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Interim Hearing on AIDS Prevention Strategies

Senate Select Committee on AIDS

AIDS PREVENTION STRATEGIES

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

December 18, 1987
West Hollywood Park
Multipurpose Room
West Hollywood, California

STATE OF CALIFORNIA

INTERIM HEARING

SENATE SELECT COMMITTEE ON AIDS

AIDS PREVENTION STRATEGIES

WEST HOLLYWOOD PARK

MULTIPURPOSE ROOM

640 NORTH SAN VICENTE BOULEVARD

WEST HOLLYWOOD, CALIFORNIA

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SENATOR ART TORRES

STAFF PRESENT

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JUDY SPIEGEL
Director of Education
AIDS Project Los Angeles

SANDRA THOLEN
California School Nurses Organization

CAROLANN PETERSON
California Federation of Business and Professional Women

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PROCEEDINGS

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CHAIRMAN HART: We'll begin. I want to welcome everybody to the Senate Select Committee on AIDS hearing in West Hollywood.

My name is Gary Hart. I'm the State Senator who Chairs the Committee. I represent portions of Santa Barbara and Los Angeles Counties in the California State Senate.

Senator Diane Watson, who Chairs the Health and Human Services Committee, was with us through the lunch hour, but she had another engagement and is not going to be able to remain with us for the rest of our afternoon session.

Senator Art Torres, who serves on the Health Committee and has a number of other leadership responsibilities in the Senate, and represents the East Los Angeles portion of Los Angeles County, is expected to join us shortly.

The other persons that are here with me on the dais I'd like to briefly acknowledge. On my far left is Debra Smith, who is the Committee Secretary. Next to Debra is Drew Liebert, who is on my staff and has been very active in the AIDS education prevention legislation that I carried last year and will be reintroducing this year. On my right is Kathryn Duke, who is the staff Consultant to the Select Committee on AIDS.

I want to welcome everyone here to the final interim hearing of the Senate Select Committee on AIDS. This Committee has had a busy schedule these past three months since the Committee was formed by the Senate Rules committee. We've just

returned from a trip to Washington, D.C. and New York City, where we discussed federal AIDS policies, and to also see what's taking place in New York State, one state that has a greater number of AIDS cases than we have here in California.

We've also held hearings on -- for want of a better term we'll call them AIDS Overview, AIDS and IV Drug Users, Treatment of People with AIDS, and today our subject is AIDS Prevention Strategies, which in a sense, I think, is the most important subject of all.

This morning we visited AIDS Project Los Angeles and talked to volunteers about their activities there, including the AIDS Hotline. We also learned what it's like for someone to go through the AIDS test process by participating in an enactment of someone visiting an alternative test site and going through the entire testing and counseling procedure.

In today's afternoon hearing, we will consider what our overall strategy should be for preventing the spread of HIV infection and subsequent progression to AIDS. Our scheduled witnesses will cover such topics as education, testing, behavioral counseling, special efforts among ethnic minorities, and prevention or treatment of intravenous drug use.

If we want an effective, sensible AIDS prevention policy, we must understand the different kinds of prevention activities and then look at how each of these fits into our larger AIDS policy here in California.

Following the testimony and discussion from our scheduled witnesses, we've reserved time at the end of the

hearing for anyone who wants to make brief remarks directly related to AIDS prevention and, perhaps, comments that have already been made today. If you're so interested in commenting, please sign the sheet near the door so that we can accommodate you towards the end of the session.

I want to thank everyone for being here this Friday afternoon. It's not the best time of the week or the year, given the holiday season, to generate attendance at a meeting like this, but that in no way detracts from the importance that I believe that this Committee and the Legislature places upon the issue of AIDS Prevention Strategies. It's clearly one of the most important public health and overall issues affecting the State of California today.

I'm pleased that we're having this hearing, and I look very much forward to the testimony.

Our first witness is Dr. Martin Finn, a physician.

This is a little bit artificial, in that we have this lectern over here, but I think that it's probably the best way to proceed.

DR. FINN: Thank you, Senator Hart, Members of the Committee.

I am Martin D. Finn, M.D. I am the Medical Director of the AIDS Program Office of the Los Angeles County Department of Health Services.

The AIDS Program Office in the Los Angeles County Department of Health Services is responsible for the coordination of all activity within the Department relating to human immuno-

deficiency virus infection. Therefore, we work with the hospital system and with our comprehensive health centers and public health centers.

The Program Office is also pivotal for the development of AIDS policy and for ongoing relations with other agencies, be they public, private or voluntary. The educational aspect of the Departmental activity also reports directly to the AIDS Program Office.

I've been asked today to briefly set the stage for the succeeding testimony which will be presented before your Committee.

In Los Angeles County, we now have 4,069 cases which meet the CDC criteria for the diagnosis of AIDS. This new count does include the additional cases as reportable now to include dementia and the emaciation or the wasting syndrome. This number is cumulative in Los Angeles County to the end of November, 1987.

While we are extremely careful not to make comparisons between one month or another, there is no evidence that the number of cases is going in any direction other than up at this time. For October, we reported 192 cases, and for November it was almost 200 cases.

This number of cases is, by itself, motivation for the development of a reactive service system to the needs of those who are so afflicted. It further, though, is motivation to do all possible to prevent escalation of this number in the future.

The larger picture is the picture which includes all of those who have been infected by the human immunodeficiency virus

and who at this time may manifest this infection only by the positive antibody test, if testing has been done. Based on the assessments coming out of the alternative test programs and other studies within Los Angeles, it is valid to say that this community already has a large population of infected, and the estimates range anywhere from 130-150,000 infected individuals in Los Angeles. The majority at this time are in the gay or the bisexual community.

This dictates an immediate service need in terms of evaluation and treatment and support. Such support can occur in outpatient clinics in hospitals, or as is becoming more and more evident, in alternatives to the patients being in acute care hospitals.

In Los Angeles County, we continue to be impressed with the opportunity which we have in terms of limitation of the infection, particularly in the intravenous drug abusing community. All assessments to this time have indicated that our seropositivity in the drug abusing population, intravenous drug abusing population, is below five percent.

Contrasting our picture with that of the Northeast part of the United States, where such seroprevalence is as high as 60 percent, is good evidence for the development of an immediate response to this particular community, because it is through this intravenous drug abuse that the infection is anticipated to spread further and faster into the heterosexual community. And of course, in doing that, it will involve more women and more children.

One aspect of prevention is the relationship to minority community activity, and of course at this time, the Black and the Latino community each account for about 15 percent of our cases. As we view the picture in the Northeast part of the United States, we see that the intravenous drug abuse picture, as it increases inappropriately in terms of population percentage, touches on minority communities. Of note is that in the City of Pasadena, in its cases, 32 percent of the cases at this time are Blacks.

As is well known, the only existing preventive is education. This education is basically of two types. First there is the basic knowledge relating to transmission of the virus.

For members of the general community not now engaged in high risk activity, this is critical and keeps them from the possibility of infection. A major example of such a population would be the teenagers and school children in our community. Adequate knowledge at this time can prevent infection down the road for them.

The second type of education is that which must be directed to those already with a history of engagement in high risk activity. This calls for a degree of behavior modification or change. Education does not have, to this time, a good record in producing behavioral change, but there is the hope that because of the fatal nature of this illness, that this may be a first and major success.

Certainly there is increasing evidence that the gay community has heard the message and is doing more and more with respect to modification of activities that can place individuals at risk.

I firmly believe that we understand the elements involved in transmission of the human immunodeficiency virus. The three categories of transmission occur in sexual activity, the sharing of blood products which includes intravenous drug abuse, and congenital transmission from mother to infant.

With this knowledge given appropriate to any individual, there is no reason related to individual activity which should extend or prolong the epidemic.

I do not deny that words are easier than actions, but we do have the understanding how to turn around this epidemic. It calls for innovative educational direction, and it calls for a commitment at all levels with the proper funding of such education.

With respect to service needs, many systems are now overwhelmed, and with the future projection of infected individuals, such systems must be extended and amplified.

In a humane sense, there are many things that can be done to better the lives, at least for a period of time, for those who have a diagnosis of AIDS. Availability and accessibility are and will be major issues as intervention becomes possible for those who have already been infected by the virus.

An example at this time is the question of availability and accessibility of AZT as the major element of hope for those who are infected. I would certainly hope that funding mechanisms may be found so that no one must go without this drug at this time if it is indicated and if it is tolerated. At this point in time, for those who are not Medi-Cal eligible, we have AZT, but we are limited by 200 percent of poverty in our community. That's the criteria for eligibility. That excludes many individuals who should be, by the advice of their primary care givers, receiving AZT and who face that most difficult decision: Must they give up working in order to get down to a level of about 11,000 a year before taxes in order to be given this access to AZT.

In terms of prevention, one of the aspects or the factors is seroprevalence. If we are going to appropriately target our education, our intervention preventive activities, we are going to have the need for understanding of who is infected, which parts of our population. And in the geographical county with 4,000 square miles, what part of the county deserves such attention. So that testing, as is now the major thrust coming out of the federal government, has a role, but it is not the answer-all in turning around this epidemic.

These have been general comments. I do have a fair amount of knowledge of our programs in Los Angeles. I hope that the succeeding testimony will be more specific as to directions and strategies related to the points which I have generally discussed at this time.

I would be most happy to answer any questions which you may feel are indicated. I certainly thank you for the activity to initiate this discussion.

CHAIRMAN HART: Thank you very much, Dr. Finn, for your testimony and for your presence here today.

I'd like to ask a couple of questions, but before doing so, I'd like to introduce my colleague, Senator Torres, who has joined us. He's just come from San Francisco, where he was successful in getting a very substantial increase in the minimum wage in the State of California.

Congratulations, Senator Torres, and welcome to our hearing this afternoon.

Two questions I had, Doctor, were, first of all, earlier at one of our hearings in San Francisco, we heard quite a bit of testimony as it relates to the IV drug using community, about rehabilitation programs and abilities of communities to be able to respond to people who are desiring treatment but are not able to get into treatment immediately. That there's a waiting list, and sometimes people have to wait for a substantial period of time -- weeks, months -- before they can receive appropriate counseling and treatment.

Is that a concern of yours here in Los Angeles? Is the problem a similar one in Los Angeles to what we heard in San Francisco?

DR. FINN: Yes, that situation is equally a problem for Los Angeles. It is estimated that we have between 80-100,000 intravenous drug users in our community. Perhaps 50 of those at

this time have the availability of a slot, be it an outpatient methadone slot, outpatient detox, or residential care.

We are attempting to learn more about the other half of our drug abusing community now by the development of outreach programs. But in terms of getting to the street addict -- if I may call the addict such -- we have to do more, or they're still out there as a target for this virus.

CHAIRMAN HART: The second question I had was, San Francisco sort of has developed its own reputation in terms of a treatment model and an education model.

I'm wondering if you're familiar with that model, and to what extent do our education and treatment programs here in Los Angeles differ in significant ways from that in San Francisco?

DR. FINN: Well, San Francisco is a very good broadcaster of its methodology, and I would say that in general we adhere to the same principles. However, we're dealing, as you know, with a county of large geographic size compared to a small area, even in the Bay Area, in its totality.

This calls for some innovation, because we lose the homogeneity of San Francisco when we begin to look at the San Fernando Valley, when we begin to look at the San Gabriel Valley, way out into Pomona. So, as we apply education, we have to do it in concert with public thought in those areas, and we also have to acknowledge cultural differences. I think in this respect we certainly have a larger problem, not just in terms of numbers of citizens, but in diversity of citizens in Los Angeles County.

That strikes home to minority education and to intravenous drug education as a part of that.

CHAIRMAN HART: What sort of coordinated role, if any, do you have with the public school system here in Los Angeles in terms of AIDS education?

DR. FINN: We have, as I mentioned earlier, the educational aspect of the Department of Health Services is under the AIDS Program Office. And one of the sections relates to school children, and that particular unit relates to, particularly, the County Superintendent of Schools, and to individual school districts.

Although I must indicate that there is varying success in promoting AIDS education in school districts. They have a degree of autonomy that has been surprising to me. The leader, I would have to say, is probably the Los Angeles Unified School District, where the Board very early on took a position positive with respect to AIDS education and also even funded the education. That's our largest district, as I'm sure you know, and its smaller amount is voted by its Board and now augmented by a new grant that's going to approximate $400,000.

CHAIRMAN HART: Are there some school districts in Los Angeles County that refuse to participate in AIDS education, or that you've found are basically uninterested or uncooperative?

DR. FINN: I would put it the latter. We don't have much force with them, but there is a variability in acceptance and enthusiasm. We have to deal with that.

One of the suggestions -- this was the day of our new AIDS Commission -- and one of the suggestions made this morning was that we might have greater success going through the PTAs than through the school districts themselves, so we'll be investigating that as a possibility.

CHAIRMAN HART: Thank you very much, Dr. Finn.

DR. FINN: Thank you.

CHAIRMAN HART: Our next witness is Linda Rodriguez, who's with the Minority AIDS Project in Los Angeles.

Is Ms. Rodriguez here? Perhaps she'll be coming later.

Next is the Mayor of the City of West Hollywood, Alan Viterbi.

I don't believe the Mayor is here, but here's his able assistant.

MR. KORETZ: My name is Paul Koretz. I'm Deputy to Mayor Alan Viterbi, who offers his regrets that he wasn't in town to be able to testify before you.

I welcome you, Senator Hart and Senator Torres, to our city.

This is a very high priority issue for the City of West Hollywood. We believe that to effectively address the growing AIDS crisis, community organizations, city, county, State and federal governments must work in a coordinated and concerted manner to educate the public, to assist persons with AIDS and ARC, to fund AIDS research, and provide AIDS prevention information and materials to those at risk for developing the disease.

We've taken a very proactive approach. We've funded between August, 1985 and June, 1988 almost a million dollars' worth of AIDS-related programs. That works out per capita to over $26, which as far as I know is the highest amount per capita of any city in the country in dealing with this.

The agencies that have received some of this funding are: AIDS Project Los Angeles; Being Alive; the People with AIDS Coalition; Shanti Foundation; the Gay and Lesbian Community Services Center Counseling Department; Aid for AIDS; West Hollywood Cares; the Southern California Women for Understanding; Lesbian and Gay Community Training Project; and the L.A. Gay and Lesbian Community Services Center, Edelman Health Clinic.

In addition to that, we've employed an AIDS legislative advocate, Helyne Meshar, who's quite able, and I'm sure you've all met her, to lobby in Sacramento for the City's position on AIDS-related issues and legislation.

We've also put together a program on AIDS in the workplace, and we've created a comprehensive and humane policy and procedure which guarantees the respect, dignity, and privacy of employees with AIDS and ARC, and provides for the training and use of volunteer advocates, and calls for mandatory training of all City employees in AIDS transmission, prevention and other issues.

In addition, the City allows for creativity in work schedules, work at home options, and expanded long-term disability plans, as well as in-house counseling and information and referrals to people living with AIDS and ARC or other catastrophic illnesses.

And I have to admit in doing this, we only really began to take this approach at City Hall when it hit home and a couple of our own employees did contract AIDS and died from that. And when you look at a city as enlightened as ours on this issue, and you consider the fact that it took us a while to begin to address AIDS in the workplace, you can imagine that many cities and most corporations are far behind in addressing this in a similarly appropriate manner.

We also have addressed this in terms of our business licensing. When we have adult businesses that come back for a business license renewal, we require that they disseminate information on safe sex practices and make that one of the conditions that allows their licenses to be renewed.

We've also -- back again on the AIDS in the workplace approach -- we've also had some grief sessions with a psychologist to help employees deal with the loss of fellow employees who have died from this catastrophic illness.

Personally, I'm very proud to live and work in a city that's taken this approach and made dealing with this deadly illness a high priority. And I have to admit, I've been a little bit disturbed that higher levels of government -- the county, the State and the federal level -- haven't yet followed suit and made this as high a priority as we have at the city level. Particularly, I would say, Governor Deukmejian's recent refunding of trivial amounts of tax dollars to each resident of the State of California, rather than using those millions of dollars that were potentially available to be used in dealing with this deadly

illness was an unfortunate choice of priorities. But I hope that at the State level, that will be remedied in the near future.

I thank you for letting me make this presentation to you.

CHAIRMAN HART: Thank you, Mr. Koretz.

Speaking for Senator Torres and myself, we certainly share your concern about the lack of commitment at various other levels of government, including the State of California. We've done some good things, but we've also, I think, made some serious mistakes, particularly in terms of some of the vetoes that have taken place. We're not nearly as far along as we would like to be.

Let me ask a couple of questions. You mentioned that the City of West Hollywood has expended over a million dollars in AIDS-related programs.

What is the source of funding? Are those out of general funds that accrue to West Hollywood, or are those special grants that you've received from the State or federal government?

MR. KORETZ: To the best of my knowledge, those are -- I don't know, the overwhelming majority or all of those funds are general funds. It's been a very high priority of the City, and we've felt that it was vital to expend those monies to deal with this catastrophic illness.

CHAIRMAN HART: Dr. Finn, I believe, used the figure that there were now over 4,000 cases of persons with AIDS here in Los Angeles County.

Do you keep those kinds of figures for your own city? How many cases of AIDS are there, residents who reside in West Hollywood?

MR. KORETZ: To the best of my knowledge, I don't believe we have statistics based on purely our own city; at least, I'm not aware of them.

But I can just say on an anecdotal level that it's very frequent an experience on the part of all of those involved in City Hall and in the City to have people that we know well die of AIDS. I know I've had the experience in one week of having three people that I knew in the City die of AIDS at the same time.

We've had City Council candidates that have later died of AIDS. We've had every profession, every sector of the City has had numerous examples of people who have contracted the illness.

CHAIRMAN HART: It's sometimes said when people have kind of a head-in-the-sand approach to this disease, in Northern California the phrase is, "Oh, that's a San Francisco disease."

Do you hear similar kinds of comments as it relates to West Hollywood? I'm sort of interested in to what extent you're able to work closely with other cities in this area and able to generate a concerted effort? Or do you find yourself operating too often in isolation from other cities who may not at this point feel the impact of the disease as much as you feel here in West Hollywood?

MR. KORETZ: I know occasionally we've been the victim of disparaging comments because of our large gay population, and

as a result, the large number of people who have contracted AIDS or have tested positive.

We're starting to get more cooperation, I think, from some of the other local cities. We're currently in the process of attempting to fund jointly with Los Angeles and other sources an AIDS hospice, for instance, with a site downtown that we're looking at. And hopefully, that'll be an example of the kind of cooperation that we can put together between the cities in our region.

It's been shown that, I believe -- I don't remember the projected year -- that at some point in the next five years, that 80 percent of hospital beds will be occupied by AIDS patients unless we put together a substantial hospice program. And that's one of the things, with Los Angeles and other cities' cooperations, we hope to begin in the very near future.

CHAIRMAN HART: Thank you again for your testimony. We want to thank the City of West Hollywood for your hospitality here today, and ask for your help not only in lobbying for legislation that will be of assistance, but also to share your information and expertise with the State Legislature and other communities throughout the state. We look to you for leadership on this issue.

MR. KORETZ: Thank you, Senator Hart.

CHAIRMAN HART: Our next witness is Judy Spiegel. Is Ms. Spiegel here?

Is Dr. Thomas Mundy here?

I guess we're moving along more quickly than people expected.

Thelma Fraziear, the Chief of the Office of AIDS, California Department of Health Services.

We're interested in hearing from Ms. Fraziear about the Department's educational efforts and effectiveness, materials, and funding as it relates to prevention programs.

Thank you very much, Ms. Fraziear, for joining us today.

MS. FRAZIEAR: Mr. Chairman, Members of the Committee, I am Thelma Fraziear, Department of Health Services, testifying today on behalf of Dr. Kizer, who's the Director of the Department.

I'd like to thank you for this opportunity to participate in the hearing and to share with you some of the progress and plans of the Department in respect to education and prevention programs.

Let me begin first with a brief overview of the Office of AIDS.

The Office of AIDS was created in 1985 to provide information and education, epidemiologic investigation and surveillance, research and treatment to address public health problems related to AIDS. Out of all of the dollars within the Office of AIDS, the greatest portion of that money is in the Education and Prevention Unit.

We currently have in that unit a budget of 11.6 million, of which 4.8 million funds a variety of statewide projects, including: a toll-free Hotline; an AIDS Clearinghouse;

Hemophilia Project; Computer AIDS Information Network; American Red Cross; California Youth Authority, Department of Education, and others.

The remaining 6.8 million supports local agency-operated AIDS educational programs. Although the numerous local educational efforts may vary in scope and target groups, the majority of the activities are targeted to high risk populations, namely homosexual/bisexual men and intravenous drug users.

Community-based educational programs funded through the Office of AIDS are awarded on a competitive basis through a process we call a Request for Proposals. The actual funding decisions are based upon proposal evaluation and ranking, as well as the documented unmet need for educational programs in a given service area or for a specific target group.

In comparison to previous funding periods, this current fiscal year's RFP included two major changes which significantly impacted the overall configuration of the Office of AIDS. The first change constituted a more explicit delineation of the target groups to be addressed by the State-funded projects. In the previous year, we simply lumped everything together and attempted to fund, quote, "high risk groups."

This year, we split those groups out and funded -- and made two efforts to fund homosexual/bisexual men, intravenous drug users and their sexual partners, as well as heterosexuals at risk, emergency service workers and health care workers.

As a result of this redefined directive, the funds supporting programs targeted to the IV drug user have currently

increased from 5 percent to 23 percent. An increase from 18 to 39 percent of the Education and Prevention funds now support AIDS education programs and activities directed towards the homosexual/bisexual male.

The other major change occurring within this current fiscal year is that at least 25 percent of these funds were committed to supporting AIDS programs targeted to ethnic minorities. The Requests for Proposal that we will release this year will also designate approximately 35 percent of the available dollars to support new minority AIDS programs.

In the near future, the State AIDS Clearinghouse will become operational and have the major responsibility for collecting and assessing all educational AIDS materials. Based upon their assessment, the Clearinghouse will be able to identify and determine unmet needs for new material development and distribution. The Office of AIDS will then be committed to support in the efforts directed towards the development of these needed materials.

Relative to the effectiveness of our educational programs, in fiscal 86-87, a comprehensive evaluation study was performed to assess the effectiveness of State-funded AIDS education and prevention programs in changing knowledge levels, attitudes, and behavioral intentions of the general public, health care and social service workers, homosexual/bisexual men, and intravenous drug users. The study was conducted by the URSA Institute, which is based in San Francisco.

In summary, the report findings indicate that California AIDS community education programs overall were very successful. In regards to the high risk groups of homosexual/bisexual men, the study concluded that educational interventions with small groups are most effective in producing short-term changes in knowledge and behavioral intentions with the targeted population. Interactive methods in long session, four hours or more, are particularly effective in stimulating positive behavior change, at least as measured by behavioral intent.

However, on the other side of the coin, as for intravenous drug users, it was recognized that there are greater difficulties in reaching this target group. Based on the report findings, in contrast to the other audience groups, IV drug users exhibit the least positive change in all three dimensions of interest, namely: knowledge, attitude and behavioral intent. Less success has been achieved in educating IV drug users with traditional methods. Educational programs directed to this high risk target population require materials specifically tailored to their educational abilities, cultural backgrounds, and life experiences in order to be successful in controlling the spread of AIDS.

Recommendations in the report emphasize that AIDS education programs and message targeted at the IV drug user community need to include the active participation and involvement of individuals, agencies, and groups that have established credibility among this target group.

Continued and expanded educational efforts are presently under consideration. A study measuring the outcome and cost effectiveness of different types of educational interventions -- that is, street outreach, support/small groups, and others -- on achieving desired behavioral changes is one of the studies currently being considered.

There is currently a lack of comprehensive sero-epidemiologic data for human immunodeficiency virus infection among IV drug users in this state. The level of infection has been found to be about two percent in most areas of the state. However, it is believed that in San Francisco and possibly other areas, that the percentage may be doubling every year.

As a matter of fact, Dr. Wayne Clark, who's the Director of the Alcohol and Drug Program for the City and County San Francisco, has reported that the level of HIV infection among San Francisco IV drug users has doubled from 4 percent to 8 percent between 1985 and '86, and may be doubling again in 1987.

In an effort to quantify the level of HIV infection among IV drug users outside San Francisco and Los Angeles, the Department of Health Services has just completed a sero-epidemiologic survey of persons with self-reported high risk behavior. Among the 1875 survey participants, 2 percent, or 38, of the individuals reported a history of IV drug use since 1977 and were found to be HIV positive. Black IV drug users were found to be 9-10 times more likely to have become HIV infected than White or Hispanic IV drug users.

These data suggest that while the overall infection level may be relatively low, there are pools of infection throughout the state with great potential for increasing the spread of AIDS.

To date, 3 percent of California's 10,400 AIDS patients have reported IV drug use as the primary risk factor for infection. As you're aware, this is in stark contrast to the New York and New Jersey experience, where 30-50 percent of all AIDS cases are related to IV drug use.

The well-documented ability of the virus to spread rapidly in the IV drug user community and the evidence of increasing infection throughout the state should provide us with strong motivation to implement aggressive prevention programs. At present, 23 percent of the 6.8 million supporting local community-based AIDS programs fund educational activities and interventions targeted at the IV drug user community. Of the 80 local agency educational contracts, 76 percent have some activities planned for the IV drug user population. Activities specified in these contracts include: street outreach; training for substance abuse treatment providers; educational session in methadone clinics; and court-ordered drug diversion programs; and support groups for the sexual partners of IV drug users.

At present, one of the most promising AIDS education interventions for the IV drug user community involves direct street outreach and the use of peer education.

As for those IV drug users desiring to enter a drug treatment program, there are currently an estimated 17,000

methadone treatment slots in California. The Department of Alcohol and Drugs recently received a 5 million grant from the federal government, which is being used partially to expand treatment opportunities for IV drug users. The remainder of those funds will be used for prevention and education.

Expanded voluntary HIV antibody testing does play a major role in this state's AIDS prevention efforts. Since the knowledge of one's antibody status may prompt an individual to adopt the necessary risk reduction behaviors, HIV antibody testing can have major impact on curtailing the spread of the HIV infection. Through expanded voluntary testing, more HIV persons would be identified and provided education on behavior changes that would prevent them from transmitting the virus to others or from becoming infected.

Expanding testing to encourage periodic follow-up serologic testing may also prove beneficial in supporting risk reduction behaviors. Individuals who are seronegative and remain seronegative through periodic testing receive positive reinforcement that their behavior changes are beneficial.

I will stop at this point. Thank you for the opportunity to present and take any questions.

CHAIRMAN HART: Thank you very much.

Before we entertain questions, I want to acknowledge the presence of Senator Roberti.

Senator Roberti, welcome.

Senator Roberti was instrumental in establishing this Select Committee, for which I as the Chair am very grateful, and

also has been a great leader in the Legislature on AIDS-related issues.

Let me being by asking a couple of questions, Ms. Fraziear.

Did I understand you correctly that the chances of a Black IV drug user in California being seropositive are nine or ten times as great as an Hispanic or an Anglo IV drug user?

MS. FRAZIEAR: That came forward out of the sample study that was done. We tested individuals in 21 clinics throughout this state, and although there was an overall 2 percent positive among all groups, it was discovered that the Black IV drug user, there was a 9 percent positivity rate in that population.

CHAIRMAN HART: Do you care to speculate or hypothesize on why it is so very, very much greater in that particular ethnic group than others?

MS. FRAZIEAR: Understand that is probably speculation and nothing more than that.

Keeping in mind that, first of all, the IV drug user probably is not getting in for health care. And they probably aren't getting in for testing. And so, there's probably a lot of them out there who probably share a lot more needles.

So, there are a lot of them out there that probably never had a test. It's going to be extremely difficult to get them in for a test.

Who knows, maybe there are more Black IV drug users. I don't want to speculate on that, but that is always a possibility.

CHAIRMAN HART: Another question I had was that you said there were 17,000 methadone slots in California, and there are federal grants to expand that.

Do you have sense as to how many people could be placed in methadone treatment but -- in other words, is there a waiting list for those 17,000 slots?

MS. FRAZIEAR: I'm only -- I'm going by the information that I got from Alcohol and Drug.

Yes, there is a waiting list.

I need to make one clarification on the $5 million. The $5 million is one time only federal money, so when the money was given out to some of the counties, it's my understanding that they used a lot of it for prevention and education.

Given one time money, to put it into methadone treatment slots, they would not be able to keep those slots beyond one year.

CHAIRMAN HART: At some previous hearing or in a conversation, I was asking about the Department of Health's involvement in the IV drug use issue as it's related to AIDS and issues like being able to get into treatment.

And the comment was, "Oh, the Department of Health doesn't involve itself really in that. That's the Department of Drug and Alcohol issue. We don't see that as our role or expertise."

Is that an accurate characterization of that? What steps are we taking or not taking to coordinate our efforts among different bureaucracies at the State level to see that, you know, whatever needs to be done is done to deal with the problem?

MS. FRAZIEAR: We have in fact -- that is not an accurate statement. We do have an interagency task force of the various organizations: Mental Health, Developmental Disabilities, Alcohol and Drug, Social Services. So, we work very closely with those organizations.

We are putting money into IV drug users, the Department of Health is, but I think the one that we're looking at is basically the street outreach. I mean, the nontreatment addict, if you will.

Granted, we could put money into methadone, but we also feel we have a population out there that no one's touching at this point, which is the out of treatment addict. And that is the group right now that we're putting our efforts into.

But we do coordinate with Drug and Alcohol.

CHAIRMAN HART: Senator Roberti.

SENATOR ROBERTI: You indicated that the number of Black IV drug users are 8 percent of a larger group.

Now, what's the larger group? How do you determine infected Blacks?

MS. FRAZIEAR: That's -- what I looked at at that time, Senator, was the sample study that we had done with 5,000 patients -- I mean, 5,000 persons.

SENATOR ROBERTI: This was 8 percent of your sample --

MS. FRAZIEAR: Eight percent of our sample.

SENATOR ROBERTI: How was the sample put together?

MS. FRAZIEAR: We tested -- we used 21 clinics in various counties and did some blind testing, if you will, the money went to testing, to get a sense of where the --

SENATOR ROBERTI: These are clearly people who were addicted?

MS. FRAZIEAR: Well, we used Sexually Transmitted Disease Clinics, we used some of our methadone treatment clinics, and basically many of them were self-reported.

SENATOR ROBERTI: Could one reason be that there is less education in the Black area on sterilization preparations -- I hate to even raise the point -- on how to inject yourself?

MS. FRAZIEAR: I think up until this current year, because the disease started in the homosexual population, that not only in the IV drug users community as it relates to Blacks, but we didn't do a lot in the IV drug user community at all. So that any educational effort that is made is really just getting started in this current fiscal year.

SENATOR ROBERTI: What are we doing, or you doing, or is the State doing right now to educate people on how to prevent the spread the AIDS through IV drug use?

MS. FRAZIEAR: Basically what we're going to be doing is, we are going to be training community outreach people, persons who are from within the community, who are able to go out in the community and provide education.

I know there's some controversy on whether or not we should provide written stuff, but my --

SENATOR ROBERTI: Provide what?

MS. FRAZIEAR: Written information or written literature, but my feeling on that is that you can do a much better job if you're out there in the community, walking the

street, and really able to tell the person what they can or cannot do. That's going to be the best effort.

And that's in essence what a lot of the projects are doing and what we will be doing over all.

SENATOR ROBERTI: And it would occur within, I would suspect, a controlled group of people who are already suffering from the problem of over drug use?

MS. FRAZIEAR: Well, I won't say it's going to be in a controlled group.

I look at it from two perspectives. First of all, the IV drug user who's out there in the streets probably is never going to come into a formal setting. I'm not going to get that person into a clinic.

So, you're going to have to go into the communities where they're sitting on the corner, or the various houses that they visit.

The other population that I think is important is the partner of the IV drug user. And we're also going to have to start to try to reach that group and sincerely hope that they will take the word along with them. In other words, help us do the education once they get the information.

So, I don't want to say it's going to be controlled.

SENATOR ROBERTI: Right.

Are there any written materials available right now that are put out by any publicly funded agency?

MS. FRAZIEAR: There are a number of written materials. Most of the organizations, because sometimes the State has a

little censorship policy, most of the organizations will use other funds that they get from other private sources to do the educational literature. They have used some of our funds, but they usually try not to do that.

SENATOR ROBERTI: Is it your feeling that written information is essential?

MS. FRAZIEAR: It is very essential, but I also think the word has to get out, too. Sometimes we leave someone a document who simply throws it in the trash can.

Perhaps if we talked to the individual ahead of time, as well as give him a document, it becomes much more beneficial.

SENATOR ROBERTI: Thank you.

CHAIRMAN HART: Senator Torres had a question, I believe.

SENATOR TORRES: Yes, Ms. Fraziear, I appreciate the opportunity to have you here and congratulate you on the tremendous effort that you've been doing with not enough support, as far as I'm concerned, from the administration on issues that are important, especially written information.

Clearly, the educational materials which Senator Hart and others fought so hard for in the legislative session, are important.

I am concerned, however, about your comments regarding testing. And just what is the administration's position, or is it just your personal position in representing the Department of Health Services, regarding the nature of testing?

You indicated in your testimony that testing ought to take place periodically; that those who have received negative result are reinforced psychologically by receiving those results.

But I'm still unclear as to what is the position of the administration on testing? Are we advocating, or will we be seeing legislation by the administration advocating for mandatory testing for the HIV virus among risk groups? Or are we going to be advocating for mandatory testing across-the-board in California?

What is the nature of the testing issue with respect to the Department of Health Services?

MS. FRAZIEAR: Maybe I misread that wrong.

No, my emphasis, and thus far the administration emphasis, is on voluntary testing. But when I talked about testing, it was not mandatory.

One of the things that is happening, though, is I think we only right now have the anonymous testing sites. What I would like to see is that there be voluntary testing -- and I underline voluntary testing -- in some of our clinics out there, in family planning, maternal and child health, and in primary care centers for those individuals who would like to be tested on a confidential basis. At least they'd have some place to go.

What I meant when I said a negative, I don't think we should test anyone who comes up with a negative, and then we give him the impression that that means you're negative for life. We need to provide some education so that they will know that, you know, that the virus is a latent virus, and that they really need

to consider what they're doing, or to come back in within a three to six month period of time for another test.

SENATOR TORRES: So, you're advocating mandatory voluntary testing.

MS. FRAZIEAR: No, not mandatory. Voluntary. The same thing we have right now. We do not have mandatory.

What we say is, if an individual wanted a test, we'd have alternative test sites out there that they could go into.

That's the same principle, except we're going to put it in the clinics where it can be more accessible to individuals, but on a confidential basis. They still have to sign the consent and everything. It is not mandatory.

SENATOR TORRES: So under the present administration guidelines, testing for the virus is voluntary?

MS. FRAZIEAR: Voluntary; that's correct.

SENATOR TORRES: But you are advocating voluntary retesting?

MS. FRAZIEAR: Not -- no, we've said this all along, Senator.

We always say, in any counseling or any education that is given out there, the post-counseling should indicate that just because you are a negative, do not feel that you're safe. And they should be also indicating to these people that, you know, based on your sexual life style, you really should be coming back in for testing. They should be doing that right now.

SENATOR TORRES: No, I agree with what your position is. I just want to make sure as to where you're going with this.

So, do you have the necessary funds to provide this kind of direction and focus?

MS. FRAZIEAR: What we have done this year, one of the things we discovered in the alternative test sites when we took a look at who was going there now, is that we are getting a lot of the heterosexual population who are going in for anonymous testing.

The feeling is that if those same tests were offered in some place that they're probably going to go -- if a woman is pregnant, she's probably going to go in for prenatal care -- I think once that individual goes in, they ought to be given information and let know that there's a possibility that they can take the test. If they say, "No, I don't want it," that's it, but at least they'll have received the education on that.

SENATOR TORRES: All right.

What direction is the Department of Health Services going and what funds do they have available to them, to you, to increase the education among the IV drug users in California?

MS. FRAZIEAR: We took money of this current year's budget. We took approximately $900,000 out to get the program off the ground in terms of training outreach workers. We will get that off the ground beginning January the first. We'll probably use that same money for next year if it's still in the budget.

SENATOR TORRES: What do you need in addition to what you have now?

MS. FRAZIEAR: Senator Torres, that's very difficult to say.

SENATOR TORRES: Come on, Thelma. I'm sure you've thought about it. Tell us what you feel you need to combat this.

If anyone has read the Shilts book -- [Ed: Randy Shilts, And The Band Played On]

MS. FRAZIEAR: I've read it.

SENATOR TORRES: -- these questions were asked years ago, and people did not tell us what they needed publicly. I think it's important, because I've known you for many years, and you are of a character that will tell the truth and honestly as to what you need to combat this disease that you don't have now.

MS. FRAZIEAR: I think we have to look at the disease in its entirety.

While I would be the first to agree that I think AIDS prevention is absolutely necessary, I also think that I have to take a look at what's happening in the whole treatment arena out there.

One of the greatest efforts -- things that we're going to have this year facing us, and not only in the IV drug user population, and the homosexual population, is going to be alternatives to institutionalization. The whole --

SENATOR ROBERTI: I missed that. Is what?

MS. FRAZIEAR: Alternative hospices, home health care, those kind of services are going to be desperately needed.

I think we're going to have to do more in the IV drug user population, and we're going to have to use nontraditional methods. The traditional Master's level health educator is not going to go into the IV drug using community.

We're going to have to use those people who have been there, who are accustomed to going into those communities, and who're accustomed to really working with them. That's going to mean some training. I mean, we aren't talking about people that you're just going to send out there. We first have to tell them what the whole AIDS thing is all about.

So, that's going to take time and effort, but that still remains where we need to go. We're talking about a population of IV drug users that is going to be extremely difficult to reach.

SENATOR TORRES: Have you talked to George about this?

MS. FRAZIEAR: George?

SENATOR TORRES: Deukmejian.

(Laughter.)

MS. FRAZIEAR: Well, I preach this every day, so it isn't like I'm saying anything I haven't preached over time.

SENATOR TORRES: Well, has he heard it?

MS. FRAZIEAR: Well, I don't know. I think he has. I think we've gotten some more money in the budget.

I think the one thing I should say in all fairness is that we do need time to sit down and plan. One of the problems that I had when I first walked in this job was, there was no planning going on. We were just putting out money out there, not really knowing what we were doing.

I think we have to have that kind of time to do it, rather than to just be putting money out there on top of money. That's not to say that I don't think we'll ever need any more money, but I think you have to give us time to plan for the kinds of things that we need to do in this whole AIDS epidemic.

SENATOR TORRES: Well here you have a very powerful Senator, the President of the Senate, who's waiting to listen how much money you're going to need next year.

Do you have an amount?

MS. FRAZIEAR: No, I don't. I'm sorry, I really don't.

SENATOR TORRES: Will you have an amount?

MS. FRAZIEAR: Well, but not today.

CHAIRMAN HART: It's only a few days before Christmas. Santa's making his list, checking it twice.

SENATOR ROBERTI: Have you recommended an amount to the Governor? He's preparing his budget State of the State, so I have to believe that either you directly or through the Secretary of your agency, someone has come up with some sort of an amount to the Governor.

MS. FRAZIEAR: Well, let me just say what we've done. We have come up with some ideas and some plans in terms of where we think we should be going with the AIDS program.

I will let them put the dollar amount on there. I have refused to put the dollar amount on.

SENATOR ROBERTI: I think you're doing a very good job, but I think what you're saying is symptomatic of what we've all said about this administration. You may not necessarily be the person to harangue on that.

SENATOR TORRES: But she's here.

(Laughter.)

SENATOR ROBERTI: But the administration wants to do things, but they think things can be done without talking about dollars and cents.

What I hear from you today is exactly what we've heard for the last couple of years, this incredible attitude.

I'm not talking about you personally, but it's as if this major health problem can be treated without any discussion of financial encumbrances on any of us. That's what this part of your testimony is telling me.

Please relay the message.

MS. FRAZIEAR: I will relate the message.

SENATOR ROBERTI: If they haven't heard it already.

CHAIRMAN HART: One last question I would like to ask is about contact tracing.

Does the Department or do you personally have a view on contact tracing? We hear a lot about that in Colorado and other places. Does the Department have a position on contact tracing?

MS. FRAZIEAR: Currently there is some contact tracing going on in some of the counties, but it is entirely up to the counties whether or not they want to do that. Generally what they do is, they do it through their Sexually Transmitted Disease clinics. It's not a statewide effort, and we don't have anything on that, and no policy, per se.

I personally have no problems with contact tracing, but I think we have to be very careful in terms of how we do it. I think we do have to maintain confidentiality. I think we should not take anonymous phone calls relative to this and call people because it creates a problem.

I think first of all we need to try to get the individual to tell the person about their status. And I think,

on the other hand, something that's going to be entirely costly, and I have heard that -- let's see, IV drug users have approximately 12-20 partners per month. I don't know how true that is, but if you get into that, it becomes a big ticket item in terms of trying to do contact tracing on a statewide basis.

CHAIRMAN HART: Thank you very much for your testimony.

I understand that Dr. Mundy has arrived. We passed over him and moved on.

Is Dr. Mundy present?

We appreciate your joining us this afternoon. Dr. Mundy is with the Department of Pediatrics at Cedars Sinai Medical Center.

DR. MUNDY: Senator Hart, Senator Roberti, and I turned around and --

CHAIRMAN HART: Senator Torres is here somewhere.

DR. MUNDY: I'm sorry for being late. I'm sorry for not having more prepared remarks, but seem to never have the time to prepare them, so I just have a few notes to myself.

You had asked me in particular to talk about a study on neonates that I'm involved in at Cedars Sinai, a study which has gotten some notoriety in the last few weeks.

What we are doing is sort of the second wave of transfusion-related AIDS "Look Back" studies. The first wave, which really came into vogue in 1986, and which we began in 1985, is to look at recipients from donors who later have AIDS or are anti-positive. That part of the study we have already completed. Other places are just beginning doing that sort of study now.

What we're doing on our neonates, or premature infants born at Cedars and who receive transfusions is notifying and calling back every neonate who got a transfusion as opposed to ones that we know anything about the donor of. This is sort of phase two of the look back type studies.

And for some reason at times we have been criticized for not doing this study sooner. As far as we know, we were the first hospital in the nation doing this sort of "Look Back" study to recall back all transfusion recipients. We know we're the first neonatal intensive care unit doing this sort of study. We're also the first place that the Centers for Disease Control has --

SENATOR ROBERTI: How many call backs is that procedure?

DR. MUNDY: That -- there were 2500 babies who were admitted to the nursery in those years. We have about 500 admissions per year, and we're doing roughly five years.

Of that 2500 babies, about 700 got transfusions. So, it's about 700 babies that we're trying to locate the families of and call them back in.

One thing that's interesting about transfusion-related studies, I think people think that any hospital can punch two buttons on their computer and send out letters to everybody who ever got a transfusion. It's not nearly so simple.

We knew that about 30 percent of the babies in our intensive care unit had gotten transfusions. What we didn't know was which 30 percent had gotten transfusions. It took three people working essentially full-time four months to find out which 700 out of the 2500 had actually gotten transfusions.

If there's any press around, I should make strongly the comment that other than the 700 that got transfusions, we are not at all concerned about -- if you did not get a transfusion, no matter which hospital or nursery you were in, you were not at risk for getting transfusion-related AIDS.

And clearly, of that 700 who did get transfusions, only an extremely small percentage of those will be infected.

By our data so far, we have currently contacted about half of those children, about 350. We have notified the parents, and the parents have consented to have testing on about 230 or so of those, and at most it looks like 2-3 percent will be infected.

That is not a large percent and not a large number of babies, but remember, we've identified some 20 or so now through various studies, looking at every nook and cranny for any children infected through transfusion. And we're the only neonatal unit in the state that's looking. There must be hundreds of transfused neonates, if not thousands, in the State of California, not to mention in the U.S., that have been infected through transfusion.

SENATOR ROBERTI: What is the last year on the transfusion?

DR. MUNDY: What? Before the --

SENATOR ROBERTI: Before the newer procedures took place?

DR. MUNDY: March of 1985 was when we started testing. Cedars and the Irwin Memorial Blood Bank were the first two places to institute HIV antibody testing in California. It was

in general April to May of '85 for the rest of the hospitals in the state.

The years we chose for the study were January 1 of 1980 through March 12th of 1985. That's the day we started testing.

We designed that with the Centers for Disease Control. It's a little worrisome that about six months subsequent to that, they began to have some reservations about the blood supply in 1979 and possibly even 1978.

We are not through the study going back that far, and we designed it with the CDC, but there's a question of going back a littler farther now.

As I said, it looks like at most, 2-3 percent of the population in whom we know nothing about the donor, we do not know if the donor was later positive, may be positive. But that could translate to hundreds if not thousands of children in California.

I would welcome any other hospital doing the same sort of studies that we're doing. The interpretation has been that because Cedars Sinai is looking at this population, there must be a worse problem there.

I will not say that I know for sure the incidence at Cedars is no higher than five or ten miles either direction, or in Northern California, or any other hospital, but I will say for sure that nobody knows that it is higher. And it could be that percentage at every neonatal unit in the State of California. Other places really aren't looking at theirs.

We are lucky because we have good funding from the Centers for Disease Control and are doing the study, and are getting incredibly hard and expensive things for every blood bank to do.

Just as this sort of study may identify hundreds of children infected with the AIDS virus, I want to share a little data to point out the magnitude of the problem of pediatric AIDS. I can tell you about Los Angeles County, and then you can extrapolate for the rest of the state.

There is -- I think every organization in the state has an ad hoc committee for AIDS now. And the Academy of Pediatrics in our Southern California has such an ad hoc committee, which is really five or six or seven of us that are mostly pediatric immunologists that see the bulk of the AIDS patients.

We had -- for the last year or so we've been meeting regularly and chuckled at the numbers that L.A. County carries as pediatric AIDS patients, because some of our centers individually had more than the County was saying the entire number was, and collectively we knew we had several times as many.

In March and April of this year, we did a very informal study where we mailed a questionnaire to eleven pediatricians or hospitals in the County that we were certain would have seen some AIDS patients. Of that eleven, five or six were us on the committee.

At the time the County of Los Angeles said that there were 18 children under 13 with AIDS in Los Angeles County. Out of that survey, we found 183 children that were infected with the

AIDS virus, ten times the number that the County was carrying. Even if you counted only CDC defined AIDS, which we asked people to do, living or dead, there were 35, which is a factor of two over what the County had counted.

It is partially a problem of recognition by pediatricians. It's partially a reporting problem, and it's partially a problem of some county institutions not having the resources to really pull those numbers in in the way that they should.

We sent this as sort of an editorial comment to the judge. The pediatrics bottom line is, if we would agree we had not the 18 pediatric AIDS patients the County has carried but we really have almost ten times that number, in a county the size of Los Angeles that translates into a major problem of 183 infected children, all of whom in the future may become ill and may die. It really points out the magnitude of the problem. Clearly that 183 is not every child in Los Angeles County. We only sent the questionnaire to pediatric specialists whom we knew would have seen AIDS. It doesn't count any of the ones that would have been missed by people in general pediatrics.

I was going to say, you seemed particularly interested in what we could do to prevent the spread of AIDS in California. And specifically that for pediatrics, what we can do is discuss AIDS and discuss AIDS risk factors with women of childbearing age so they will not bear children with AIDS.

Transfusion-related AIDS has ceased to be a problem. There are essentially no new infections with the AIDS virus

through transfusion in the country today. We'll continue to see AIDS develop in patients who were infected before 1985, but no new AIDS admissions.

A couple of things that will not be useful in preventing the spread of AIDS to children would be mandatory either marriage testing or testing of all pregnant women. There was a nice article in the Journal of the American Medical Association about three months ago, going through the numbers on the cost and the yield of marriage testing. There are about 2½ million marriages in the country a year. If you assume two people per marriage, that's about 5 million tests a year, which would cost conservatively $100 million to carry out.

A $100 million is more than the education budget on AIDS for the entire nation. So you would be spending more than all your education efforts just to test married couples. You would identify fewer than 500 infections that way. You will tell --

SENATOR ROBERTI: Fewer than 500 infections --

DR. MUNDY: By testing every -- by mandatory marriage testing.

SENATOR ROBERTI: Out of 100 million?

DR. MUNDY: Not $100 million.

SENATOR ROBERTI: Out of 2½ million.

DR. MUNDY: That's 2½ million marriages.

SENATOR ROBERTI: And you'd only come up with 500?

DR. MUNDY: Right.

SENATOR ROBERTI: Why is that?

DR. MUNDY: It's in general quite a low risk population. If you were testing that many IV drug users or gay males, you'd come up with a very high number. You are testing a population, since they're getting married, that is predominantly, presumably, heterosexual and therefore not at very high risk. Part of the argument statistically for not testing mandatorily at least lower risk populations.

The other data that comes out that's extremely important, you would tell approximately 300 infected people -- you would tell approximately 300 truly infected people that they were not infected. In other words, your false negatives. And you would tell about 200 people uninfected that they were infected, your false positives.

SENATOR ROBERTI: How many false negatives did you say that would be?

DR. MUNDY: I'm sorry?

SENATOR ROBERTI: How many false negatives?

DR. MUNDY: It's 350 false negatives; 200 false positives.

I did not have a chance to pull that paper right before I came over. I would send it along for inclusion in the proceedings if you'd like. It's quite a good paper on the data.

It turns out there are approximately as many births as there are marriages a year, and the same would hold if you were testing all pregnant women, because it too is a low risk population. Not that you wouldn't prevent any infections, but on the prevention per dollar yield, not nearly enough infections.

The things that we can do are to discuss AIDS risk factors with women of child bearing age from doing that, hopefully before they become pregnant. And if they desire testing then, be able to provide confidential or anonymous testing at that time so they don't become pregnant.

And the other thing strongly to be done for preventing AIDS transmission in children and educate the public in general is education about AIDS in the public health system. I would commend Senator Hart for his bill last year, which did not make it into final signature by the Governor, and perhaps ask that maybe something could be worked out to satisfy the Governor's relations about that bill in the new session. I think the Senator got caught between the Governor and Mr. Honig, and that's not a convenient place to be.

In fact, I saw in Mr. Margolin's office yesterday a picture where you, Senator Roberti, were sitting between the Governor and Mr. Honig. And I commented at the time that that was not a position I would like to be in.

SENATOR ROBERTI: No, no.

Of course, sometimes it's nice to have somebody sit between me and the Governor.

(Laughter.)

DR. MUNDY: The importance of education in school, I think, is several-fold.

One, schools are places that we are used to learning. And therefore, it's a nonintimidating setting for AIDS education. Many minority groups, especially, will strongly avoid going to

any AIDS seminars because they would be perceived to be in a high risk group. Having those sorts of seminars at school, where not only the children would get the education but the teachers and the parents would get the education, will really be a nonintimidating site for the public to get better AIDS education.

Our teachers in the public schools are logical educators about AIDS in general. It's an excellent place to get to parents for general AIDS education in a sort of nondiscriminational light as well as risk reduction education.

Several things that would be useful specifically for children regarding HIV infection, we need pediatric treatment centers. I would commend Mr. Filante's bill of last year that basically sets up some sort of drug testing for California, even if the FDA doesn't go along.

Traditionally the Food and Drug Administration has wanted drugs to be totally tried and approved for use in adults before they begin the studies in children.

That is not acceptable for AIDS and HIV infection. One of the calls I took just before coming over was a call from Burroughs Welcome in North Carolina, giving me the results on blood levels of AZT in a child who I was treating with AZT. Unfortunately, we don't know very well exactly what dose of drug to use in children, and those studies drastically need to be done. If those studies had been done now 18 months ago, when we began adult trials with AZT, we wouldn't be having to draw drug levels to know exactly what dose to use. And unfortunately, the calls on the drug level came 48 hours after that patient expired.

Also, if I had been able to use AZT in children 18 or even 12 or even 6 months ago, I wouldn't be going to memorial services on Sunday morning.

SENATOR ROBERTI: It's your feeling we're slow in allowing new drugs to be obtainable by the public?

DR. MUNDY: Yes, definitely. And particularly slow in even beginning the trials for drugs in children.

There are now three drug trials going on for children using AZT. They are all three on the East Coast; two are in cities where there is not background pediatric AIDS. One is at the NIH, one is at Duke, neither of which has large populations of children with AIDS. The other's in Miami, where there is.

The NIH has actually called our patients in California and asked them to come back there for study without calling their physicians. And wants them to come to the NIH and spend a full month in their unit getting IV AZT, and come back there for 48 hours every month.

For parents that realize they may not have their child around many more months, they're not willing to spend 28 days of it in Bethesda.

SENATOR ROBERTI: Why are we slow? Is it just bureaucracy, no money, overly cautious?

DR. MUNDY: As I said, the FDA has always been cautious -- I'm not sure overly cautious -- on drug testing in children. They have wanted to go through years of adult trials before even beginning the trials in children.

We have always been conservative -- perhaps overly conservative -- about new drugs in children. If you're talking about using a new and fancy antibiotic that is only replacing last year's antibiotic, I would agree with being conservative over new drug trials in children, because they may have different side effects, and you may cause ill more than harm.

In a disease where the life expectancy may be 6, or 9, or 12 months, we can't wait 18 months to begin drug trials in children.

I think pressure needs to be borne on the FDA for faster drug trials on children, and also part of the drug treatment units to be done in California should definitely include pediatric trials. There is very much an East Coast bias by the FDA on doing the trials in the East Coast and doing it very slowly on children.

The drug trials on children didn't begin until well over a year after good results with AZT. Not just beginning the AZT trials, but knowing that there were good results.

It turns out that the data out of the NIH study is that there are fewer side effects in children than they saw in adults. It looks like it is easier to use and safer in children, but they began the trials much later.

One other California problem, I would say about two-thirds to 75 percent of the drugs in the Physician's Desk Reference, the so-called PDR, say that they are not specifically approved for use in children. That does not mean we do not use them in children; it just means we're hanging out in the breeze

as far as malpractice because they are not specifically approved for use in children.

Within a week after AZT was approved for use in adults, and Burroughs Welcome had dropped the old distribution network, where we had to go directly to Burroughs Welcome, I began children on AZT. Private insurers so far -- and knocking on wood -- have covered that. I even know of one health maintenance organization that has covered that care.

California Children's Services, on the other hand, is refusing to pay for AZT because it is not specifically for use in children. In spite of Ms. Waters' bill of two years ago that said that California Medi-Cal would begin paying for a drug as soon as it was approved, I believe, even for investigational use. CCS has not read those regulations that way and is refusing to pay for children on CCS who are otherwise covered for their HIV infection, but they're not paying for AZT in children.

The final thing, I think, would be terribly useful for children is alternative or confidential test sites for children. These are well-funded. There are now five or six in the County of Los Angeles, which is an expansion of Mr. Roos' bill from now three or four years ago, but the State requests -- and I believe for very good reason -- that those alternative test sites not perform testing on children under 12 years of age. The counseling before and after testing, and even the physical nature of drawing the blood, is much different for children than it is for adults. I think it is probably wise that those centers not be doing testing on children.

But there is no center in the State of California where a child under 12 can get confidential or alternative site testing. When there was so much publicity about the study I was doing, and luckily we're funded for doing lots of testing, we were getting calls not only from all the county but all over the state, "Could you test my child?" Unfortunately, most -- many of the calls that we got didn't fit the criteria of our study; we're looking at Cedars patients. But it really pointed out that there is no place that the parent can take a child that they think is in a high risk group, whether they're in a high risk group because mother is in a high risk group, or because they got transfusions, or because they're a hemophiliac, there is no confidential or alternative test site for doing that.

I couldn't talk about my study in AIDS testing without saying another word about confidentiality, which is what I have said before. When committees in Sacramento begin thinking about relaxing the confidentiality rules -- not when something gets out of committee; not when something passes one or the other House; not when something is sent to the Governor -- but when some committee member begins talking or thinking about relaxing confidentiality, our patients cancel appointments.

There was a front-page L.A. Times article back in the winter talking about the AIDS bills that were pending, and the possibility of relaxing the confidentiality protections, and that Monday morning, three patients called and cancelled appointments. My patients are more afraid of the disclosure of results than they are of the disease itself.

To keep from driving the disease underground, those confidentiality protections must be kept in place.

CHAIRMAN HART: Thank you very much, Doctor, for some very interesting and sometimes disturbing testimony, particularly your comments about drugs as they relate to children.

One question I wanted to ask is, the Legislature this past year had enacted into law a measure that requires people applying for a marriage license to be informed that there is a test available and, as I understand it, the physician is supposed to -- there is supposed to be some kind of recognition that they are aware of that and they have signed it one way or the other whether they want to have that test.

One would be analysis of that legislation, if you think it's a good idea or bad idea. And if you think it's a good idea, or a neutral idea, for want of a better term, would you support similar legislation for pregnant women?

DR. MUNDY: Actually, I'm glad you brought it up. I didn't think about mentioning that.

I think that is not a bad idea, the marriage testing checkoff system. As you well know, that was an end up compromise on a bill that started off as mandatory.

CHAIRMAN HART: As mandatory, yes, by Senator Doolittle.

DR. MUNDY: That's the sort of thing I'm saying. Bring it up at that point to discuss risk factors, even having that checkoff on a form and the doctor knowing he has to check it off yes or not, and therefore he has to have talked to the patient, makes them talk about AIDS risk factors, and is this something you should consider doing.

Bringing it up, and having physicians talk to patients about that, I think is an excellent idea.

There is a similar bill in the "1,000 series" over mandatory testing of pregnant women. A suggestion that I had made to Mr. Doolittle is to mirror -- there was legislation about three or four years ago on neural tube defects and alpha feto-protein testing, that women between certain weeks of pregnancy -- I think it's up to the 14th week or so of pregnancy -- be advised of the availability of alpha fetoprotein testing. That's a rather simple serum test that indicates the possibility of myelomeningocele in the baby. That that be mandated to be discussed with pregnant women in those times with the same sort of checkoff form, "Yes, I discussed this with my patient and offered it to them." The State does not pay for those. Medi-Cal would pay in Medi-Cal patients, but otherwise they're done by private insurers or the patients themselves.

But it brings it to the forefront of letting pregnant women know that such a test is available and having it offered to them. I think something mirroring that for HIV, that either in visits to a gynecologist or obstetrician before pregnancy, or in the early stages of pregnancy, that be discussed with women and have some sort of checkoff system for that, I think is an excellent idea. To have the physician discussing that with her or his patient.

But to have it mandatory, I think, wouldn't be cost effective. But the checkoff system, I think, would be excellent.

I, as I said, suggested that to Mr. Doolittle's staff last year. I don't know if they have gone anywhere with that.

CHAIRMAN HART: Thank you very much for your -- sorry, Senator Torres.

SENATOR TORRES: How many children do we have that you know of in California are infected now with the virus?

DR. MUNDY: I quite honestly don't know the total California data. I think that the reported number of pediatric AIDS cases, which is really the only data we have, is somewhere 50-75 or so. Los Angeles County is still now only carrying about 21.

But the total number infected with the AIDS virus, if you extrapolate the study that we did here in Los Angeles County, is at least ten times that.

SENATOR TORRES: And AZT, according to your testimony, is not available through Medi-Cal now for pediatric use?

DR. MUNDY: Medi-Cal non-CCS, I'm not sure. It should be, because of the bill making it covered under Medi-Cal from last year, but --

SENATOR TORRES: For example --

DR. MUNDY: But California Children's Services, CCS, of which HIV infection would be a covered disease, is denying coverage for AZT treatment on the grounds that it is not an approved drug for use in HIV infection in children.

SENATOR TORRES: Approved by --

DR. MUNDY: The FDA approves it as a drug.

That is not to say, though, that CCS is not -- they do cover other drugs for other diseases that are not approved for use in children.

Thank you.

CHAIRMAN HART: Thank you very much.

We're going to take a break. I apologize for not doing it sooner for our stenographer. At least five minutes, and then we'll resume. We have two additional witnesses with a brief opportunity for public testimony.

(Thereupon a brief recess was taken.)

CHAIRMAN HART: Let's continue.

We have a 3:00 o'clock deadline, so we're going to have to move along.

Linda Rodriguez is our next witnesses. Is Ms. Rodriguez here? Ms. Rodriguez is with the Minority AIDS Project of Los Angeles.

MS. RODRIGUEZ: Good afternoon. I want to talk a little bit about the Minority AIDS Project.

The Minority AIDS Project is an outreach of the Unity Fellowship Church, and basically was started to provide services to the minority communities here in Los Angeles, which were being and continue to be under-served in terms of the amount of resources.

The Project is twofold. We have education, outreach, prevention is part of the Project. The other part of the Project is direct services to PWAs, to persons with ARC, and also HIV positive.

We also in Los Angeles have a residential house, Dignity House, for homeless PWAs, and that's been in existence for a little over a year.

Some of the things that we're seeing in terms of the minority community is that one of the issues is that there are little or no financial resources for many of the clients that come to us and to our Project. We are one of the -- we are the only agency in Los Angeles County that does provide direct cash assistance, and we'll do that on an immediate basis.

Many of our clients have long hospital stays, come out, they've lost their apartment; they've lost where they're living, and therefore need some time to get into the system so that they're able to collect benefits. In the meantime, that person has no resources, we're finding that that's a real issue.

Eighteen percent of the clients that we have are homeless at the time of referral, so they have no place to stay. And we're finding that increasing all the time. In fact, before I came over here, we had a call from an agency here in West Hollywood, a couple blocks, that had a PWA who was homeless, no place to stay. Also has severe dementia, so that even if we were to place that person in a motel room/hotel room, they probably would not be able to care for themselves. And there is no place to send that person right now.

We are also finding in terms of eligibility problems, in terms of people getting into the system, many of our clients are illiterate, or their education level is very low, or they're monolingual, most predominantly Spanish speaking, and if anyone

has seen the forms that one has to fill out either at County or Social Security offices, it makes it very difficult for them to access the system in terms of receiving their benefits.

For most of the minority community, we're seeing that there is a delay in up to six months, so that when a person is presenting symptoms, there usually is a delay of about six months before they present themselves for treatment. Where they're presenting themselves for treatment is the Emergency Room for County Hospital.

All of our clients -- I think we have very few, and we're seeing over 200 clients right now, that have a private physician. So, most of them are relying on County Hospital for their care.

Along with this comes the idea that minorities have not had access to good health care, so they are resigned to, when they are presenting symptoms, they're resigned to the level of discomfort. There's a much higher level of denial, which means that in terms of -- if you're looking in terms of transmission, they may be continuing to engage in practices that are often putting others at risk because of the level of denial, and because of the difficulty in seeking appropriate health care.

One of the issues is that early on, in terms of the AIDS epidemic, it has been signified as being a gay disease. And for the minority communities, that still is very prevalent, and that's how it's being identified as still something that's gay and does not affect them. So, it's been very difficult to break through in terms of education in the community to alert them in terms of what this epidemic is all about.

There is a real reluctance to also identify to AIDS service providers for fear of being stereotyped as being gay.

One of the real issues that we're seeing is the undocumented, and that's a very, very severe problem. Approximately almost 38 percent of our caseload is the undocumented clients. Most people aren't aware that they are entitled to absolutely no benefits. So, after they are diagnosed and are unable to work, there is no Social Security; there is no general relief; there are no food stamps. They get absolutely no cash assistance. And many times the family will not care for these people. They want nothing to do with them, especially after they've been diagnosed, because their sexuality often times may have been closeted. Sometimes it's much more difficult to keep that issue closeted, and so we are seeing people that we are paying their rents on a monthly basis and are the mainstays in terms of providing the care and the services that they need at this point.

Also, even though most of them will present at County Hospital for treatment, County now has a form that they must fill out, which is a CAC-6, in which they have to present themselves for an Immigration interview, which means that the fear and the concern is that the information will be used for enforcement purposes.

So, in terms of the minority going ahead and accessing health care at the County facilities, there is a deterrent -- there's a greater deterrent now for them to access health care. So what you're going to see is a real continuing denial of the symptoms in these particular individuals.

We are also finding that because of the lack of culturally sensitive health care providers and also those that are bilingual, there are many, many clients who have been diagnosed but have no understanding of what the diagnosis means, what that means in terms of changes in their life style, behavior and habits. It's not uncommon for us to get clients who really have no idea about what AIDS means. Some clients don't even know still that it is a fatal disease that they're looking at. Some clients have not been counseled in terms of altering their sexual practices because they have not had someone to sit down with them and spend the time to do appropriate education with them.

And that's one of the issues that we're finding at the Project, is that there are very, very few bilingual service providers, very very few. And in terms of the social workers I know, just in L.A. County, who are bilingual, it's very small who are trained to work with AIDS patients and deal with AIDS issues.

We're also seeing that there is, in terms of home care, home care is very limited in terms of the services that are being provided, and not just for this community, for the minorities community, but that would flow across for all patients at this point.

One of the things that happens is that home care also means that you have to have an adequate house to provide home care in. Many of our clients, some of them are still living in cars, in the street, or they're living in one room, you know, single hotel occupancies, buildings downtown, which means they don't have a bathroom. They don't have any cooking facilities,

so even though additional money for home care could be utilized, you'd have to have the appropriate living conditions to be able to make full use of home care.

We're also finding that as the number of diagnosed minority patients increases, that we're seeing a large number of women and children, and no housing facilities at all for women and children who have AIDS. There is not one in this County. So that oftentimes they are either put into substandard housing, or in the one case, we have a mother and a child who they bounced from single occupancy hotel to single occupancy hotel.

Some of the needs, as we look at our patients, there needs to be better education about the disease in the minority community. There needs to also be better education when people are diagnosed. It's just not being given.

Also, in terms of symptom identification, making, you know, the information more accessible to minority communities. And in terms of there also being much more emphasis being done in terms of it being culturally appropriate.

Those for us, those are the basic issues that we're up against here in terms of the clients that we see.

CHAIRMAN HART: Thank you very much.

You're obviously dealing with clients that are really very desperate in many years.

Could I ask, what is your source of funding?

MS. RODRIGUEZ: State and county funding.

But in terms of the residential shelter, that is not funded at all through State or county. It's all private

donations, and the cash assistance that's given to clients is also donations. So there is no funding for that.

CHAIRMAN HART: How large a staff do you have?

MS. RODRIGUEZ: We are a staff of six.

CHAIRMAN HART: Thank you very much for your testimony.

Our last invited witness is Judy Spiegel, I believe.

Ms. Spiegel is the Director of Education at AIDS Project Los Angeles.

MS. SPIEGEL: Good afternoon.

I want to thank you for inviting me, and I apologize for not being able to have made it here earlier today.

I'll just start out by saying that I started in public health 12 years ago dealing with pregnant teenagers, and the same kinds of problems that we experienced with pregnant teenagers -- both educating them and trying to prevent pregnancies resulting in adoption, and abortion, and mothers who are old enough to be the sisters of the kids that they were bearing -- are the same things that we're seeing with AIDS today.

I started with the AIDS Project Los Angeles as the Education Department four years ago, when California first funded our AIDS education programs. And I think the struggles that we've seen over the last four years are greater than I ever would have perceived would happen.

Preventing AIDS today is like trying to stop a flood with tinker toys. We don't have a vaccine. We don't have a cure. We don't even have any effective treatments on the horizon that are accessible or particularly useful to the bulk of the people who have AIDS.

The only thing we really have today is education, and even that's restricted. It's restricted by limited funds; it's restricted by the language, and it's restricted by a limited vision that somehow the possibility of offending a few members of the general public is more important than the probability that if we don't educate the public, we will kill tens and hundreds of thousands of people.

I was asked in preparing for this to talk about the issues. What are the issues that we're talking about in preventing AIDS? I think it's very simple. We're talking about life and death. We're not just talking about the lives of a select group of people. We're talking about the lives and deaths of all of our American citizens, our taxpayers, our work force, homeless men, women and children, as Dr. Mundy talked about earlier. It affects all races, all economic groups, and every state of this nation.

If we have to -- we have the power to save lives at far less than it costs to take those lives, or even to support them through the course of the illness, and that's come up again and again and again. But we still ignore the less costly ways for letting it go and end up having to pay for it through poor services and not enough money to provide the care to the people who, in the end, do come down with AIDS.

Experts in human behavior know that people don't change on the basis of facts. Yet again, and again, and again we hear that we should give out pamphlets, simple pamphlets that state the facts and expect that people can change, and that those behavior changes will stop the spread of AIDS.

Humans are far more complex than that. They learn through experience and through practice. They receive information from many sources over long periods of time, not over night. We've already seen years of preventive education programs, attempts at stopping cigarette smoking, the more effective use of seat belts, high blood pressure, and alcoholism, and again, and again, and again we see that it takes more than a pamphlet, or a picture of some blackened lungs, to change that behavior.

It takes repeated messages and creative messages, and the use of experts and peers spreading these words again, and again, and again through public personalities to create even the smallest hint of the change in behavior. That's also what it takes to stop AIDS.

And it does work. There are surveys in both San Francisco and Los Angeles that have shown that gay men who have been exposed to education over the last several years have changed their behavior and taken on more risk reducing behaviors.

If you look at recent reports to the contrary of some of the sexually transmitted diseases spreading among heterosexuals, there have been recent reports that diseases such as Chlamydia and venereal warts and others are spreading more rapidly today in heterosexuals, particularly in Texas, and San Francisco, and New York, and Chicago and Los Angeles -- the same cities that we see the focus of AIDS.

So, if you look at that, we can assume that we're going to see the same -- we are liable to see the same kind of spread

of AIDS among heterosexuals as we've seen in the gay community, because it is the same cities.

AIDS isn't different from the other health concerns that we've talked about -- smoking and high blood pressure and alcoholism. Everyone needs to know about it. And without the knowledge and skills to prevent infection, anyone who has sex, or picks up a needle is at risk of being infected by the virus. To reach the public, we have to use many strategies, many languages, and address all the components of our public, not just the general public.

Advertising agencies know this. Look at McDonald's ads to distinctly sell hamburgers and salads to all different components of the population. They don't use one ad to reach everybody.

People who market alcohol products market them very differently in every different neighborhood that you go into. You can go into Inglewood and Crenshaw, and you see Black models selling brandy. If you go into East Los Angeles, you see Latinos. If you go into Century City, you see billboards with upscale Whites in black velvet clothing to sell liquor. That's what works. And we have to do the same thing with AIDS.

We can't worry about a brochure targeted for Blacks, that won't be meaningful for the rest of the population, or that if we print a brochure in Spanish, that it won't have any meaning to anybody else and they'll be offended because it's not in their language, or because a brochure with a picture of a gay man with tight jeans, the selling message is the safe sex to other gay

man. The fact that it doesn't meet everyone's moral standards does not mean that it's not important. That's what saves lives.

If we don't use these kinds of population-specific tactics, then we're all contributing to the spread of AIDS.

It's not an easy disease to catch. And in fact, it's very difficult, and you really have to work at it. But people shouldn't have to work at getting the information they need to not get AIDS, and that's what's happening now.

We're restricted in the language that we use. We're restricted by the dollars allocated toward education. Granted, there's a lot more money going to education now than there was four years ago, but it's not enough.

To make it more complicated, we've got dollars coming from all different levels of public government, and each different component has different restrictions on it. There's money that flows from federal government to State to county, and then to private agencies like AIDS Project Los Angeles. And by the time it reaches us, we have to be accountable to all four of those different funding sources, meeting all of their different restrictions. By the time we meet all of those restrictions, our messages are so whitewashed and benign that they have no effect.

AIDS prevention involves more than getting the facts out. It means getting the ears and the hearts of the people who need to learn about it. There is no reason for people to become infected today if they know about AIDS, how to prevent it, and how to use it. That means that we have to talk about sex, and condoms, and drug use, and pregnancy, and all the other side

issues that are affiliated with AIDS. It means we have to talk with people about how to talk to their partners about sex; about parents talking to their children; about teachers talking to their students; about health care providers talking to their patients. We have to teach people how to talk about AIDS, how to talk about sex, how to say no, and how to use condoms.

I worked in Family Planning for six years before I got into AIDS. And we always gave instructions to our patients about how to use the methods of birth control that they were going to use, including condoms. It never occurred to me that condom manufacturers do not give the same instructions in their -- on packages, and the truth is that they don't. If you walk into a drug store today and buy a package of condoms, it comes with no instructions.

Where are people supposed to learn how to use them if we can't talk about it? Who's going to get the message out? It's not the people who are marketing the products. It's not easily gotten across in the schools --

SENATOR ROBERTI: Why don't they?

MS. SPIEGEL: Beats the hell out of me. I really don't know.

SENATOR ROBERTI: It would solve a lot of problems.

MS. SPIEGEL: It could make a big difference.

We know that sex doesn't go away by not talking about it. We've seen that for years, and years, and years, and years, by the millions of pregnant teenagers every year. The number of pregnant teenagers is not going down in this country, and we have

restrictions about talking about sex and using effective sex education programs in the schools. And we've seen that not doing it doesn't make it go away, despite our greatest desires.

So, we have to talk about it now.

AIDS Project L.A. has been educating residents in Los Angeles County and in Southern California and the rest of the country for over four years now. We take more than 5,000 calls a month today. We took 300 calls a month four years ago. We've begun with the East Los Angeles Rape Hotline and the Spanish language line so people can get AIDS information in Spanish as well. In only nine months, the number of calls that they are getting is exceeding 600 each month.

We conduct nearly 100 presentations and workshops every month that reaches thousands of people a month in churches, in schools, in businesses, in hospitals, police departments, sheriff's departments, probation institutions. We distribute hundreds of thousands of printed materials monthly. We produce public service announcements. We educate the media. For the last two years, we've run Southern California media campaigns focusing on AIDS to the whole region. And we know that those have been effective. They get people to call the Hotline.

But now we need to take the next step. We need to teach people how to change their behavior.

The calls that we're getting from people, and the requests and the questions, are getting much more specific. People want to know when we talk about safe sex, and we talk about protecting themselves, what exactly does that mean? And we

can't tell them exactly what that means because we're not allowed to use the words in writing.

And as long as we don't --

SENATOR ROBERTI: You're not allowed to use --

MS. SPIEGEL: Well --

SENATOR ROBERTI: -- by whom?

MS. SPIEGEL: Funding sources.

SENATOR ROBERTI: So it's generally a compendium of all these various groups you're getting money from that tell you what words you can and cannot use?

MS. SPIEGEL: Right.

Over half of my education budget comes from the State of California. We haven't had risk reduction guidelines acceptable to the State for almost -- for over one year now, which makes it very difficult to do our job. All of our materials have to be screened by the State. In and of itself I don't think that that's a problem.

But when we're more concerned from a political process or a public process that we might offend a few individuals with certain materials that are not geared toward them, that would never be distributed to the whole public, and say, "You cannot say explicitly what safe sex is, and you cannot use sexual terminology; you have to be very technical," the majority of the public doesn't understand technical terms. We're talking about a lot of people who don't have more than a junior high education. Many people, particularly in the Hispanic and Latino communities, we've been told we need to gear our publications toward a third

grade education now because we have so many people coming across the border who don't have an education.

And yet, we're geared toward producing more materials in English than any other language. Most of the materials that have been produced are at a college education level. And yet most of the readers who obtain those materials aren't college graduates. They don't use words like "condoms" and "digital manipulation". They don't know what those things mean. We have to talk very clearly and simply.

And it's not even as simple as, well, if we get X percent of our money from the State, for example, that in the other materials that we publish with our own money, we can be more clear. Because the regulations that guide us say that if any of your people, or any of your programs are connected to the State dollars that fund you, those dollars govern how you can say your words.

So, I can't have volunteers going to the public and speak differently than a State funded employee would.

SENATOR ROBERTI: Is the State the most restrictive?

MS. SPIEGEL: No.

SENATOR ROBERTI: Who is?

MS. SPIEGEL: I think our county is probably more restrictive. There are materials that have been approved by the State that our County Board of Supervisors has not approved for distribution by county offices.

I think that --

SENATOR ROBERTI: Do you have any of those materials, maybe not with you now, but that you could --

MS. SPIEGEL: Yeah, we have a few that I could get to your office, sure.

But I think really what we're saying is that if we're going to prevent the disease, we have to be explicit. We have to put our money where our mouth is, literally. We have to increase the funds for education, and we have to loosen the gags that have bound the AIDS educators for the last four years.

This is not a disease that's going away. When I started, I think a lot of AIDS organizations were not doing any long-range planning because nobody could believe that this was a disease that was going to take off and as disastrous as we've seen.

But it has, and it's going to be here for a long time. And if we don't do our job, it's liable to take hundreds of thousands of lives that could have been prevented.

Thank you.

CHAIRMAN HART: Thank you very much.

As someone who's been involved in some of these AIDS education battles and controversies in Sacramento, I think you've stated the case very persuasively.

MS. SPIEGEL: Thank you.

I certainly appreciate your support.

CHAIRMAN HART: Thank you.

We have two other witnesses that have signed up to speak under our public testimony period. The first is Sandra Tholen,

if I'm pronouncing that right, California School Nurses Organization.

MS. THOLEN: First of all, I'd like to thank Senator Hart and the Committee for the efforts on behalf of AIDS prevention, and the opportunity to provide testimony on behalf of the California School Nurses Organization.

As the primary health professional in public schools, we too are deeply concerned about the impact of the disease on children, the families, and the communities that we serve.

We do currently have children in schools who have been diagnosed with AIDS. Confidentiality for the most part has been maintained, and services have been provided to protect the child, other students and staff.

Recent litigation established the right of faculty members to continue to teach despite being diagnosed with the AIDS virus.

Clearly, issues of communicability, hygiene, staff inservice, physical health care services are of concern to our organization and the public school system.

It appears unlikely that we'll see revolutionary progress in AIDS treatment in the immediate future. We can, however, anticipate that AIDS will become more and more of an issue in California schools.

Hopefully, we will see effective treatment and a cure soon. But at the same time, at the present time, the primary weapon against AIDS continues to be education. And again, that's going to become more and more of an issue in schools.

It's our position that education about AIDS is critical. As noted in Senator Hart's Fact Sheet, AIDS has most devastated young and middle-aged adults. And if we're going to impact these age groups, it's critical that we begin with the young so that they can begin to collect the tools and the information that they need in order to protect themselves.

Unfortunately, myth and misinformation continue to be widespread. Public fear and hysteria is communicated to and often magnified in students, in the young. I think it's critical that young people have access to the most current information available, and perhaps more importantly, an opportunity to discuss these particular concerns.

If AIDS education is going to be effective, it has to be taught by knowledgeable, appropriately trained personnel. There needs to be opportunity for follow-up discussion. There needs to be an opportunity for the students to discuss their fears and concerns and the personal issues, as well as providing a resource for students to turn to when they have additional questions or personal concerns.

Education isn't showing a film, turning off the projector and discussing English. AIDS is a highly emotionally charged topic, and each of us brings personal feelings, values, attitudes into any discussion. And without an opportunity to address these fears, these questions, and these concerns, we really do a disservice to our students, and I think we fail to achieve the education that we are trying to seek.

In a sense, I think the AIDS education crisis is part of a larger problem in California education. That is the problem of comprehensive health education and the lack thereof. Comprehensive health education is not provided in any consistent manner in California. Some school districts have made health a priority and have implemented comprehensive programs, but most have not.

Ideally, AIDS should be introduced as part of a comprehensive program, with a basis for understanding concepts like infections, communicability, and general physiology, with that foundation already in place. It's not appropriate that a third grade student necessarily be taught about condoms or the specifics of AIDS transmission. But a third grader can be taught about the nature of germs, the nature of disease, the nature of communicability, and so. And with this foundation, it becomes possible to teach a tenth grader to understand and accept more technical, more explicit information about the transmission and prevention of AIDS.

As was alluded to here previously, it's important to know that health education is somewhat different from other education. The purpose of health education is to impact behavior, to change behavior. And provision of simple information is not enough.

What we want to do in health education is encourage students to make healthy life decisions, whether those be in the areas of smoking, nutrition, drugs or sexuality. And we can't expect a brief presentation to make those kinds of behavior changes. We need comprehensive, effective health education.

In summary, I would suggest that while the California School Nurses Organization believes that the nature of the AIDS crisis makes it imperative that AIDS education be implemented now, that any program must provide for discussion and follow-up by appropriately trained personnel, we would further suggest that this committee not lose sight of the need for comprehensive health education; that AIDS can be most effectively addressed within the context of a program that provides a sound basis for understanding health and illness.

And we look forward to working with you on these goals.

CHAIRMAN HART: Thank you very much, Ms. Tholen.

An excellent statement, and I hope that the Legislature and the various school boards around the state will take your words seriously.

Our last witness is Carolann Peterson, who's from the California Federation of Business and Professional Women.

MS. PETERSON: Thank you for this opportunity.

In the past two years, the California Federation of Business and Professional Women has included the issue of health on its legislative platform, focusing on osteoporosis and AIDS.

As the debate of AIDS increases, Business and Professional Women will continue to monitor proposed legislation, and that legislation which discriminates regarding the right of privacy and employment will be of great concern to BPW.

However, our primary goal is to educate our members that AIDS is not contracted through casual contact, and that AIDS prevention is a responsibility of everyone.

Therefore, we urge the Legislature to provide continued support, and we especially urge the Governor's Office to provide support and continued funding to combat this disease.

Thank you.

CHAIRMAN HART: Thank you.

This concludes our hearing. I want to thank everyone for attending and for some excellent testimony today.

This also concludes the interim hearing process that the Select Committee has been engaged in over the last couple of months. Having heard testimony and engaged in numerous discussions and sort of fact finding endeavors, staff and Committee Members will put our heads together and, hopefully, come forward with a legislative package for this next year that will respond to many of the concerns and suggestions that we've heard both today and in other meetings.

We obviously have a long ways to go in combating this disease, and the State Legislature and the Governor need to be partners and not obstacles to overcoming this dreaded disease. And I hope that 1988 will be the year that we can look back on as the year in which substantial progress and thoughtful legislative recommendations were followed by the State of California.

Thank you all again for attending. Happy holidays.

(Thereupon this hearing of the Senate Select Committee on AIDS was terminated at approximately 3:20 P.M.)

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