one of a very large fear syndrom, like Newsweek with the Queens, New York situation hits the covers of the magazine.

Yet, as far as AIDS is concerned within public education, it is a very low-incident disease. We have other diseases that are much more critical as far as kids are concerned, and we deal with them on the basis of what their contagion is,what the risks are to all people involved.

CHAIRPERSON WATSON: Senator McCorquodale?

SENATOR McCORQUODALE: I just wondered if you would be able to comment, since you've been involved in some discussion about this and whether maybe it involves too great a self analysis to be able to do it, but it's somewhat interesting to me to watch from a distance the issue. That Carmel School Board made a decision and, I think it was the San Jose Board which covers part of my district, and another--and then I think San Francisco. So, it's been in the news, across the board, of what's been going on.

I just wondered if you could comment on some of the issues that arise and some of the attitudinal concerns and problems that people have to come to grips with in deciding, because nobody ever creates any--there never gets to be any issue about; if a child breaks their leg and is severely injured, and they get a home teacher until they're well--I don't even know if that gets to the School Board decision or not.

MR. LINDSAY: Usually not. However, in our district we have had some infectious diseases that have--and I don't even recall the name of it, but it's one of those nice, good, long medical terms, but the outcome of it was that

it could very seriously damage a pregnant woman as far as carrying the baby to full-term without having any difficulty. That particular one forced us into a situation of dealing with it with the child out of the classroom. We could not educate the child, and fortunately for our district, the problem is someplace else right now. The child left our district. We no longer have that problem.

The problem, though, was we couldn't find teachers of a child-bearing age that were willing to be in the classroom with that child, because of the potential damage it would cause her and her ability to bear a disease-free child sometime hence.

We are dealing with it continually in that type of a situaion, whereas AIDS, we have relatively little experience. I think that the problem we're faced with, though, is that the community becomes hysterical at the thought that no one--and if you look at any of the language of the Atlanta Disease Control Center--in that particular case they said, "We believe," and it keeps coming back to that. "There will be no harm," "Statistically, we believe." And to a parent that has a five-year-old entering a classroom that has a child with AIDS in it, belief is not enough. Can you guarantee? And you get some very strong, hysterical outbreaks, and people gather around with that and do this type of thing.

There are no good answers when you get hysteria into a community such as that.

SENATOR McCORQUODALE: It does seem to be a difficult

issue to even come to grips with. In most of the discussions that I've been involved, usually we sort of break up before we ever get to the point of having to make any real final, definitive--forcing ourselves to say things.

I had children in school when--when polio was a fairly significant issue, and in that one it was a little different in that you said, "Well, we'll balance off the possibility versus the freedom, because even if they catch polio, they may live. They may not be too badly damaged, or there may be a chance for complete recovery," and yet then you're dealing with something in which the medical people tell you there's no recovery.

MR. LINDSAY: Right.

SENATOR McCORQUODALE: Then you start having to re-examine what you thought were fairly significant issues that you had resolved years before.

MR. LINDSAY: I think, we're all trying to avoid the same type of situation that existed during the Black Plague, the tuberculosis situation, you bring up polio, and we've done some very--very bad things as far as people are concerned, without good facts. That's why--one of the things that I really feel important to the public schools is to have system or network of information that will be provided to schools, so that we can deal with the best facts that are available.

The lady that preceded me, however, shows that sometimes some of the facts that you think that you have may not be as good as you thought they were, and that is

really a concern of why I feel there needs to be some kind of a channel, whereby you can trust the information you're getting to the best of its ability to be factual and correct.

So, that's why we feel that that's important to us.

Thank you.

CHAIRPERSON WATSON: Thank you for your testimony.

Carolyn S. Harris, the Inland Counties Health Systems Agency.

MS. HARRIS: Madam Chairman, and members of the Committee.

I'm Carolyn Harris, Associate Director of Inland Counties Health Systems Agency and project director for the agency's Inland Empire AIDS Coordination and Education Project. Thank you for the opportunity to discuss AIDS prevention and treatment issues today.

My comments reflect AIDS-related health systems development issues from the perspective of our regional health planning agency--

CHAIRPERSON WATSON: Excuse me.

MS. HARRIS: Yes.

CHAIRPERSON WATSON: Can you highlight this, rather than read it all?

MS. HARRIS: Sure.

CHAIRPERSON WATSON: We have it in print.

MS. HARRIS: Sure, okay.

CHAIRPERSON WATSON: Thank you.

MS. HARRIS: Okay, just to give our perspective, our

first goal is as a health systems agency that serves approximately 2 million residents. It covers the counties of Inyo, Mono, Riverside, and San Bernardino, or about one-fourth of the state in area. We have a 45-member AIDS task force that has been established as part of our State Department of Health Services and county funded education project.

We do have--unfortunately, in Riverside County, while the area ranks ninth in population in the state, it ranks seventh in the number of AIDS cases. So, while we're not in that top tier by incidents of AIDS, we're just at the next level down.

Our case load varies a little bit, too. Our case load is older, and our case fatality rate is also 68 percent compared to the 40s and 50s at the state and national levels.

The issue that I'd really like to focus on today is Question Number 2, regarding to the types of services that are needed. Patient care in our area requires the expanded development of the array of services which comprise the long-term care support system, and in the appendix materials of the testimony, I have provided a listing of a broad array of long-term care services several of which have the word "geriatric" in their name, but they're perfectly suitable for treatment of AIDS patients.

In terms of our local concern, the Visiting Nurse Association of Inland Counties, a home health care agency, has provided care to about 20 patients to date, and has identified several service needs, and I'm bringing those

to you today: affordable, with the word affordable underlined; private pay attendants; homemakers; and nurses; outpatient mental health services to address the psychosocial aspects of the patient and family in the home care setting, with the need for a direct mental health interface in the home setting, not taking patients out to outpatient mental health services, but bringing mental health services into the patients home. Also, there is a need in some of our areas for outpatient therapies and volunteers, and there is a statement there I hope you will be able to read at a future time, on why volunteers are especially needed.

A lot of organizations work with volunteer resources but not without associated costs. Where will financial assistance come from on a sustained basis to provide for the recruitment, training, monitoring, and coordination of volunteers? Without volunteers, we risk premature institutionalization of patients.

In terms of the institutional long-term care in AIDS, our task force representative from the San Bernardino-Riverside Association of Health Facilities has cited three AIDS-related concerns:

One, current licensing regulations governing the operation of skilled nursing facilities with respect to accepting or retaining patients with infectious diseases;

Two, and that's been mentioned in the context of acute care, previously. Medi-Cal reimbursement rates that do not presently reflect additional costs that would be incurred to provide all infection control activities

necessitated in the care of patients with AIDS;

And third, confidentiality issues. They're quite concerned, because reportedly, patients with AIDS have almost been admitted to skilled facilities, without the provider knowing that AIDS was included in the diagnosis. This is especially a concern for those facilities with young, chronically mentally disturbed patients whose sexual behavior is difficult to continuously monitor.

I have include an article from Outreach, which is the Journal for the California Association of Health Facilities, which identifies some of the legal issues and concerns of that organzation.

Also, the need for case management, I have provided a definition in the testimony. Case management provides, then, the opportunity to move a person through the appropriate levels of care including monitoring and follow-up. Reimbursement for case management, however, will need to be developed. The client-based utilization data by service generated through a case management system would enhance the ability to project future service needs and identify budgetary impact on both private and public sector agencies.

We had some comments, several of which have already been addressed. I won't go over those in terms of the Medi-Cal negotiated rates not being sufficient to cover costs. Also, the issue of retroactivity and Medi-Cal, in terms of the costs incurred prior to diagnosis that meets the CDC criteria, and then lastly, but certainly not least, those patients with disabling conditions that

are included in the variably defined area known as "AIDS-Related Complex" that presently do not qualify for Medi-Cal.

In terms of sufficiency of insurance coverage, of those 20 VNA patients, 2 that were referred had not insurance coverage at all that would cover home health care.

In terms of clinical research needs, we just ask, since we're out in the "hinterland" so to speak, that to the extent possible expanded clinical research drug trials consider geographic access.

And then another issue in terms of Question Number 5, the issue of confidentiality of patient medical records for various health care settings--hospital, home health, etcetera--have been expressed. Various interpretations as to what AIDS diagnostic-related information can and should be included on the record have been disseminated. State guidelines would be very helpful in this area.

In conclusion, California has taken the lead in responding to the AIDS challenge. Your hearing here today reflects the Legislature's continuing attention and leadership in addressing changing needs and issues associated with AIDS.

Thank you for providing us the opportunity to share our concerns.

CHAIRPERSON WATSON: And thank you for providing the key questions that we will be looking at on an extended basis.

MS. HARRIS: Thank you.

CHAIRPERSON WATSON: Appreciate it.

Paul Boneberry with the Mobilization Against AIDS group.

MR. BONEBERG: I'm Paul Boneberg. I'm the coordinator of the Mobilization Against AIDS. I'm giving verbal testimony, but I will be expanding upon that to the Committee in the next week. Some of you may not be familiar with our organization. I'm passing out some brochures to you about it.

The Mobilization Against AIDS is less than a year old. We are the largest national membership organization dealing with the politics of AIDS. We have three active chapters in San Francisco, Seattle, and Pheonix, and chapters forming in San Jose and in Los Angeles.

I want to address three specific urgent issues that deal, basically, with misconceptions around the war against AIDS. One, and perhaps the most important, is the very definition of AIDS itself. It's been reported that there are three to four thousand Californians who have been ill, seriously ill, from AIDS. But in fact, the number is much greater than that. Most figures indicate that there are two people with severe ARC for every person with AIDS, which would indicate another 8,000 people who have severe AIDS-Related Complex.

Other studies indicate, that for each person with AIDS, there are 10 people total with ARC, some being severe and some not. That would tend to indicate there are thirty to forty thousand people with ARC in the State of California.

Since there is estimates of a hundred--of, I'm sorry, 1 million people exposed to the virus in the United States, and since California is 10 percent of the population, it's reasonable to assume that there are approximately 100,000 Californians who have been exposed to the causative agent for AIDS.

Now, one of the things you will be told is that 100,000 people are, in fact, not ill. That is not so. What they mean is their immune system is not compromised. However, most of these people are infectious for the AIDS virus, which means that the very least their sexual life is totally disrupted, and their ability to have children has been removed. That is, in fact, a severe illness that will in all likelihood be with them for the remainder of their life.

So, therefore, what we're talking about is a tremendous need in this state to redefine, What is AIDS? and What is ARC? I was in a meeting of physicians, clinicians who treat people with AIDS in San Francisco, about a week ago. They could not decide among themselves how you define ARC. How do you diagnose a patient who has ARC?

If the clinicians who treat people with ARC in San Francisco cannot decide on a definition, then certainly all throughout the state lesser informed clinicians are having tremendous problems. One of the things that this has resulted in is a second-class citizenship for people in this state who have AIDS-Related Complex. They can't get into treatment programs. They can't get into counseling programs. They can't get in the social service programs,

simply because of the lack of a clear definition of AIDS-Related Complex.

It's a critical need in this state that we redefine, What is Aids? What is ARC? and the treatment services we provide for those people.

A second point is the lack of effective treatment. The State of California is spending millions of dollars in research for, specifically, treatment of people with AIDS. However, thousands of Californians are fleeing across statelines into Mexico to get treatment. The question, therefore is raised, if we are spending millions of dollars for treatment, why is it Californians are fleeing across the country line to get other forms of treatment? The answer is simple. Effective treatment of AIDS consists of two parts. One is anti-viral agent that would kill the virus. The second is an immune modulator that would stimulate the immune system.

In the State of California, there is no combined treatment therapies. There are no combined treatment therapies planned. What that means is, if you are a person with AIDS, or AIDS-Related Complex, and you wished to have an effective treatment program consisting of both treating the virus itself and stimulating your immune system, that is not being made available through the research programs funded in the State of California. That is why people are fleeing to Mexico to get Ribrivarin and Isoprinosine because those--Ribrivarin is an anti-viral, and Isoprinosine is an immune enhancer, and those two things combined provide

the combination treatment that is essential.

Until the State of California or the United States government funds combination treatment, Americans are going to continue to flee country to get this combination treatment.

I would urge you to consider directing the Department of Health to fund a combination treatment of people with AIDS in the State of California and not just to continue to fund just drug trials. Drug trials only deal with one half of what is necessary to cure the patient. The patients know that, and ultimately, if they wish to be cured, they will try to self-treat themselves to find an effective treatment. This doesn't need to continue, and it shouldn't continue.

And the third thing is the lack of civil right guarantees, which are absolutely essentially to protect the medical efforts that we're engaged in in the State of California. The fact is, we're often asked to make a choice between the health of the state and the civil rights of certain individuals. It isn't a choice. Without basic civil right guarantees, we can't proceed with the basic efforts to defeat this epidemic.

Let me give you an example in terms of education. In the State of Colorado, there was a 17-year-old child who tested positive for HTLV-III. The child told the school nurse that he had tested positive for HTLV-III. The nurse informed the superintendent, and the result is that the child is now removed from the school system in Denver. That means, if you're a child in the school system of Denver,

don't ask the school nurse, don't get into a discussion with the school nurse about AIDS. It undermines the education policy. The same thing is true in the United States military.

In terms of research, if you are researching some--testing someone, monitoring for example, groups of populations of people, whether or not they are going to test positive for the HTLV-III virus, and simultaneously people are proposing mass firings of people from teaching positions, health positions, food handlers--what that means is the people who are volunteering to participate in these research studies are, in fact, being threatened.

There needs to be minimum civil right's guarantees in the State of California, so that people who volunteer for research studies who are trying to become informed are not going to be penalized for their efforts to defeat this disease. There are now guidelines put out by the Centers for Disease Control about how to handle people with AIDS and people who may be positive for HTLV-III in terms of school and employment. Those guidelines should be given the force of law in the State of California, so that Californian is not turned against Californian in the struggle, but rather there are certain minimum guarantees given to people around civil rights in terms of their efforts to fight this medical epidemic.

I realize this state is the best state in the nation in terms of fighting AIDS, and I realize a lot of that is because of those of you who are here in the Legislature who have forced this state to become as good

as it is. But there is an urgent need on three issues: to redefine what is AIDS and what is ARC; to make sure that people with AIDS and people with ARC can get effective combination treatment, which is the only treatment which may save their lives; and finally, to pass basic civil right's guarantees, so that people who are volunteering for research studies and attempting to become informed in terms of education are not going to be penalized for their efforts.

Thank you.

CHAIRPERSON WATSON: Thank you for those recommendations. We'll take a good look at them. We appreciate that.

All right. Dean A. Doolittle-Sandmire, People with AIDS-Related Complex Caucus.

Is Dean Sandmire here?

MR. SANDMIRE: Thank you, Madam Chairperson, and members of the California Legislature Committee on--

CHAIRPERSON WATSON: Do want to speak right into that mike, please.

MR. SANDMIRE: --on Health and Human Services.

My name is Dan A. Doolittle-Sandmire, and I am speaking to you today as the co-Chair of the People with AIDS-People with AIDS-Related Caucus of Mobilization Against AIDS. I am also a member of People with AIDS Alliance, San Francisco and a member of the National Association of People with AIDS, which has its national office in Washington D.C., and I am a member of the AIDS and ARC

Vigil Committee.

Although I am here as a person with AIDS, I am coming before this Committee to present our organization's concerns of two separate issues around the issues pertaining to People with AIDS and People with AIDS-Related Complex.

The first area of concern is around the issues of People with AIDS-Related Complex. Still to this day, the State of California has been one of the top leaders, not only in AIDS education, but also with the medical and social support for People with AIDS. But, we as a state have either just put aside or are forgetting about those who have been diagnosed with AIDS-Related Complex.

Statistics will show that these people do exist, but they are either only being offered very little, or no, medical or social service support at all. For those who are being given the medical support, the medical profession keeps saying they cannot do anything for them, and they do--they are not sick enough to fall under the use of protocol drugs such as Isoprinosine and Ribovirin.

One of such diseases that a person with AIDS-Related Complex might come down with and which the medical profession says they do not know what the treatment to give is Toxoplasmosis, a virus which is found in the patient's spinal fluid and starts affecting, not only their brain, but also their neurological system, affecting the coordination, and eventually their whole--their other bodily systems, some getting to the point of being unable to work, and yes, some do eventually die.

But when the people with AIDS-Related Complex get to the point of economical strain because of not being able to work, and go to apply for Social Security, SSI, and Medi-Cal, they are turned down on the basis that they do not fall under the current Center for Disease Control Guidelines. Yes, they can apply for General Assistance, which is only $144 every two weeks, and also become eligible for food stamps, which ranges from $39 to $79 a month. For those who are eligible to receive State Disability, they are only eligible to receive up to $400 every two weeks, for a total of fifty-two weeks.

But what happens when their State Disability runs out, and they become economically unable to survive as their medical bills, rent, and utility bills start to mount up--not to a mere couple hundred dollars, but to thousands of dollars? What happens when their doctor says that they cannot treat them any longer, because they either cannot pay or that they do not have the proper medical insurance coverage, or Medi-Cal, or MediCare?

What about the Shanti-type support programs? They also are either nonexistent or short-termed. But they go through the same emotional problems as do people with AIDS, and for some even more severe, because of the unknown, where a person with AIDS has a diagnosis of pheumocystis carinii pneumonia or Kaposi's sarcoma.

I am aware of numerous disgraceful incidents that have occurred throughout this county that have resulted with people with AIDS-Related Complex being given termination

notice at their place of employment, being evicted from their apartment, being denied proper social services, being denied proper medical care, and being denied proper funeral services. And, yes, some of these incidents have occurred in the Stateof California, showing that the general public's ignorance and superstitions even surround AIDS-Related Complex.

Changes must be made for people with AIDS-Related Complex, and the California Senate Committee on Health and Human Services can help to bring such changes about--then showing that they rightfully deserve to be treated like human beings and not like lepers.

The main area of our organization's concerns are around the issues pertaining to people with AIDS, people with AIDS-Related Complex, and those who are HTLV-III positive, who are now inmates in the federal and state prison systems, and not only here in State of California, where the issues of AIDS, AIDS-Related Complex, and the HTLV-III test are dealt with on a very serious manner, but also how these same issues are being dealt with in other federal and state prisons.

As I speak to this Health and Human Services Committee today, there are 27 known cases of people with AIDS, people with AIDS-Related Complex, and those who have been administered the HTLV-III test and who have tested positive to the test within the Northern California Correctional Facilities now being housed at the medical facility at Vacaville. These inmates have been transferred from San Luis Obispo, Sacramento

County's Rio Cosumnes Correctional Center, and San Quentin, as well as from other state correctional facilities.

Our concerns are around the way the inmates are not--are being or not being medically treated by the prison's medical staff, but also how they are being treated as human beings as an inmate, not only by the prison guards, by other prison staff, as well as by the fellow inmates. We are also concerned about the housing of these inmates. We are also concerned that the same AIDS educational materials, which is being readily available to us on the outside of prison walls, is not being readily available on an ongoing basis for all personnel as well as for the entire prison population.

Along with the educational process, there is also the concern about the psychological support for such organization--from such organizations such as Shanti, not only for these inmates, whom we speak of today, but also for their families and friends.

Yes, we are all aware that these men and women have committed a very serious crime and are serving sentences ranging from 5 to 10 to life in prison for such crimes, but, members of this Committee, those who actually do have AIDS, AIDS-Related Complex, or who are HTLV-III positive are being sentenced even to a further death, not only because of this very serious human disease, but also by the lack of concern stemming from our concerns stated here today.

Again, while I am speaking to this Committee, if any inmate here, in the State of California, shows any

signs of AIDS symptoms, or AIDS-Related Complex symptoms, or turn out to be HTLV-III positive, are being segregated from the general prison population and are being transferred to the Vacaville facility, where until recently these inmates were being housed on Ward G-2, which is the infectious disease ward for those inmates who have been diagnosed as having TB and hepatitis B. Being housed in the same ward, even--this same ward, even threatens the live of an immune suppressed inmate even more.

Now, the not so very seriously ill AIDS, and AIDS-Related Complex, or HTLV-III positive inmate is being housed in A-1, which used to be the old psychiatric building, which is 20 by 40 feet, with very few urinals, and very small shower area, no room to exercise, and enough bunkbeds which will eventually house 50 such inmates. They are being attended by EMTs, and there is no real medical triage area available in the building. Thus, if one does become seriously ill, they must wait for a doctor to come down from the other building and then determine if the inmate should or should not be transferred back to G-2.

The only way they are able to get proper exercise is if five or more inmates want to go out to the exercise yard, and then it's only for a fifteen minute period. To our organization this, indeed, is a form of unwarranted quarantine.

Of the 12 being housed in A-1, some have never been medically proven to have AIDS, AIDS-Related Complex, nor has the test been administered in the proper manner

as suggested by the Federal Food and Drug Administration. The doctors who administer the HTLV-III test to these inmates, retest those inmates who show a positive reading, again, 24 hours later, and do not take into consideration the ratio of false positive to the test.

Yes, some of these same situations do exist in other states and state and federal prisons, but for some reason, more so in the State of California. All of which leads to the following questions:

Why isn't there an ongoing inservice education being allowed to be set up for the entire prison administration, from the Warden, to the doctors, to the EMTs, to the prison guards, to the food service personnel, to the laundry personnel?

We're not talking about one day orientation by the AIDS Foundation, but an ongoing inservice education program with videos, such as the AIDS Lifeline, and other AIDS education materials in every language possible.

Why aren't these going on now? Or is it because the prison administration does not condemn rape or sex within the prison community, but are so homophobic around the issues concerning AIDS, AIDS-Related Complex, and HTLV-III positive that these inmates should just be allowed to die.

Yes, there have been unwarranted deaths, not only at Vacaville, but other correctional facilities, both of the non very seriously--but also of the very seriously ill AIDS patients because of the very lack of concern around the AIDS education, not only by the doctors, but also the

entire medical staff as well as the prison guards. For example, Alexandria D'Allessandro, a 27-year-old prisoner, who died last August at Riverside General after being transferred from the California Institution for Women. She was showing persistent infections of her throat, vagina and spinal cord, which according to the prison officials are usually easily treated, but because they were all combined together, the immune system should be suspected.

But the prison medical staff, not only failed to make proper diagnosis, but failed to prescribe the proper treatment for AIDS, and thus Alexandria's autopsy showed that she was the first female inmate in California to die of AIDS complications.

Then on August 27th at California's Men's Colony in San Luis Obispo was the unwarranted death of inmate Thomas C. McGann, who was never confirmed as having AIDS, but showed many of the AIDS symptoms, such as pneumonia, swollen lymph glands, unexplained high fevers, and when administered the AIDS antibody test, it showed that he had been exposed to the AIDS virus.

And then there is an unwarranted death of an inmate at Vacaville, whose name is unavailable at this time, who died from the lack of concern of the doctor on duty, who even, after being called several times by the nursing staff, who then after 12 hours of not getting a response from the doctor took it upon themselves and transferred the inmate to Fairfield Community Hospital to hopefully get the proper treatment for his pneumosistis carinii pneumonia

but unfortunately it was too late.

These are only a few of the unwarranted deaths that have occurred here in the State of California. Yes, there have been some unwarranted deaths in other states, but, again, not like there has been in California.

But still, to this day, Dr. Nadim Khoury, Chief of Medical Services of the California Department of Corrections, tries to make us believe that his staff is contained of qualified phsyicians. Then why is Vacaville being investigated by the United States Department of Justice? Then why has Vacaville, still to this day, never been fully licensed as a fully licensed medical facility, which Dr. Khoury is claiming it to be? Why didn't they ever apply for a Hospital Facility License from the State of California, and why was the JAC Medical Approval suspended?

Why, to this day, has there never been any form of AIDS education including safe-sex guidelines being offered to the prison population? Or is it again because of prison administration does not condemn rape or sex within the prison population, but will condemn sex if a prophylactic is used and safe-sex guidelines are being distributed, and charge the inmate with practicing homosexuality?

CHAIRPERSON WATSON: Can I ask that you summarize now?

MR. SANDMIRE: Sure.

The rest of this is just stating that the Shanti support program should be established. Our organization receives many letters from inmates from across the country

where safe-sex guidelines and safe-sex education and AIDS education is being used.

We're asking that the CCPOA be allowed to send representatives to such prisons, such as in New York and New Jersey, and we are also concerned about the IV drug users, also. About the use of needles being still available to them, but it's not on a full basis, but they get it through a friend and it's still being used among themselves and not one made available to each prisoner who is still under drug abuse.

What happens to all of these that are going to be paroled tomorrow? Will they receive the proper medical and social services and psychological support, or will they be denied because of their criminal background? Or is their lives worth more to society to keep them alive once they are paroled than their lives are worth being in prison?

We hope that this Senate Committee on the Health and Human Services help us today in getting a lot of these answers, and that this Committee ask for a full state investigation of the medical facility at Vacaville as well as the state correctional facilities where inmates have died unwarranted deaths from AIDS or AIDS-Related Complex.

We're also asking that this State Committee on Health and Human Services be one of the initiators calling for strict prison rape reform. Without such adequate legislation, not only would the statistics of people with AIDS, people with AIDS-Related Complex, and those who tested

HTLV-III positive will rise higher, but the cost of prison systems to take care of these inmates will even rise higher than that. A man or woman's personhood will be taken from them because of the force rape, which is being allowed to occur in the prison systems here today.

AIDS education, even in the federal and state prisons, should be one of the Number 1 priorities to stop the spread of this disease within the prison systems, and we also call upon this Committee here today to bring forth that process about, as I am bringing it about in such prison systems, such as in Nevada, Minnesota, and Georgia.

I personally commend this Senate Committee of the Health and Human Services for the actions they have taken around this critical issue, which is affecting every human being's life in one way or another each and every day. I also personally want to thank you, Madam Chair, and members of the Senate Committee of Health and Human Services, for letting me present the People with AIDS and People with AIDS-Related Complex Caucus testimony to you today.

Along with this testimony, I present to you a copy of San Francisco's Board of Supervisors, John Molinari's City Policy Regarding AIDS-Related Complex, which established the City's policy regarding its definition of, treatment, and services for people with AIDS-Related Complex. This City Policy was presented to the San Francisco Board of Supervisor's Committee on Health and Human Services last Wednesday.

CHAIRPERSON WATSON: All right.

MR. SANDMIRE: Thank you.

CHAIRPERSON WATSON: You will probably want to know that we are having a hearing in San Francisco on Wednesday from 10:30 to 1:00, and that meeting will be in the State Building there, Room 1194. So, you might want to contact some of your people. I think we might have them down to testify already.

We appreciate you pointing up the problem in our prisons, and we'll certainly take that under consideration.

MR. SANDMIRE: Thank you.

CHAIRPERSON WATSON: Thank you.

Dave Gooding, the Association of California Life Insurance Companies - The Task Force of AIDS.

MR. GOODING: Senator Watson, and members of the Committee, my name is David Gooding. I am senior vice-president for TransAmerica Occidental Life Insurance Company. With the Chair's permission, with me today is Mr. Brent Barnhart, of Blue Cross of California--representing Blue Cross.

MR. BARNHART: Madam Chairman, I only wanted to point out that Margaret Kelly, who is slated to testify towards the--later on in the hearing, from Blue Cross of California, will not be present today. So, essentially, we'll be presenting the industry all at once.

CHAIRPERSON WATSON: Okay.

MR. GOODING: I'm here today representing not only my company but the Association of California Life

Companies in my capacity as Chairman of the ACLIC Task Force on AIDS. The purpose of this task force is to develop and set guidelines for industry involvement in California public policy issues arising from AIDS and to present such guidelines to the Association's Board of Directors in February.

The companies represented by ACLIC sell medical care coverage and administer such coverage through employer-employee relationships, through unions, associations groups, etcetera. In addition, a number of the companies sell small amounts of individual medical care coverage within the state. A vast majority of the employee population is covered by such arrangements through, either insurance companies, Blue Cross-Blue Shield, or health maintenance organizations. These latter two provide most of the individual medical care coverage that's made available to people within the state.

Insurance companies, Blue Cross-Blue Shield and the HMOs, are regulated with respect to insurance matters by either the Department of Insurance or the Department of Corporations. Approximately, one-third of all employed persons are covered by employer self-insured programs and are not subject to such regulation.

I'd like to speak for a second about the basic position of the Life Insurance Company, or the life insurance organizations within the State of California regarding AIDS, and that is a very simple one. We believe that AIDS should be treated, for insurance purposes, as any other life-threatening disease.

With respect to in-force coverages, and here I'd like to draw a distinction between those coverages that are currently in force and those coverages which may--or are being marketed with respect to new policy owners in the future. With respect to in-force coverages, medical care expenses are covered according to the terms of the contract, without regard to the nature of the disease underlying the medical expense. I think there has been rumors around recently that insurance companies deny claims with respect to AIDS-related illnesses. That, to my knowledge, is completely false. There are no such claims that have been denied under in-force existing coverages.

In fact, there is a further--

CHAIRPERSON WATSON: Well, let me just query that a bit. You said, as far as "enforced" policies.

MR. GOODING: In force. No. I mean currently in force, already operational.

CHAIRPERSON WATSON: Currently in force. What has been denied? We have gotten reports that people with AIDS or an AID virus cannot get insurance. Are these new policies?

MR. GOODING: Yes. That, I think, is the issue that I'd like to cover under the concept of "new insurance policies." What I would like to put to rest is the rather persistent notion that insurance companies are denying claims simply because an individual submits a claim with respect to AIDS. That is not correct, to the best of my knowledge, for any insurance company either in this state

or throughout the United States.

CHAIRPERSON WATSON: Okay.

MR. GOODING: There has been also a rather persistent rumor that there has been a conspiracy among physicians and individuals within the physician and medical care community that death certificates and medical care records are being altered, to show that people have not been ill with AIDS or have not died from AIDS. Once again, we have no evidence to that effect, and quite frankly, it seems irrelevant to me since none of the--since the cause of the illness is not relevant to whether or not the claim is paid.

On the issue of new coverages, again to the best of my knowledge, there is--there are no companies within the state that include exclusion for AIDS or ARC-related expenses in their sale of new coverages. Again, I'd like to make a distinction among various types of coverages now, if I might. Group insurance for particularly groups of people--the normal evidence of insurability required by an insurance company to put coverage in force, in programs sponsored by, let's say, an employer and paid for in part or in total by an employer, generally require an "actively at work" provision. There generally is no further evidence of insurability necessary to put such coverage into effect.

There is another group of individuals, that is those who belong to or are employees of small groups--we define small groups as generally being six lives or less in a group--where they are subject to a limited amount

of individual evidence of insurability.

And then finally, there are individuals who are underwritten for life insurance--by life insurance companies for individual medical care coverage where full evidence of insurability is required by the insurance company as a condition precedent for entering into the contract.

That basically concludes my remarks. I'd be perfectly happy to answer any questions that I can.

CHAIRPERSON WATSON: Now, the latter group, you say just a few number of those require insurability?

MR. GOODING: As individuals applying for medical care coverage, only a relatively small number purchase medical care coverage on an individual basis from an insurance company. Most do so from Blue Cross-Blue Shield or from HMO.

CHAIRPERSON WATSON: I see.

Senator--

MR. BARNHART: Perhaps I should intercede, because actually we, Blue Cross and a separate company Blue Shield, probably sell more individual insurance than any other company in the state. Most of the ACLIC companies that Mr. Gooding represents do not.

Now, on individual health insurance, we currently ask for a health record. Now, sometimes that doesn't happen for somebody that goes to work for a large company and is simply insured as a matter of course in the group health plan.

When you apply for individual health insurance

now, it has nothing to do with AIDS, or long before AIDS was even diagnosed, we would ask for your health history, and if you had an active disease, particularly a life-threatening disease like cancer, you would not be insured. That probably is what's going to happen now.

CHAIRPERSON WATSON: What if you just had the virus? Now, there's a difference between the active disease and having--

MR. BARNHART: You're talking about somebody who is diagnosed with something that is now called "ARC" or AIDS-Related Condition?

CHAIRPERSON WATSON: Yes, ARC.

MR. BARNHART: There is no company policy on that, to my knowledge, we're not declining coverage. However, there is a--if anybody is actively--is in fact diagnosed as having a disease, probably what's going to happen is that the coverage is going to be limited to things other than the diagnosed condition, and that has to do with any disease, not just AIDS.

I think that's probably the kinds of things you're going to be hearing from constituents, their inability to get individual insurance. That issue, I might add as a footnote, is not necessarily the subject of this hearing, but it certainly is related. Mr. McAllister is carrying a bill to deal with the whole mass of uninsurables out there, and that's a lot of people--for example, diabetics by and large--that even are otherwise healthy can't get individual health insurance from anybody.

So, that that whole issue of the uninsurability of people is something being addressed in another bill which certainly commend your attention. It's a major issue which is part of a whole mass of issues relating to uncompensated care which of course you're attempting to wrestle with.

CHAIRPERSON WATSON: Now, you mentioned that one of the factors that is looked at is the health history. Are you requiring that people who seek these individual policies have some kind of medical examination if they're within the age range, not without of it?

MR. BARNHART: Currently, they don't have medical examinations as a matter of course. What happens is they fill out a health history form, and if there's anything on there which--for example, if they had had some sort of mental health therapy, we normally will ask for a letter from that person's doctor to basically flush out what that background was and if there's likely to be a recurrence. That would be true again for any kind of a condition.

As I understand, on our contracts, there's no box on the contract application for AIDS at this point, but if there were anything down there--there is a catchall which says any other condition for which you received treatment. I would imagine if someone checks that box, then a--we probably ask for, Who is your physician? and we would ask the physician for some kind--a letter basically explaining what your health condition is.

CHAIRPERSON WATSON: They would only be denied

if they had an active case?

MR. BARNHART: That's right.

CHAIRPERSON WATSON: Not ARC?

MR. BARNHART: I don't know, Senator. I don't know. I doubt--I think I would be misleading you if I said, well it's got to be within the definition of the Center for Disease Control or you're--if you're not within the narrow confines of the Center for Disease Control definition of AIDS, you're home free. That would be a misleading statement.

My guess is what will happen, if a person has been--has seen a physician, and the physician is concerned the person has ARC, that's reported, then more than likely that person is not going to get health insurance with us or anybody else--at least not in comprehensive policy covering that condition. They might be able to get health insurance but waiving the circumstances of the disease under present circumstances.

SENATOR McCORQUODALE: I guess the other question related to that though is what about the investigation that might go into, specially, life insurance. Would you start asking--would you have investigators start inquiring if the people belong to gay rights organizations or other types of identifying lifestyles?

MR. BARNHART: Well, that depends, that's why--

MR. GOODING: No. The answer is categorically "no." We have standards, of course, for individual evidence of insurability. They tend to be much more stringent as

the amount of insurance applied for increases. We have added to our tests in California, recently, for policies that already require full medical examination and submission of a blood sample, which tends to be policies of $700,000 amount--we have added a requirement that the T-cell count test be used to determine the status of the immune system of the individual. We do not, and to my knowledge the other companies in the state, do not routinely gather information on sexual orientation of their applicants, and we feel that such information is not necessary to sound underwriting practice.

SENATOR McCORQUODALE: Have you done any--or has the Association done any work on projecting out to what point, what percentage of the population might be affected, that you would feel that you'd really need to change the policies in order to protect the financial liability of the companies or anything like that?

MR. GOODING: Senator, we are obviously very concerned about the issue, as I think everyone who deals with the health care industry is concerned. I think you do have very separate and distinct issues revolving around medical care insurance and particularly group medical care insurance versus individual life insurance.

Within group medical care insurance, as you probably know, there is an ability to pool and spread risk among members of a particular group, so that the inordinately high claims of one particular subset of the group does not completely disrupt the pricing and premium mechanism

for that entire group. So, there is at least some ability to spread the risk of increased medical care costs through groups by gradually increasing premiums. We think that's a mechanism that may need a little support in the future, and there may need to be some--a few creative things, such as some pooling mechanisms put together, through the private sector or through the public sector, to handle that.

The issue on the other side of the house, and that is of individual life insurance is really a much more serious issue in terms of the ability of insurance companies to cope with the tremendous financial prospect for financial loss that may occur as a result of life insurance policies.

MR. BARNHART: Senator, there's one more thing I wanted to add. Mr. Gooding has already point it out, but I wanted to underscore it. For a significant proportion of the active employees in this state, that are covered by some kind of health benefits through their employment, about a third, they are--they are insured under self-insured policies, meaning that we don't have any--we don't cover them.

The picture is muddied a bit, because in some instances various insurance companies provide a claim service for the self-insured outfits, but if a self-insured employer decides to cut off any kind of health benefits for AIDS or health benefits for any person with any kind of a sexually transmitted disease, for example, which is one case I know of in California, there is nothing we can do about it, nor, unfortunately, is there anything you can do about, because

they're beyond the reach of the state law.

It really lies with Congress to resolve that problem because of the Arisa Preemption that was passed some years ago. So, I just want to stress that in order to deal with the problem--to deal with the total problem, a good portion of it, is beyond your reach, which is not something that I'm sure makes you very happy.

CHAIRPERSON WATSON: You know, we'll find some way to reach it, don't you?

MR. BARNHART: Congress certainly can reach it.

CHAIRPERSON WATSON: Thank you for your testimony. I appreciate it.

A. J. MacDonald, Wisdom Clubs of America.

MR. MacDONALD: Madam Chairman--Chairperson, members of the Committee, Wisdom Clubs of America is interested in the subject, in order to testify here today, namely blood, and the purity of the same.

CHAIRPERSON WATSON: I'm going to ask you to speak right into the mike.

MR. MacDONALD: Yes.

We're an organization that was founded about fourteen-and-a-half years ago of elder citizens that comes out of the free enterprise system, the civil service, the arts, and the professions of the United States, and we're interested in subjects and people coming out of the industries that goes on into the activity of the community and recycled into the community for the wisdom in which they hold. That's the basis for our interest here today in this blood operation.

We have a specialist here that we would like to have testify in our behalf of Wisdom Clubs of America. He's the--he's a professor, research professor and a professor of economics, at Claremont College, Dr. Eckert. I'd like to call the doctor to the stand.

CHAIRPERSON WATSON: Yes, we do have him on the list. He was at the end. He can come up now.

MR. MacDONALD: Yes.

CHAIRPERSON WATSON: Dr. Ross Eckert.

DR. ECKERT: Thank you.

Thank you, Senator Watson, members of the Committee, ladies and gentlemen. My name is Ross D. Eckert. My biographical resume and qualifications are attached as Annex A to my testimony today.

I am a professor of economics at Claremont McKenna College and Claremont Graduate School. My fields of specialization include natural resources, regulation, and antitrust. I have jointly authored, with Edward L. Wallace; Securing a Safer Blood Supply: Two Views; Washington, D.C.; American Enterprise Institute for Public Policy Research, 1985.

CHAIRPERSON WATSON: May I also ask that you summarize, since it's written? Summarize your presentation.

DR. ECKERT: Yes. It's only five pages, so I'll try to summarize as I go.

I was asked to testify here by the, two groups, the American Association of Women Voters and the Wisdom Clubs of America.

My research on AIDS via blood transfusion and the economics of blood collection is relevant to Item 5 of the Committee's issue for today's hearing. The incidence of AIDS, hepatitis, and other transfusion diseases is unnecessarily high owing to the failure of blood collectors to take feasible precautions to make volunteer blood less hazardous. Public fears of receiving "potluck" blood from traditional blood collectors are rational and explain why 21 percent of those interviewed in a recent Gallup Poll would postpone surgeries.

The best long-term approach for coping with AIDS is to prevent it. Transfusion-transmitted AIDS occurs far more often than is necessary, but prevention requires strengthening California's statutes and regulations to force blood collectors to err on the side of caution rather than risk by screening blood and donors more carefully.

Adopting the measures I am going to suggest to you today will require blood collectors to reject more blood. They oppose this, because it could cause layoffs and reduce the size and importance of their organizations. Most big blood collectors in California are monopolies, and monopolies, without pressure, will not cater to consumer's demands like competitive industries will.

Preventing transfusion AIDS requires strengthening statutes or regulations in California seven ways. The Legislature's authority, here, is clear from a 1985 Florida case in which the United States Supreme Court held that the FDA's minimal regulation of blood collectors did not

preeempt stronger local regulation.

What are these seven ways?

One, require additional blood test. Blood is now routinely tested for syphilis, the hepatitis B virus particle, and antibody to the AIDS virus, anti-HTLV-III. But this is not enough. No tests are available for the non-A, non-B hepatitis virus or the HTLV-III virus itself, except by culturing which is a slow and expensive process. But non-specific surrogate tests for veneral filth, herpes, elevated liver enzymes, T-cell reversals, and the hepatitis core antibody have been shown to trap donors who also carry HTLV-III. Effective surrogate tests should be required of all blood and plasma collectors.

Two, require adequate donor screening. Until 1983, blood collectors routinely solicited donations from persons at "high risk" for AIDS and hepatitis, and they continue to solicit blood from hospital workers who donate generously but often have been exposed to hepatitis. An inadequate self-screening program for donors, adopted in 1983, failed to eradicate transfusion AIDS because too many people lacked the medical sophistication to know whether they were sufficiently promiscuous to be at risk. This lamentable fact was acknowledged in recent revelations by the American Red Cross that some of its regular blood donors was antibody positive and belonged to at least one "high risk" group.

The way to stop the erosion of public confidence is to require that blood collectors serve patients who

want to select their own blood donor--what are called "designated donations." Most blood collectors oppose designations on the grounds that there is no proof that they are superior to "potluck blood" and that they would not be cost-effective. Public confidence might be higher if blood bankers had done research on the relation between designated donations and disease rates before rejecting the concept categorically. Cedars-Sinai Hospital, here in Los Angeles, found that designations yield extra blood for the general inventory because some cannot be used for the intended recipient. Another hospital also found that designations cost less than blood blood collectors charge.

Recently, the Red Cross Services for Los Angeles and Orange Counties noted that its donations were declining. I expect this is because more patients are going to hospitals like Cedars-Sinai and Long Beach Memorial which permit designations.

CHAIRPERSON WATSON: Since we do have a copy of your presentation, I would appreciate if you would just hit the highlights.

DR. ECKERT: All right.

I'm sorry. Skip which?

CHAIRPERSON WATSON: Just hit the highlights, each one of your numbered points--if you just hit them and give us a brief explanation.

DR. ECKERT: Yes. I will be happy to.

Third, blood should be labeled by gender. Patients

prefer getting--receiving blood from friends and family and blood that they can be more likely to rely upon as being free of disease. Consumers can choose different kinds of aspirin and other medications, so why shouldn't they be able to choose their blood donors, too? But in Los Angeles and Orange Counties, men made almost half again as many donations as women in 1983, and the percentage of donors who are men increased with the number of donations, whereas the percentage of women declined.

Assemblywoman Doris Allen, next year, will introduce a bill for gender labeling that urge you to support. Employers give employees time off form work to donate, which increases the supply of men who donate, so blood collectors should use credits or travel vouchers to encourage donations from women who work at home.

Fourth, I urge you to require registries. The pool of blood donors in the United States is now about 8 million persons. Twenty five percent of these are new donors each year. Drawing blood from so many people with so many random, first-time donors is bound to spread disease. Registries would limit donors to persons who were known to be health, had incentives to maintain their health, gave blood as often as good health allowed, and were replaced with new donors only when--from the same groups, only when absolutely necessary. These would exclude people in "high risk" groups.

These registries are effective. We've seen

cases where fine hospitals in the United States have used registries of cash and noncash donors before with complete success and had minimal incidents of hepatitis in their donor populations. California blood collectors should be required to maintain registries and exchange data via microcomputers.

Fifth, permit tax credits for donations. California's revenue code should be amended to provide a tax credit incentive of, say, $75 for people who are registered donors, by the criteria I've just mentioned, and yet who could donate up to a maximum, say, of five times a year.

Sixth, re-establish negligence liability. One of the principal reasons that blood testing and donor screening in California has been so lax is that blood and plasma collectors are free of tort liability for the diseases their services transmit. Why should blood transfusions be exempt from liability when their dangers exceed those that a badly-designed power lawnmower can cause, when full liability is applied against those manufacturers?

Seventh, require a lower rate of anti-HTLV-III false negatives. As has already been mentioned today, some people will donate before they've developed antibody, and it has been estimated by one study, co-authored by Dr. Gallo who is one of the co-discoverers of the HTLV-III virus, that an estimated four percent of AIDS carriers will not develop antibody at all, and therefore will be missed by tests that screen for antibody only.

It is not clear that these tests have been calibrated to minimize the rate of false negatives. In a recent study in the Journal of the American Medical Association, doubling the threshhold for a positive test, reduced its sensitivity, and cut false positive, but raised false negatives, especially among "high risk" groups, and false negatives, of course, are people who carry the virus and are capable of spreading infection, but who are not trapped by the test. Blood centers are the principal markets for these test kits, so there's-- the authors of that study suggested that the tests' "sensitivity may have been compromised to afford the high specificity values that were advertised." If that is true, it supports my contention that blood quality has been sacrificed for quantity.

Blood collectors now realize the antibody test does not fully protect the public. As has already been mentioned, the American Red Cross has expressed misgivings to the United States Senate Committee on appropriations concerning the theoretical and practical defects, quote-unquote, of these tests, and emphasized that we need new ones to directly identify infective blood.

So, Madam Chairman, I would say in conclusion, until these tests are developed and their accuracy is known, only the surrogate tests that I have spoken of before, gender labeling, and registries will reduce the threat of AIDS, hepatitis, and other viruses

that have yet to service. How well Californians are protected from these insidious diseases depends in large measure on the Legislature responds at this critical juncture.

CHAIRPERSON WATSON: Thank you.

DR. ECKERT: Thank you for the opportunity to speak, and I'd be glad to answer any questions that you may have.

CHAIRPERSON WATSON: We do have your testimony, and we certainly will take under consideration as we will all the others.

DR. ECKERT: Thank you.

CHAIRPERSON WATSON: Thank you.

Donald Gorman, Documentation of AIDS Issues and Research Foundation, Inc.

MR. GORMAN: Madam Chairperson, and Honorable members of this Committee, in the interest of brevity, I will not read the complete testimony before you--

CHAIRPERSON WATSON: Thank you.

MR. GORMAN: --but rather will refer you to lists of certain specifics contained therein. In addition, extensive documentation is also submitted for the written record for the perusal of this Committee in reference to the issues raised in my presentation.

The testimony which I am presenting is not meant to be a total assessment of all aspects of AIDS health care management. The needs and complexities of this situation are so multifaceted as to require

the participation and input of persons working in a variety of AIDS-related capacities. I trust that the combined testimony presented before this Committee will contribute positively towards further development of a comprehensive and successful strategy for management of the AIDS epidemic.

Specifically, this testimony will address the following issues: further educational developmental needs aimed at major "high risk" populations; co-factor research, specifically, intestinal parasites and nitrate inhalants and the implications of this information for epidemic management; current and future treatment strategies regarding research on combination drug studies; and, present and future clinical research needs.

Historically, there has been great reluctance on the part of health department to provide education on sexually transmitted diseases. The reluctance stems from a fear of being perceived as advocating eroticism in general, or promoting the gay lifestyle, in the case of AIDS. This reluctance does not contribute positively to risk reduction behavior.

People will continue to have sex whether educated regarding sexually transmitted diseases, AIDS, or not. The development of educational materials to catch the attention of sexually active "at risk" populations must be explicit by the very nature of the subject.

We are dealing with a highly-lethal disease which is transmitted mainly through specific types of sexual behavior, and these must be directly addressed

in educational materials if people are to understand how to protect themselves against AIDS. As public health and hygiene are no longer taught in many schools as part of the general curriculum, vaguely worded and or euphemistic guidelines will fall on deaf ears. to be less than honest or explicit with sex-positive materials will directly contribute to a devastating death toll from the spread of this lethal disease. Now is not the time to adopt one minority's precepts at the expense of another minority's constitutionally guaranteed rights to life and liberty.

Therefore, the Documentation of AIDS Issues and Research Foundation urges the Department of Health Services to implement the following:

- promote educational materials targeted to all "at risk" groups;

- continue to educate health providers through initial workshops, lectures, followed by ongoing updates.

- implement programs for all public schools throughout the state to educate the general population regarding hygiene and modes of disease control; and

- develop model programs to disseminate information to county health departments.

Specific risk-reduction techniques must include education regarding condoms about which further details are enclosed. Also, information about nonoxynol-9, which is a mild spermacide that effectively kills the HTLV-III/LAV virus on contact. We also desire that

the DHS be directed to conduct a study on the oral and anal use of this product, in that the Center for Disease Control has been unwilling to accept this responsibility. Further specifics regarding condoms and nonoxynol-9 are included, herein.

Making this information widely available to sexually active people will drastically reduce AIDS transmission. Condoms with the added protection of nonoxynol-9 would benefit the majority of individuals in society at risk for AIDS who may not successfully change sexual mores, but could adopt to using condoms. While it is fine to encourage individuals to engage in other sexual activities at less risk for AIDS, such as mutual masturbation, frottage, etc., the DHS must recognize human sexual behavior as it is if educational programs are to be respected and heeded. To degrade prevalent forms of sexual expression, motivated by archaic morality, will only serve to alienate targeted populations and promote the continues spread of AIDS.

It was demonstrated in 1982, that 60 percent of gay men surveyed in San Francisco had intestinal parasites, although most were asymptomatic. It is also known that besides gays, parasites have been epidemic among Haitians, Zairians, and IV drug users, other groups at "high risk" for AIDS.

How can this information assist in the control and management of the AIDS epidemic? Basically, by eradicating widespread exposure to intestinal parasites

it is possible to effectively decrease the incidence of development of the disease even in the presence of exposure to the HTLV-III/LAV virus. In the absence of an effective treatment, this is a sensible and logical approach.

There are a number of management interventions which need to occur and for which the DHS could assume responsibility, and they're listed for your reference. Just to highlight a couple of them:

- There is a need for treatment on the basis of any parasitic infection with or without the presence of symptoms.

- There is also a need for widespread community education regarding parasite screening, and the following list is also provided for your reference.

In San Francisco, we have been fortunate to have the support and cooperation of Dr. David Werdeger and the Department of Public Health, who have responded positively to a number of the previously mentioned areas of needed attention. This is, obviously, a major problem in that parasites are also epidemic and have been among gay men in this country since the late '70s. Conceivably, this problem could now be under control if the attention of public health departments had not been usurped first by the hepatitis B epidemic, followed by the emergence of AIDS, whose immediate results produce a life-threatening situation.

We only now are beginning to realize how widespread

parasitic exposure has set up the risk populations for development of AIDS. This effort will require millions of dollars, initially, to provide adequate management. However, further delays will simply ensure increasing financial constraints in the future. Also, further delays will allow the AIDS epidemic to continue unchecked among individuals exposed to the HTLV-III/LAV virus. This information is invaluable to AIDS prevention. The time to act is now.

Similarly, poppers have been shown to be another major life-style related risk factor. Poppers is a generic name for nitrite inhalants, and I have enclosed an extensive amount of research done on this in my written testimony to denote how poppers have been shown to statistically correlate with presence and development of Kaposi's sarcoma in persons with AIDS.

These drugs were never licensed by the FDA, but were allowed to be marketed as "room deodorizers" although very few individuals purchased them for this use. Finally, poppers distort the judgment of the user and like other recreational drugs, possibly making the user more likely to engage in "high risk" behavior.

On the subject of combinations of drugs, it is widely recognized that to provide effective treatment for people with AIDS, and AIDS-Related Condition, a combination of antiviral agent and an immune booster will be the most likely effective approach. Mr. Boneberg also referred to this in his testimony, so I'll skip ahead slightly.

Presently the Documentation of AIDS Issues and Research Foundation is conducting a study to determine the effects of Ribovirin and Isoprinosine in persons with AIDS, and AIDS-Related Conditions in combination. Although it is legal to obtain these drugs in Mexico in personal use quantities, there is not attempt on the part of federal or state health departments to monitor the effects of these two drugs in combination.

This study, known as Project Inform, has been criticized on the basis that it is not a double-blind study, but we believe that individuals whose lives are threatened by AIDS should not be made to suffer the anxiety of lack of treatment of choice because they are recipients of placebos in traditional drug studies. Anonymous audits of records of persons with AIDS not receiving therapy or single-blind studies which include volunteers who choose not to do a drug or drug combination, are reasonably valid approaches for ascertaining information regarding drug efficacy.

We also question why the ethics of Project Inform have been challenged when researchers from Drs. Gallo to Montagnier, Drs. Kessler to Volberding, and others admit that a multidrug approach combining an antiviral and immune augmentor is the most likely beneficial direction of treatment development. One wonders if this is not another defensive maneuver to deflect attention from the fact that single drug studies of various immune stimulators persist, sponsored by federal health agencies,

which quite possibly enhance the development of AIDS when used alone, without an antiviral agent.

Availability of sufficient numbers of AIDS--

CHAIRPERSON WATSON: What is supporting that information? What supports that?

MR. GORMAN: There is--there is information that has shown that in studies of gamma interferon for instance, which is an immune stimulant, has been shown--

CHAIRPERSON WATSON: Is that through CDC, their studies?

MR. GORMAN: Well, gamma interferon has now been discontinued, but it was National Institute of Health sponsored, and one of the related agencies, and it was to actually accelerate the development of the disease, because it stimulates the T-cells which are infected and generates more T-cells and promotes further infection by creating a greater medium for the AIDS virus to persist. There are other immune stimulants, which are currently being tested, which have the same potential.

The NIH, in the FDA--in the workshop sponsored June 3rd, by the NIH, FDA, and CDC admit that combination studies are the most likely approach, and yet because of cumbersome FDA regulations they insist that two to five years is necessary to study certain of those drugs in order to meet current regulations, and this is not acceptable under these circumstances.

Availability of sufficient numbers of AIDS

treatment programs are necessary which provide treatments of choice utilizing a wide variety of medications currently being researched. Provisions for using such medications in controlled setting by individuals making informed decisions in conjunction with qualified medical personnel for personal health management, is the responsibility of state and federal health agencies. The priority should be the health and welfare of the population for whose needs and concerns these agencies exist to serve.

Finally, my last point is the issue of viral culture availability which needs attention at the level of AIDS management and the Department of Health Services. Limiting factors, regarding viral culture, are: the cost, which is 600 to $1,000 presently; limited facilities for performing cultures; limited numbers of individuals skilled in viral culture technique; and previously limited state or federal commitment to developing facilities which could provide this service.

This is an important issue even though one hears that viral culturing is not really necessary and that other factors are more significant. However, the CDC definition of AIDS, presently, is based in part on a positive serologic or virologic test for HTLV-III/ LAV virus. It is also known that viral culturing facilities are necessary in order that researchers can, under certain circumstances, qualify for federal funds.

Viral cultures are further necessary for individuals to participate in most experimental treatment programs, and

these programs are the only treatment that currently exist. Use of viral cultures can identify presence or absence of virus in individiuals who are antibody positive. Widespread viral culturing availability would also contribute valuable information on what difference may exist between persons with antibody positivity and persons who may manifest the disease.

It is no minor point that there is a great need--a great need for further development of more sophisticated diagnostic research techniques which would permit early identification of individuals likely to develop severe ARC or full-blown AIDS. Based on this information, early drug treatment, when developed, could be started with a high likelihood of success.

For these and many other reasons, viral culture testing should be widely available to anyone who is antibody positive or symptomatic for AIDS or ARC. Viral culture testing should be widely available without cost to those in need and available anonimously just as the antibody test is in this state. The importance of utilizing state of the art techniques for detection of this virus needs to be affirmed by the Department of Health Services. In addition, necessary funding should be allocated and action taken to ensure its increasing availability.

For many reasons, societal, cultural, and circumstantial, we are facing a disease which threatens several segments of the world community. However, research being done in the field of AIDS has potential benefit

for increasing our understanding of a wide variety of disorders. It is also certain that AIDS will change the way health care is delivered in this country forever.

There is an increasing awareness of the need for individuals to assume more responsibility for their health maintenance. There is also the realization that working together in the face of extreme obstacles makes us stronger individually and collectively. Affirmation of such positive effects provides an important sense of balance in this difficult situation.

Objective analysis, aggressive management, in terms of increasing financial commitment to AIDS research, treatment, and care of persons with AIDS and AIDS-Related Conditions, and heightened compassion for those with this disease, or at "high risk," are important elements in a success-oriented approach to winning the war against AIDS.

I thank you for the opportunity to express these concerns and commend this Committee for its attention and commitment to developing effective management of this grave health crisis.

CHAIRPERSON WATSON: Thank you. We appreciate your scholarly presentation.

Thank you.

Steve Russell, AIDS-Related Complex-AIDS Vigil.

MR. RUSSELL: Thank you, Madam Chairperson, and distinguished guests.

I am a person with AIDS-Related Complex, commonly

referred to as ARC. My name is Steven Russell, and I'm here to testify on behalf of all persons with ARC, the the ARC-AIDS Vigil in San Francisco, and in the interest of all humanity.

I would have preferred to have been able to present an accurate definition of what ARC is to this Committee, but after five plus years of dealing with the ARC-AIDS crisis, there is still no definitive consensus of opinions.

People with ARC have many of the same symptoms as people with AIDS. Our immune systems are depressed to the point to where our susceptibility to any illness is greatly intensified. The common cold can mean a death sentence to an immuno-depressed person. ARC is claiming lives in ever increasing numbers.

After extensive searching to the best of my ability, I have learned that as of this point in time, no figures have been kept on the number of deaths from ARC. Dr. Spira, of the Center for Disease Control, CDC, in Atlanta, says that enough research has been done to safely estimate that ARC outnumbers AIDS cases by a factor of 10 to 1.

The CDC also states that as of October, 1985, there were 14,400 reported cases of AIDS in the contiguous United States. Using the CDC estimate of a 10 to 1 ratio, this means that there are at least 144,000 people with ARC, every one of which might result in death.

Since we are diagnosed as ARC instead of AIDS, we

are not eligible for the benefits people with AIDS receive. We do not get Medi-Cal, MediCare, State Disability, or Social Security. This is very disturbing considering many people have had their diagnosis changed back and forth between AIDS and ARC several times. While diagnosed with AIDS, they receive these benefits, but as soon as their diagnosis gets downgraded to ARC, their benefits are cut off.

I am fortunate. I live in San Francisco where I am eligible for general assistance, which is welfare. That is $288 a month. I have to use that money for rent, food, and all living expenses. There are many times I cannot even afford bus fare to get to the doctor.

There are countless thousands of people with ARC across this country that don't have welfare of any kind to fall back on. I know. I lived in Florida where I was told not to work, yet no welfare agency would even consider my case. I was told by one welfare worker, "Please don't come to the office. We don't want to catch what you have."

Many of us have been fired from our jobs, solely because of our diagnosis. Then we lose our health insurance and are left with going to the few facilities that treat medically indigent adults. These facilities are not able to handle the enormous caseloads. Therefore, we wait hours for rushed exams and treatment.

I personally have sat for six hours waiting to see the doctor, only to be told, "You have ARC. We

see this all the time. There's nothing we can do."

This would not have to happen if people with ARC had Medi-Cal. We would be able to choose which hospital we wanted to go to rather than be forced to go to one very over-crowded hospital.

Many of the people with ARC and AIDS in California, San Francisco in particular, come here from across the country, because it is common knowledge that the West Coast is the place to be for treatment for people with ARC or AIDS. Families are being torn apart by this disease. Parents disowning children, throwing them out on the streets if they live at home, or refusing any contact if they don't, is not an unusual occurrence.

ARC-AIDS hysteria is a reason we need laws against discrimation. People who can work should be allowed to. I have been fired twice, strictly because of my diagnosis. Also, I have been refused dental treatment, service in restaurants, evicted from apartments, and basically treated like a leper. This is all a result of ARC-AIDS hysteria, and it is blatant discrimination.

Needless to say, the stress factor is very great on a person with ARC. We may or may not have a fatal opportunistic infection. We may or may not die. We may or may not get better. We are told all of these things, and subjected to all of the stress I have been telling you about, and then told the best thing that we can do is to avoid stress.

Now, I wish to give you a bit of background

on the ARC-AIDS vigil in San Francisco. The vigil began on October 27th with a one night, permitted rally and vigil. On October 28th, at the end of the permitted vigil, myself and another person with ARC decided to chain ourselves to the Federal Building, that houses the Department of Health and Human Services and the Food and Drug Administration. We were willing to mar clean police records if our arrest would draw any attention to ARC and the needs of people with ARC.

We had a support team of seven people, including a person with AIDS, who slept on a blanket on the pavement in front of us. They were there to protect us from physical abuse and to notify our lawyer upon our arrest. We were not arrested, and a week later, the San Francisco Board of Supervisors unanimously passed a resolution supporting the vigil and our moral appeals.

We also have the support of Senator Wilson and Congresswoman Burton, as well as several churches, labor unions, and others. The vigil has since grown to include several tents and at least a hundred active participants.

Below are the moral appeals of the ARC-AIDS vigil. I strongly urge you to support them.

Number 1, we appeal for a federal government commitment of $500 for research to find a cure--

CHAIRPERSON WATSON: $500 million, you want to say, don't you?

MR. RUSSELL: 500 million, excuse me.

Whatever it takes.

CHAIRPERSON WATSON: It will take more than 500.

MR. RUSSELL: Yes.

--find a cure for ARC and AIDS. This will not be taken from existing social programs.

We appeal for federal recognition of ARC as a critical dimension of the AIDS crisis. We call for proper funding for medical care and support for people with ARC as presumptive evidence of disability. This must include Medi-Cal, MediCare, Social Security Disability Insurance.

Number 3, we appeal for the FDA to allow American physicians to prescribe medicines and treatments for ARC and AIDS available in other countries.

Number 4, we appeal to President Reagan and government officials at all levels to publicly condemn discrimination related to ARC and AIDS, and to repudiate incitements of fear and hatred which exploit this tragic epidemic.

In closing, I wish to thank you for your time and interest. I hope my testimony will increase your awareness as to the gravity of ARC and its inherent problems.

Thank you.

CHAIRPERSON WATSON: We appreciate your testimony and bringing attention to those with ARC. I think your request is reasonable, and we certainly will take it

into consideration.

MR. RUSSELL: Thank you very much.

CHAIRPERSON WATSON: I doubt if we will be getting any help from the federal government, because of the Gramm-Rudman as you already know, and they're cutting back on funding social service programs. The fight will be in the coming years as to which programs get cut and how deeply are they cut.

So, we all have to be vigilant, put the pressure on our Congress, Representatives, and Senators to protect the interests of the majority of the people, and especially as this disease is concerned, because it could spread through this population--I mean through the entire population in a way unheard of by other diseases--recent diseases.

So, we've got jobs cut out for us.

MR. RUSSELL: Thank you.

CHAIRPERSON WATSON: Dr. Hal Frank, San Diego AIDS Project.

Dr. Frank's not here.

Porter Warren, Florence Nightingale Nursing Service Aid for AIDS Patients.

Is Mr. Warren in the room?

I'm sorry. Porter--that threw me off.

I guess I should have known if it's Florence Nightingale, huh?

MS. WARREN: Good afternoon.

CHAIRPERSON WATSON: Good afternoon.

MS. WARREN: I'm here for two reasons. A; Aid for AIDS Patients of which I'm a board member is a survival committee that needs--that gives money to AIDS patients who don't make it on Social Security or have lost their jobs like the young man with ARC, who have no money to live. We pay the money. We need extra help from the government, grant, whatever is necessary to help us administer to our people, our clients. They don't have any money.

There is--welfare takes six to eight weeks. ARC patients get nothing. These men are being kicked out on the streets. They get kicked out of county hospitals. They need help--financial assistance. Whatever--more grant to the counties to help us get more money for these people or whatever.

And the other reason I'm here is I run a nursing service that specializes in AIDS cases. When I first started this I realized there was homophobia in nursing and with people abounding in the community. I have a doctor at Cedars-Sinai Hospital, Irving Posowski (phonetic) is his name. He refused to treat a patient. His comment was, "Let the patient die."

Needless to say, the patient died because he refused to take care of the patient. It is documented with x-rays and nurse's notes. These are the problems we're facing.

The gentlemen said, "Well, let them go to County Hospitals." County hospitals are treating patients

like lepers. When they get kicked out of County, there is nowhere to go. Medi-Cal does not pay for in-home nursing. There is no support, medically, for patients after they get out of the hospitals. We need Medi-Cal. We need hospice care. We need the government to help people with AIDS who are not private insured, and this is my main concern.

There is bad nursing care, because of homophobic nurses, abandonment of patients. I'm asking you people to help--some way or another, to help our patients live their last months or years with dignity, and darn it help with the money, because a county will--USC Medical Center will release a patient, a pneumocystic pneumonia patient. Medi-Cal will not pay for 12 hours of nursing. County does not want the patient. There are no SNFs, skilled nursing facilities, that will take a patient. It is illegal to put a contagious disease in a skilled nursing facility.

We need skilled nursing facilities down here. San Fancisco, at least, has Hospice. We have none of that. We are in desperate need of medical care for AIDS patients. We're in need of doctors who know what the disease is and are not homophobic that say, "He's gay, let him die." It's his judgment for his lifestyle.

For nurses at UCLA, who drop a patient off in a patient's room and refuse to feed the patient the patient died two weeks later from starvation.

I can recite episode, upon episode of criminal

negligence to AIDS patients. Somehow it's got to be stopped. Somehow they should be able to have care--proper care, and the ones who are paying the biggest penalty are the Medi-Cal patients.

There isn't anything for them once they're released from the hospital.

CHAIRPERSON WATSON: We're quite aware of that problem. It has been brought to us by LA County personnel, and they're personnel refusing to provide services to the AIDS patient. That's one of the reasons for this hearing.

So, we intend to follow-up and pursue and see just what we can come up with to very clearly define what the responsibilities are.

MS. WARREN: The responsibilities--I can name home health agencies, well I won't name the names of them, who will send nurses or attendants out to patients who abuse them physically, steal something, are drunk, refuse to show up. These are problems that are happening in LA County. So--

CHAIRPERSON WATSON: Well, we'll be in touch with you.

Thank you very much.

MS. WARREN: Thank you.

CHAIRPERSON WATSON: Corinne Sanchez, El Proyecto Barrio, Inc., and the Southern California Program Directors.

MS. SANCHEZ: Thank you, Senator Watson, for having us here today. I will make my comments brief, and

submit written testimony subsequent to this hearing.

I am here on behalf of not only a nonprofit drug abuse community based agency, but also Southern California Program Directors, which consists of approximately 50 executive directors of drug and alcohol programs throughout Southern California. These programs offer residential services, outpatient counseling, methadone, early intervention, and prevention services including detoxification.

It has been conservatively estimated that approximately 20 percent of AIDS victims are IV drug users. This is a serious risk group in our particular target population of people which we are trying to serve. In an attempt to help these victims with this disease, the Southern California Directors, in cooperation with the Alley AIDS Project and with California State University-Los Angeles, will be sponsoring a two-day conference.

The conference major concern is how to provide the personnel these drug and alcohol programs throughout Southern California with information that is valid and not myths, which many people are functioning from.

Secondly, to provide the actual personnel on a day-to-day basis to work with these victims. We will provide this in January. It is a mere, small attempt on our part, as private executive directors of these programs to put our money where our mouth is.

We come to you today to testify that there is a serious lack of information and money to service

AIDS victims, not only a general in the general population, but in the substance abuse-drug abuse community.

We feel there needs to be additional dollars to provide additional information, educational material, training, specialized training of administrators, and to deal with the issue of insurance liablity. Presently, right now, insurance liablity is skyrocketing, and now with many of our clients that are AIDS victims, the insurance is going to go up.

We're concerned on the part of programs, and as directors, how can the state help offset these costs and these services so desperately needed.

Our recommendations to you today is there is a need for additional dollars from the ones that exist, presently offered, or provided to drug programs to expand the legislative--or to provide money from the Legislature to expand research on AIDS, particularly in the substance abuse community. This community is not a popular community, but it does inflict many minority populations which have been ignored seriously in the past as well as the general drug community.

We feel there is a serious lack and need of more educational information and materials to be developed and disseminated to the community at large on AIDS as it affects the substance abuse community.

Thirdly, we feel there needs to be additional dollars to provide technical assistance that will be able--that will provide training to staff, drug and

alcohol programs that are dealing with AIDS clients. One of the serious problems is--because of the myths, many staffs listen to these hospital issues that have been raised do not want to deal at all with the AIDS victims that are also substance abusers, IV drug users.

We feel there is also a need, as I stated earlier, to provide offset for financial assistance, for insurance costs, and suits that will probably be--or potentially be arising.

And lastly, we feel, to follow our model is to provide and allocate money that will conduct regional conferences in Southern and Northern California for administrative--administrators and program personnel in delivering direct services to AIDS victims.

Thank you.

CHAIRPERSON WATSON: Thank you for your testimony.

Sue Sedaka of the Visiting Nurse Association of Los Angeles.

MS. SEDAKA: Madam Chairman and Committee, my name is Sue Sedaka, and I'm the associate director of community relations for the Visiting Nurse Foundation, and I'm representing the Visiting Nurse Association of Los Angeles and its corporate affiliate Visiting Nurse Home Services, Inc.

We saw our first AIDS patient in August of 1983, and at that time began working with the AIDS Project-LA to coordinate a community effort to support these patients. The VNA's mission, by its own statement, is

to care for people regardless of their ability to pay or their diagnosis or any other discriminatory issue, and we have done so.

We've seen over that two-and-a-half year period several things, that I think, that need to be done with regard to how we manage this disease. Given the fact that research has not as yet found an adequate treatment, and that is not coming in the near future and the disease is not going to go away, we have two other issues that we must deal with. One is education, and the other is provision of care and treatment for these individuals.

Education, although a part of our whelm, is not our primary function, and so I'll confine my discussion to the provision of care and treatment. We see that within that area, those persons with AIDS and ARC are not adequately informed early on, when they first become diagnosed--and I'll use the term "diagnosed" with ARC, even though it isn't a classified disease--about what their options are within the health care system. They are not given adequate information on the course of the disease or where in the disease they may choose which form of health care is most appropriate to them.

This is not concerted effort on anyone's part to withhold information, given the way in which Los Angeles is constructed--it is a large community with a variety of entry points into the health care system. Many hospitals provide care. Many organizations have cropped up in the last couple of years, specifically,

to help these individuals. And so, they get specific information from different groups, and that isn't always the best way.

We feel there needs to be a educational component, when a person is diagnosed with either one of these diseases, to allow them an understanding of what is going to happen to them if the worst should happen. We would like to think that they would get well, but that has not been the statistical information.

The second area that we see that we need to deal with is a more flexible reimbursement system within both private insurance and the state. Given the current laws that govern how health care is provided in the home, it is difficult for a patient to pass through the continuum of care and receive the kinds of care they need without being pushed back into the hospital inappropriately. What generally happens is after an opportunistic infection occurs the patient is put into a hospital to receive treatment. Once the treatment modality is finished, the patient is discharged to the homefront with or without assistance from the community, most frequently without. Without any education or understand of how to optimize their wellness, deal with their adequate nutrition, and support those types of things.

The Homemaker Chore Program, through the State of California, provides money for homemakers. Homemakers are inadequate to care for a communicable disease that require semi-skilled observation for most of the patients'

term at home.

We feel that if the State of California would look at a more flexible way in which to pass the patient through the continuum of care, attendants, private-duty nursing, intermittent home health, and hospitalization as a total package could be individualized to the needs of each patient. This is being done through the insurance industry. I think we've proven with a pilot program with TransAmerica that cost-savings can be, in fact, done this way, and if we save enough dollars on the patients we're serving now, we may have enough dollars left over to care for those that come down the road. I believe this is very important in the way we're dealing with things.

In our experience in dealing with the insurance industry, we find that most of them have been most cooperative, and we have not had any cases where an insurance carrier, per se, has declined service. As a matter of fact, with a diagnosis of AIDS most of them have gone out of their way to support the patient, and some patients who had their insurance lapse, because they were unable to keep up with benefits, were allow to reinstate and go to terminal liability so they could retain their coverage.

The area that the gentlemen from the insurance companies discussed as being a loop or loss is the area of self-insureds. Those organizations are traditionally unsophisticated in their ability to understand the medical

model and what occurs, and we believe that some support for those individuals is absolutely necessary, because the patient doesn't know the difference between a self-insured or private carrier. So, some of the complaints you've had about the insurance industry may, in fact, be from another arena.

We believe patients should be informed along the road of their disease where they are, and that both health care practitioners and community service organizations must recognize that the disease does progress downhill, and that at specific stages, the patient be informed of the probability and the way in which care should be rendered next, so that the patient has some say in whether or not they choose to live longer and pursue treatment, or they choose a palliative symptom management program to support their care so that they may have some quality of life during their last days. In essence, I'm talking about hospice care.

We provide hospice, through hospice in the home, to anyone regardless of their ability to pay, and we have a large constituency of AIDS and ARC patients on service at any one time, but we do not see a sufficient number given the statistics that come from the health department in this city, and obviously, no one agency could support every AIDS patient that came--

CHAIRPERSON WATSON: How large is your agency?

MS. SEDAKA: How old is our agency?

CHAIRPERSON WATSON: How large is it?

MS. SEDAKA: How large? We're the largest home health agency in California. We cover the entire Los Angeles area. We see, somewhere in the neighborhood of, 14,000 a patients a year and make, something in the neighborhood of 200,000 visits.

Visiting Nurse Home Services, our corporate affiliate, is the provider of daycare or attendant care through the AIDS Project LA, and so we see a quite large number of patients. I wish I could give you a specific number. However, like most people in this industry, gathering statistical data on AIDS and ARC is new, and we don't have an adequate number to put into testimony, but we would be willing to submit that as soon as we have a better data.

CHAIRPERSON WATSON: Thank you.

MS. SEDAKA: And so we feel that if we had an organized model, for which to care for these types of patients--which are not dissimilar from other life-threatening illness, patients who have to deal with those--that we might be able to manage what we have to do with health care and be able to service more patients with the amount of money that obviously we have available.

Visiting Nurse Association, and other Visiting Nurse Associations throughout the LA County and Southern California are aligned in a coalition and are always available to take care of AIDS patients.

CHAIRPERSON WATSON: What we could do is look at some type of model project in a particular county

or community.

MS. SEDAKA: Currently, under the new bill that was passed, 1251, there are RFPs going out for such studies, but I'm not sure how long it will take for those studies to get done, and--

CHAIRPERSON WATSON: Rather than looking at a study, look at just instituting a model and getting the information from that model. We will call you and get some of your ideas, for what I think is--

MS. SEDAKA: I would be delighted to participate in that.

CHAIRPERSON WATSON: Okay.

MS. SEDAKA: Thank you very much.

CHAIRPERSON WATSON: Very good. Thank you.

Dr. Kamel with the Hemophilia Council of California.

Is Dr. Levi Kamel here?

Okay, Norma Watson?

Norma Watson is not here, either.

Well, that takes care of our list of those who have signed up to testify. I want to thank all of you that lasted throughout the afternoon as well as the morning, and we have collected a lot of very informative input.

I will be carrying a piece of AIDS legislation in the new session, beginning in January. What it will be, or what those pieces will be we don't know yet. We're going to review the transcription. We're going to also review the presentations and see which way we

need to go.

I think there have been very, very good recommendations that we need to look at. Here in California, our funds are probably much more readily available than they would be nationally, and I think now is the time to make that thrust with this administration.

So, we're going to need your help, and we're going to need your telephone calls and your letters, along with your input.

So, with that, I will conclude the hearing and thank you very much.

(Whereupon the hearing for the Health and Human Services Committee was adjourned at 4:15 p.m.)

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REPORTER'S CERTIFICATE

STATE OF CALIFORNIA)
) ss.
COUNTY OF VENTURA)

I, TAMARA MARIE DEUTSCH, do hereby certify that the foregoing pages, 1 through 107, inclusive, constitute a true and correct verbatim transcript of proceedings reported by me.

WITNESS my hand this 11TH day of January, 1985 at Ventura, California.

TAMARA MARIE DEUTSCH