NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

CONFERENCE

Tuesday, November 27, 1990

8:24 a.m.

Gold Room

Radisson Normandie Hotel

San Juan, Puerto Rico

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P R O C E E D I N G S

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CHAIRMAN OSBORN: Good morning.

I am Dr. June Osborn, and I am Chairman of the National Commission on AIDS. I am very pleased that you have been able to join us this morning for the first set of important sessions that we will be having here in Puerto Rico over the next two days.

I will spend very little time in my introductory comments so that we can proceed to the substantive issues of the day.

First of all, let me offer thanks on behalf of the whole Commission for the very diligent work that has been done in order to make this complicated set of arrangements for us and to prepare such a rich agenda for our opportunity here in Puerto Rico; we very much appreciate that.

A couple of details that I do want to cover before we start. First of all, I understand that last week in one or several of the papers, it was stated that there would be a session for public comments today, and that was in error. The scheduled time for public comments is tomorrow, Wednesday, at 11:45. I hope no one has been misled by that, but we are very glad that you are with us, and tomorrow will be the

opportunity for public comment. Unless people have already notified the Commission staff of their wish to speak, they can come at 11:45 tomorrow.

The second announcement is that there will be no smoking in this meeting room. If people wish to smoke, they should do so outside the meeting room, and throughout the meeting we will ask that that be the case.

A third comment is that as various people who are speaking to us are speaking, we will use a mechanism that we have found is gentle but effective, of putting on a timer so that people are aware of when about one minute is left of the allotted time for speaking. We would like very much to have a chance to ask questions and interact with the people who are talking with us, so we ask the witnesses to keep their comments brief, and the timer is just a way of helping with the sense of time when one is speaking. So I hope you will accept that and understand that that gives us a chance to interact with you.

Finally, I must apologize for being monolingual; I am not Spanish-speaking. So I hope you will forgive me for that. I wish I were able to speak Spanish, but the hospitality of Puerto Rico has been extended to me many times in the

past anyway even though I don't speak Spanish. So I hope you will put up with several of us who are unable to express ourselves in Spanish.

I'd like now to introduce Dr. Antonia Novello who is, as you know, the U.S. Surgeon General and who has some greetings and opening remarks as well.

Dr. Novello?

SURGEON GENERAL NOVELLO [Interpreted from Spanish]: Good morning. I would wish to speak in Spanish, but today I will speak in English so that the people who invited me to speak can hear my comments, which are really important. So I apologize.

[In English]: I come here today to welcome you and to offer my support for your fact-finding efforts here in Puerto Rico. Through our discussions over the next two days, I am sure we will find that we share an unrelenting sense of urgency that all persons with HIV and AIDS receive the best and the most compassionate care possible.

The HIV/AIDS pandemic is changing, and this second decade is increasingly reflecting AIDS in the world. It is increasingly female, increasingly young and, obviously, increasingly heterosexual, and in the United States especial-

ly and in Puerto Rico, increasingly enmeshed in drug abuse.

Women are the caretakers of society, the cement that holds societies and families together. Although AIDS is a worldwide problem affecting men and women, the increasing impact of AIDS on women and their children has an especially great effect on societies, Puerto Rico no different.

The public health challenge of the HIV/AIDS pandemic is unprecedented. WHO estimates that 8 to 10 million adults worldwide are now infected with HIV and that at least 3 million of them are women. Millions more women will be vulnerable to infection because of the role in which societies have placed them.

Let me make some statistics meaningful to you. In Africa, where AIDS occurs equally among both sexes, one in 40 men and women are estimated to be infected with HIV. In the United States, it is one in 75 men and one in 700 women.

According to the WHO, AIDS has become the leading cause of death for women between the ages of 20 and 40 in many major cities of the United States, Europe and Sub-Saharan Africa. Most HIV infections, at least 75 percent worldwide, were acquired through sexual intercourse, primarily heterosexual.

Over the next several decades, heterosexual transmission will increasingly become the primary means of spreading HIV infection in most industrialized countries, and by the year 2000 the annual number of worldwide AIDS cases among women will begin to equal the cases among men. For this reason all countries will need to develop HIV/AIDS prevention and control programs and other public health measures that are responsive to the growing problems of the disease among women.

More than half a million children have already been infected with HIV by their mothers, and we expect this figure to double during the next two years. We also estimate during the next two years that more than 3 million uninfected children will have been born to HIV infected mothers, and by the year 2000 there will be more than 10 million children orphaned by parents who die of AIDS.

Globally, women account for more than 3 percent of the reported adult cases in Australia, more than 5 percent in Canada, 8 percent in the United States, almost 12 percent in Europe, and 52 percent in Uganda. These are startling statistics particularly when you consider that the number of reported AIDS cases may not reflect the actual incidence of

HIV infection and AIDS.

Let me turn to Puerto Rico. As I have indicated, in Puerto Rico, AIDS has been and remains a disease of i.v. drug abuse heterosexuals. Of the 4,956 cases of AIDS in persons 13 and older reported through November 1990, 4,000 or 82 percent are in males, and 878 cases or 18 percent are in females.

In Puerto Rico, can women in their traditional roles as family caregivers and health care providers protect themselves and their children from infection? Let me articulate our real challenge here in Puerto Rico, in the United States, and in the world, to recognize that any effort to eradicate AIDS in families must embrace the key role of women, particularly as equal partners in decisionmaking.

But the effect of AIDS on women is not just a matter of numbers. It affects women as individuals, in their multiple roles, and as health care providers and educators as well as mothers and as income providers. In particular we have not begun to estimate the full impact of this epidemic on women to their partners, to their husbands, to their children, to their parents or even extended family members and friends. Ultimately, the burden of this terrible disease

will fall on women and secondarily it will fall on families.

Several factors can severely damage a woman's ability to protect herself from infection if she is infected in order to protect others. These include psychosocial, cultural or legal barriers to some of her decisionmaking, the lack of economic alternatives with the consequent dependence on a man for support, the societal role of women as primary caretakers of children, husbands and parents, and in some cases lower literacy, limited mobility, and limited access to information, not to mention societal attitudes about sexuality.

In general, we all know that it is easier for men to protect themselves from the AIDS virus. For women, the protection is much more problematic. Of course, a mutually faithful monogamous relationship is the best, but in the absence of that, prevented infection is going to need the protection of the women, and at this time, we know that for many women this safeguard is denied them because of societal and cultural restraints.

Suggesting to a husband or a partner that he use a condom may be a social tabu because it is perceived as an indication of insolence or defiance against the man, or even

for some men perceived as an indication of a woman's potential infidelity. This often results in serious problems within the relationship, perhaps even violence against the woman. In cultures where married women are traditionally expected to bear many children, insisting on safer sex or refusing to engage in sexual relations may be impossible because it limits the number of children, which in some societies is the measure of importance in defining manhood and womanhood.

It is important that programs that encourage the empowerment of women by developing negotiation and communication skills can be useful but might not always be realistic. In some countries, most women who are at increased risk of HIV infection may not have the power within sexual relationships to negotiate a change in the rules.

We have to always remember that cultural attitudes have a strong impact on expected general roles. Many women are also economically dependent on their sexual partners and cannot afford to leave them in order to reduce their infection. In those moments economic survival takes precedence over HIV prevention, and that is why it must be remembered that for any effort in AIDS eradication in families to be successful, women will have to be more and more recognized as

important if not equal partners in the development of policies pertaining to their family health. Only when this is done and realistically attempted will women be in a position to protect themselves, their sons, their daughters and their families from HIV infection.

Effective health care must take into consideration a comprehensive family-based community center approach under one roof to be able to deliver the needs of the complete family.

And so as your Surgeon General, I wanted to take this message to you. I am very much worried about the situation in Puerto Rico, but I stand with you here today to be able to listen to all the things that will come from your perspective in order to be able to help you in the long run.

Thank you very much.

[Applause.]

CHAIRMAN OSBORN: Thank you very much, Dr. Novello.

And now I am very pleased that Dr. Soler-Zapata can be with us this morning. I am particularly delighted because I think it is one of the first opportunities in the last few weeks that he has taken to join a group of this sort. So we are very grateful that you could take the time to be with us

and look forward to your remarks.

DR. SOLER-ZAPATA: Good morning, all of you. If you will excuse me, I will speak in Spanish now.

[Interpreted from Spanish]: Madam Chairman, honorable members of the Commission, dear friends, I want to start today with welcoming words, thanking you in the name of the people of Puerto Rico.

I am very happy to share with you the difficult situation that our people go through in terms of fighting this epidemic that is the concern of the members of this Commission.

In this panel, we have participants from the United States, from public health, excellent human beings, excellent Puerto Ricans as the Surgeon General of the United States, and the Secretary of Health of Puerto Rico, and the Assistant Secretary of Health, Dr. Enrique Mendez.

The presence of these persons on the Commission will help greatly for the Commission to have a more clear picture of the problems of AIDS in Puerto Rico.

There is no doubt that we will participate in these hearings and will share our opinions indicating what we are doing in Puerto Rico to fight this malady.

Dr. Novello and Dr. Mendez will clarify for members of the Commission any matters relating to the problem of AIDS in Puerto Rico.

During these greetings and welcome as Secretary of Health of the Commonwealth of Puerto Rico, I have to state with great regret that today we are among the first countries in the world afflicted by this epidemic.

However, I am also proud to state that at the same time, when we discovered the first case of AIDS in Puerto Rico in the year 1981, the Department of Health and all the government entities that are involved with the welfare of our people have been working together to fight this terrible disease.

The action plan of the Government of Puerto Rico for AIDS is perhaps a unique plan among the American nations. I urge you to listen to Dr. Johnny Rullan, who is Director of the Central Office for AIDS in Puerto Rico, who will speak to us on the public health policy for AIDS which has been established by our Governor, the honorable Hernandez Colon.

Our statements are limited at this time to express our gratitude, the gratitude of a people that every day investigates new trends to fight this national affliction.

As a matter of fact, I want to indicate the statute of limitations on necessary funds to expand our struggle against this disease. We realize that we have less funds than other States of the American Nation and possibly in other countries that suffer.

I give you the welcome of Puerto Rico, and I wish to share with you in the United States, and clarify any doubts that you may have regarding the different opinions.

Thank you very much, and God bless you.

[Applause.]

DR. SOLER-ZAPATA: Excuse my poor English.

CHAIRMAN OSBORN: Thank you very much, Dr. Soler-Zapata.

Before we proceed to the first panel, I want to thank Dr. James Mason for being with us, sitting in for Secretary Sullivan, who is represented ex officio on the Commission. Dr. Mason, do you have any brief comment you would like to make?

DR. MASON: Thank you, Dr. Osborn.

I want to say on behalf of Dr. Louis W. Sullivan, Secretary of Health and Human Services, how delighted we are that the National AIDS Commission has chosen to come to the

Commonwealth of Puerto Rico for this hearing and how pleased I am to be a participant in this process.

I am just glad to be here and look forward to hearing from many people here and visiting various sites so that we can assess as far as possible what the needs are here in this area.

CHAIRMAN OSBORN: Thank you.

I think we will proceed directly to the first panel, which includes Dr. Kenneth Castro, Dr. Johnny Rullan, Dr. Pedro Borras, and Luis Maldonado.

I would ask that the comments in general be limited time as has been planned so that we can interact with you afterwards with questions and discussion.

MS. BYRNES: Before we begin, I would like to announce for anyone in the audience who needs translation either in English or Spanish that there are headsets available in the back of the room. Please feel free to help yourselves.

DR. CASTRO: Good morning, Dr. Osborn, members of the Commission and guests.

As you know, I am Ken Castro, Assistant Chief of the Epidemiology Branch, Division of HIV/AIDS, at the Center for Disease Control in Atlanta, Georgia.

Today I come to you with very honestly what I consider to be mixed feelings. While honored by the request to speak in this forum, I am here to describe some disturbing facts about the effects of the HIV and AIDS pandemic on my native island, Puerto Rico.

I do want to acknowledge several individuals who were instrumental in the preparation of the materials I am going to present here today: Mary Ellen Fernandez [phonetic], Mitzi Mays [phonetic], Jean Smith [phonetic], Dr. Elsa Vigarino [phonetic] and Dr. John Rullan.

During the next few minutes I will focus my presentation on two main areas. First will be a description of the specific epidemiologic features of HIV and AIDS among adolescents and adults in Puerto Rico, in contrast with other areas of the United States. For this part, I have used AIDS surveillance data received at the Centers for Disease Control from Puerto Rico and other areas through October 1990. Other data were obtained from the National HIV Seroprevalence Surveys.

The second area to be covered this morning is the description of a recent outbreak investigation to illustrate the problem posed by dual infection with HIV and tuberculosis

in our population.

I believe most of the members, if not all, have copies of the materials I am presenting here today.

[SLIDES]

The first slide shows that there has been a large increase in the number of reported AIDS cases in Puerto Rico since 1988. During the four-year interval between 1983 and 1988, there were 507 reported AIDS cases. In 1988 Puerto Rico reported 1,246 AIDS patients, and in 1989 there were 1,479 cases. Through the end of October, 1,440 new cases have been reported.

The remarkable yearly increases beginning in early 1988 are probably due to the revision of the CDC AIDS surveillance case definition in 1987, which allowed AIDS to be diagnosed presumptively, without the requirement for invasive diagnostic procedures.

The next slide, among AIDS cases reported from Puerto Rico, I have two pie charts here. The left side shows cases reported from Puerto Rico. You can see that 43.4 percent have met the case definition on the basis of Wasting syndrome, shown as the yellow part of that pie chart. Another 33.8 percent have been diagnosed presumptively,

excluding the Wasting syndrome, shown in that pie chart in red. And 22.9 percent have a definitive diagnosis, which is the blue part of that chart.

In contrast, if you look at the right side of that chart, only 21.7 percent of cases in other areas of the United States were diagnosed as Wasting syndrome or presumptively, while 78 percent had a definitive diagnosis.

During the past year, Puerto Rico had the dubious distinction of being second highest in terms of AIDS incidence rate, with 56.4 cases per 100,000 population. In contrast, the rates were 113.2 per 100,000 in the District of Columbia, 46 in New York State, 32.7 in Florida, and 31.8 in New Jersey. And these, by the way, represent the five areas with highest AIDS rates in the United States.

When we look at some of the Metropolitan Statistical Areas, we see that San Juan had approximately 76 AIDS cases per 100,000, ranking fourth highest in AIDS rates among U.S. Metropolitan Statistical Areas with populations exceeding 500,000 persons.

The distribution of AIDS cases by age group is not significantly different between Puerto Rico and other U.S. areas. The largest proportion of cases in Puerto Rico and

elsewhere in the United States occurs in persons aged over 25 years. And here you can see the similarity in the distribution for all age groups.

There is a higher proportion of females among adult adolescent AIDS patients from Puerto Rico than in the rest of the United States. Eighty-two percent of cases in Puerto Rico are male, and almost 18 percent are female. In contrast, 90 percent of cases in other U.S. areas are male and almost 10 percent female. This gives a male-to-female ratio of 4.6 compared with 9.5 in the rest of the United States.

In 1989, the incidence of AIDS per 100,000 population in women was 16.7 percent in Puerto Rico, which is over five times the 2.9 percent seen in the rest of the United States. This difference implies that Puerto Rico will continue to experience a disproportionately large number of pediatric AIDS patients, which currently account for 4 percent of all reported cases.

There are, however, significant differences in the distribution of HIV exposure categories between Puerto Rico and other areas in the United States. In Puerto Rico, 58 percent of adult and adolescent AIDS patients were reportedly heterosexual intravenous drug users--this is shown by the

yellow bars--17 percent reported homosexual or bisexual contact, and 9.4 percent reported both risk behaviors.

In contrast, over 60 percent of cases from other areas in the United States reported homosexual or bisexual contact; almost 21 percent reported intravenous drug use, and 6.6 percent reported both behaviors.

In addition to AIDS surveillance data, various HIV seroprevalence surveys in selected populations have consistently demonstrated exceedingly high rates of HIV infection in Puerto Rico. These rates, shown in this map of the United States which includes Puerto Rico, were 5.3 per 1,000 in male civilian applicants for military service from Puerto Rico, the second highest when compared with U.S. areas elsewhere.

Due to time limitations, I will not present additional specific rates. However, I will state that other examples of relatively high HIV infection rates have been observed in the following Puerto Rican populations: in female civilian applicants for military service, in persons attending sexually-transmitted disease clinics, in intravenous drug users attending STD clinics as well as drug treatment centers, in females attending women's health clinics, in Job Corps entrants, and in volunteer blood donors.

Now please direct your attention to the next area which I said I was going to cover. Recently colleagues from CDC worked with officials from the Puerto Rico Health Department in investigating an outbreak of tuberculosis transmission in an AIDS unit in a local hospital. From December 1987 through August 1989, approximately 10 percent of patients admitted to the AIDS unit had tuberculosis. Additionally, several health care workers from the units converted their tuberculin skin tests in May of 1989.

The investigation suggested that tuberculosis transmission occurred from patient to patient in the unit, and factors contributing to this were as follows: 1) the obscure clinical presentation of tuberculosis in AIDS patients which precluded from adequate isolation precautions, and 2) inadequate ventilation in the unit, which has been seen to happen elsewhere in the United States. This also contributed to tuberculosis transmission both to health care workers an other patients. Finally, this particular outbreak investigation suggested that AIDS patients exposed to infectious TB were at very high risk of developing active tuberculosis.

This outbreak illustrates the importance of

recognizing TB as a health problem in our population and the potential for excess morbidity in those persons dually infected with HIV and tuberculosis.

In summary, I have presented information to indicate the severity of the HIV/AIDS epidemic as a public health problem in Puerto Rico and highlighted epidemiologic differences between the AIDS profile in Puerto Rico and elsewhere in the United States. And finally, by the use of this outbreak I have illustrated the importance of tuberculosis as a health problem in Puerto Rico, especially in the setting of dual HIV and TB infections.

I believe that it is imperative that these data be clearly understood and be used as a basis for sound public health policies.

Thank you for your attention.

[Applause.]

CHAIRMAN OSBORN: Thank you very much, Dr. Castro.

Dr. Rullan?

DR. RULLAN: Commission members, Dr. Soler-Zapata has asked me to distinguish among you Eunice Diaz. Eunice, thank you for all the help you have given us through the years.

Hello. My name is John Rullan. For the last three and a half years I have been working for the Puerto Rico Department of Health as a State epidemiologist.

In the last six months my role has expanded, and currently I am the director of five programs: tuberculosis, immunization, sexually-transmitted diseases, general epidemiology, and the AIDS Central Office known as OCAS.

My responsibility also includes being the Executive Director of the Governor's Interagency AIDS Commission, a commission formed in 1986 which includes the heads of six government agencies: Health, Substance Abuse, Corrections, Education, University, and Social Services Departments.

On behalf of our Commission, I want to thank you for accepting the invitation to hold formal hearings here in Puerto Rico.

We in the Government of Puerto Rico are very much aware that we live in a high HIV prevalence area. We continually strive to understand the complexities of our heavy migration pattern with the urban centers of the Northeastern United States, the epicenter of the AIDS epidemic.

In April 1988 we conducted an island-wide random general sample population seroprevalence study, using the

Health Interview Survey framework of 3,000 households, two per home between the ages 12 to 60.

From a response rate of 97 percent and a seroprevalence of .8 percent, that is, one out of every 125 Puerto Ricans from ages 12 to 60, we projected that around 40,000 individuals were HIV-positive in the island and that at least 80 percent were unaware of their infectious status.

Presently in Puerto Rico, four new AIDS cases are diagnosed every day, while three persons die of AIDS-related complications each day.

How many persons have sexual or blood-borne exposure daily and of those, how many get infected, is not known. That has to be quite significant if our pool of unaware HIV-infected, sexually active population infect approximately 120 babies each year.

Secretary of Health Dr. Soler-Zapata gave me the AIDS program responsibility in March 1990, and at that time my office was composed of a secretary and a messenger. We built rapidly and now, seven months later, we have 31 persons at the central level and 185 at the regional level, working exclusively for the AIDS program.

Our office coordinates all prevention activities as

well as all clinical services given to the HIV-infected individual in the public sector, representing approximately 70 percent of the total system, excluding the Municipality of San Juan, which Dr. Borras will talk about shortly.

In July 1990 we conducted a needs assessment study among 339 HIV-positive individuals representative of our risk groups to document their medical, psychological and social needs with respect to their condition. The results of the study were incorporated into our Plan of Action, and in October 1990 we opened seven regional HIV adult and pediatric clinics, using the medical/psychosocial model and with an emphasis on early intervention.

So far, 2,921 persons have attended the clinics in the first two months of operation.

This commitment to deliver needed services to our affected population puts this morning's demonstration, the Hawaiian luau show, into proper perspective and makes our team proud to serve Puerto Rico.

I would like to draw your attention now to pages 8 through 14, please. Basically, what we are proposing in Puerto Rico is a regional model with testing center in the primary health care setting that connect with our HIV clinics

that then go back and forth with the hospitals and then to the Alverga Hospice, all connected by the CBO model. That is on page 8 of the document.

On page 9, I want to draw your attention to the existing testing centers. As you can see, most regions have enough testing centers--we have 55--except for the regions of Ponce and Arecibo.

On page 10, we have the testing centers that we are going to create in the next three months with a heavy emphasis on Ponce and Arecibo and connecting with the substance abuse programs.

On page 11, we have the location of our specialized HIV clinics, one per region, except San Juan, where there are three.

Page 12 shows where our public hospitals are located.

Page 13 shows where the private Community-Based Organizations exist in Puerto Rico. As you can see, the metropolitan area has four; Fajardo has one; Ponce has two, and the rest of the regions have none.

Page 14 shows what is available, what we are working on, and what we will have in the next six months--

that is, in the metropolitan area, three hospices, one prevention service and two developmental stage; in Arecibo, three in developmental stage; in Ponce, one developmental, one for prevention, one hospice, Alverga; and in Caguas, two demonstration.

I will go back to page 3 now. Our group is composed of nine specialized teams. The health education team, headed by Juan Morales, has 18 members, and it operates a telephone hotline that receives 1,200 calls per month. On a yearly basis, this team organizes 25 training sessions, participates in 170 community activities, and provides 175 education activities for patients and their relatives. It runs an ongoing radio and newspaper prevention campaign, supplemented by a service access campaign. The team is currently developing strategies for direct intervention with high risk behavior groups in conjunction with our prevention team and Community-Based Organizations.

The surveillance team, headed by Mel Fernandez, operates an active AIDS surveillance system which covers 59 hospitals, 13 outpatient clinics and 13 private physicians. We estimate the sensitivity at 75 percent.

Puerto Rico is part of the CDC family of surveys,

and we are currently gathering crucial surveillance information from STD clinics, newborns, sentinel hospitals, women's clinics, substance abuse clinics, to be incorporated into our program review.

The prevention program team, headed by Enrique Nieves, coordinates testing, counseling, referral and partner notification activities in 55 testing sites island-wide. Approximately 25 outreach activities are performed per year in college campuses, high prevalence areas and unusual sites. This group is coordinating with the Puerto Rico chapter of the National Hemophilia Foundation for the outreach activities of our estimated 152 adult hemophiliacs.

Another activity of this group is serving as the connecting bridge between substance abuse and public health clinics, where we recently opened three of the proposed 13 additional testing sites.

The laboratory team, headed by Miriam Garcia, performs approximately 87,000 ELISAS, 7,000 Western Blots, and 34 newborn filter papers per year. These tests are mostly done at our central lab, which provides all the lab training courses and monitors quality assurance closely.

Our CD4 count flow cytometer has been installed and

will provide free counts to our HIV-positive population.

The epidemiology team, headed by Jose Paulo Ponte [phonetic], is developing a confidential computerized network with an extensive dataset that includes demographics, excluding name, clinical, laboratory, risk behaviors, and support system needs. This dataset is working in coordination with the Observational Database Project, an international community-based research project that we expect will provide us the capacity-building necessities that clinical trial committees call for.

The community coordination team, headed by Joaquin Fernandez, is assisting developing Community-Based Organizations in Ponce, Arecibo, Caguas, and San Juan. It is coordinating the consortia group that will manage HRSA Ryan White Title II moneys coming to CBOs this winter.

The external resources team, headed by Nadya Gardana [phonetic], prepares proposals, develops the proposed projects, and operates the administrative components of these projects. Currently, we have HRSA adult demo, HRSA pediatric demo, HRSA home health, CDC prevention and surveillance, and soon the Ryan White Comprehensive Care Bill.

The legislative team, headed by Julio Cesar

Gallarze [phonetic], is currently formulating legislation to discuss if HIV should be reportable, if it should be anonymous versus confidential, if it should always be voluntary, and how extensively should partner notification be done. This team has put forth a public policy statement that our Commission is reviewing. The team is in the process of setting up adequate counseling through our Region II office to defend Section 504 of the Americans with Disabilities Act.

The clinical service team, headed by Dr. Anhelas Rodriguez [phonetic], has 20 staff members in each region. The multidisciplinary group is composed of an infectious disease specialist, a pediatrician, two generalist M.D.s, three nurses, a clinical psychologist, a health educator, a nutritionist, a respiratory therapist, four disease intervention specialists, and MPH epidemiologist, a case manager, a social worker, a regional coordinator, a pharmacist, and clerical support.

T&S2 Currently, we have 1,000 persons on AZT and have begun pentamidine prophylaxis setup in all seven HIV clinics.

The regional coordinator has the responsibility of establishing effective linkages between primary care clinics, testing centers, regional HIV clinics, hospitals, shelter

hospices, CBOs and other government agencies.

As regards needs, in the coming months, we need to consolidate the referral system coordination especially between the HIV clinics and the hospitalized care. It is a sad known fact that AIDS patients in Puerto Rico spend too much time in emergency rooms waiting to be admitted. This must change.

Another area that needs attention is the OCAS/CBO partnership, especially outside of San Juan. There are too few CBOs currently delivering services on the island, and funding for seed money must be given as soon as the OCAS/CBO relationship has been linked.

Currently, we are examining five proposals to be funded in coming weeks, and once funded, OCAS/CBO relationships will improve.

A critical area that must not be forgotten is the recurrent secure funding source. Commonwealth funding must be increased immediately since we cannot depend on the federal budget. We have just received cuts in CDC prevention grants, and the CARE Bill does not seem to provide the funding we had anticipated.

By not having a Health and Human Services Civil

Rights Office in Puerto Rico, we have been limited to enforce Section 506 of the ADA. Discrimination against AIDS patients in Puerto Rico does occur, yet we cannot call a federal office in Puerto Rico to investigate such incidents.

The substance abuse/public health partnership needs to be strengthened with solid cross-training and combined comprehensive services, as Dr. Novello mentioned earlier. Over 70 percent of all AIDS cases in Puerto Rico come from drug addicts, their partners and their children.

I have four recommendations to the National Commission on AIDS.

First, Health and Human Resources Region II should open a civil rights office in Puerto Rico as soon as possible.

Second, the HIV problem is island-wide. Having MSA San Juan get all the federal money prevents other areas of Puerto Rico from developing solid programs. The Federal Government should consider Puerto Rico one MSA altogether.

Third, HRSA provides 77 percent of the federal funds to Puerto Rico, yet no direct technical assistance. On the other hand, CDC provides 23 percent of federal funds, yet direct technical assistance from four public health advisors. HRSA should provide more technical assistance as its funding

sources continue to increase.

Fourth, CBO models that work in mainland many times are not applicable to Puerto Rico. Mainlanders in decision-making positions should be culturally sensitive to this and help us develop models that will be applicable to our setting.

Thank you.

[Applause.]

CHAIRMAN OSBORN: Thank you very much, Dr. Rullan, for your very rich testimony.

Dr. Borras?

DR. BORRAS: Good morning, honorable Dr. Novello, Dr. Osborn. My name is Dr. Pedro A. Borras. I am the City Medical Director of the Capital City of San Juan.

The AIDS epidemic has affected the City of San Juan in a dramatic way, and we believe we are only seeing the tip of the iceberg.

Yesterday I ordered one of my aides to see what the situation will be in San Juan by 1995, new cases and estimated costs of these new cases. The project was that by 1995, in five years, we will have 902 new cases, and this will cost us about $92 million. He kept projecting this, and by the year 2000, we would have 1,803 new cases, which would give us a

cost of $184 million. He went further to the year 2005, and we would have 3,606 new cases, with a projected cost of $368 million. That is more than the total budget of the City of San Juan.

So as you can see, San Juan has been impacted in a very dramatic way. At present, over 29 percent of all AIDS cases in Puerto Rico have been reported in the City of San Juan.

The HIV/AIDS surveillance report from CDC in October 1990, indicated the number of cases per 100,000 population for the San Juan Standard Metropolitan Area--which we did not ask to be made a part of--was 69.3 cases for the period October 1989 and September 1990. San Juan is fourth only to San Francisco, New York City and Ft. Lauderdale.

The latest statistical data as of October 31st shows that 2,502 individuals with HIV infection have been reported in San Juan. Of those cases, 981 are actually AIDS cases; 749 are AIDS related cases, and 772 are HIV-positive asymptomatic patients. Of the actual AIDS cases, 54 percent have already died.

Seventy-two percent of our cases are related to intravenous drug abuse. The majority of the cases, 74

percent, are between the ages of 20 and 39 years old--that is three out of every four. Up to this moment, 142 pediatric cases have been reported, of which 42 were actual AIDS patients. Thirty-five of the 42 actual AIDS patients were children of mothers who were i.v. drug abusers or had had sexual relations with an i.v. drug user partner.

The City of San Juan allocates one-third of its whole budget--one-third of its whole budget--to the Health Department of the city. We have had to face the AIDS epidemic with our limited resources since the major financial subsidy for the indigent, Medicaid, has an island-wide annual cap of $79 million. This has restricted substantially the use of AZT, much needed by our AIDS patients.

What was the approach of the City of San Juan to this tragic situation? It has been to establish a centralized and comprehensive network of health services. We contracted a private institution composed of private physicians which were not in our service in the City, actually of high quality professional aid to provide through levels of care medical attention at home, ambulatory clinics, and skilled nursing and special inpatient care in the San Juan City Hospital, the medical care necessary for these patients. It is centralized,

and we thought that this was the best and most cost-effective system.

The San Juan AIDS Institute was contracted in 1987. The services have been provided on a regular basis to patients for the past two and a half years. The system was in place two and a half years ago. Actually, I have been in my position for a year and a half, so I am exposing to you a system that was not developed by me or by our actual administration, but by the previous administration, which is in my opinion an excellent health service organization to deal with this terrific problem of AIDS.

Through the Institute, a case management strategy coordinates such services as hospitalization, ambulatory clinics, home care and laboratories.

We have worked closely for the past one and a half years with Secretary of Health of the Commonwealth, Dr. Soler-Zapata, and we have worked closely with Dr. Johnny Rullan, who are in charge of the rest of the island. So I share with them the burden of taking care of this epidemic.

The San Juan AIDS Institute is centered in an ambulatory referral center especially remodelled at Rio Piedras, where AIDS patients from all San Juan diagnostic

centers, nine of them, are referred. We also receive patients from private hospitals and private institutions.

A diagnostic and treatment center is a primary health care facility and family medicine center located in a defined sector of the city, generally near the most populated and low-income areas. We have a lot of public housing in San Juan, and these centers were built around the public housing where most of the low-income people of San Juan live.

San Juan has nine of these diagnostic and treatment centers. A team of health care professionals, led by a physician, controls each diagnosed patient individually. Each patient has an attending physician who oversees his or her care during the entire course of the illness. This physician is accessible to the patient day and night; patients receive a card with their physician's telephone and beeper numbers to ensure continuity of care. A patient discusses any problem directly with his or her physician, who decides where and how the patient will receive adequate care. It could be sent from his home or picked up by our emergency services in his home to be taken to the nearest diagnostic center, because they are strategically located around the City, so we have nine options, out of which six options are

open all night and weekends.

The inpatient care takes place at the San Juan Municipal Hospital. This is a tertiary teaching institution of 415 beds which some of you will visit this afternoon.

We have an existing 20-bed semi-private unit for inpatients. Extended care, hospice care and home care are part of the services regularly offered. Several home care teams consisting of a physician, a nurse, a social worker and a psychologist visit patients at their homes.

The attending physician for each AIDS patient makes the decisions on the level of care required in consultation with the specialists working on other sections of the city.

The importance of the primary health care system as well as the need for formal preventive and educational activities was established from the beginning, 1987, and a strategy to strengthen them was developed.

In March 1989, the San Juan Health Department with financial assistance from the Robert Wood Johnson Foundation developed a community-based, integrated primary care system to prevent, detect and control HIV infection, with emphasis placed on the detection and prevention of sexually-transmitted diseases as a major risk factor for HIV infection.

We have decentralized the education and early detection strategies for the prevention of HIV infection and other sexually-transmitted diseases by the development of health teams in all of our primary care facilities. So we have eight options, the diagnostic centers.

Our plans for the next three to five years include, among others: the establishment of a new AIDS ambulatory center for the provision of ambulatory services to all our patients, and hopefully medication distribution centers to see if we can provide them with AZT and other drugs; the establishment of an AIDS clinical trial unit. This has already been established in our hospital, and we have already started clinical trials in our hospitals.

VICE CHAIRMAN ROGERS: Dr. Borras, let me interrupt you just briefly. To our sorrow, you are at the end of your time. Could you summarize rather briefly for us, because we are anxious to ask you questions as well.

DR. BORRAS: Is it already ten minutes?

VICE CHAIRMAN ROGERS: Yes. It goes very fast when you are on the stand, I'm afraid.

DR. BORRAS: Yes. There are two important things that I would like to add here. The rest, some of you will

see this afternoon.

We are worried about some news that Congress is "skimming"--is the word that has been used--funds from Title I and Ryan White for the City of San Juan. The possibility has been studied of not giving these funds to the City, but giving them to the State. This is the situation in San Juan. We have already too many cases, and the burden of the AIDS cases in San Juan is hard to take care of by our municipality with our limited resources.

Secondly, we believe we have the clinical model which is perfect, or nearly perfect, I would say, to deal with this epidemic. This is a clinical model, and we believe that it should be followed.

I thank you very much for listening.

[Applause.]

CHAIRMAN OSBORN: Thank you very much. We regret that the time pressures are so great, and we appreciate your forbearance.

Mr. Maldonado?

MR. MALDONADO: Good morning, everyone. Honorable members of the Commission, honorable Surgeon General, ladies and gentlemen, I come before you today to express my personal

views and share my experiences as well as those of other persons with AIDS in regard to treatment and care in the health care system of Puerto Rico.

My feelings personally are ones of gratitude for the support of a system which, though limited because of the impact of a serious epidemic, has responded to my needs. I know this to be true for many others.

The health system on the south part of the island, though resources are limited, has been responding within its capacity to the many demands created by the epidemic. In addition to the public health system, many people have joined our group of volunteers of the pastoral care program in offering emotional and spiritual support as well as donations for medicine.

~~As with any new problem, the health care system~~ has been overwhelmed by the AIDS epidemic. Ever-growing numbers of patients, the needs of many expensive medicines, and the lack of knowledge of the disease on the part of many doctors as well as other health care workers with negative attitudes, create very painful situations for patients.

For example, many doctors in the emergency room simply say: "There is nothing we can do because those

symptoms are part of your illness." These are patients who have difficulty breathing and who have diarrhea.

A month ago, a female patient was examined by a doctor for the first time. He told her, without any analysis or test whatever, "Oh, you are surely positive for HIV virus." At that, her mother, standing at her side, fainted and had to be treated as well.

Patients in need of emergency care are often reluctant to seek help because of negative experiences with some professionals. This means shortening of many lives. We all know that AIDS is, with the necessary treatment, becoming a chronic disease for many patients who survive many years, with adequate care.

The present situation in Puerto Rico shows the island as having such a high incidence of HIV virus that there exists a sense of panic about being infected. This panic in the population is in part the cause of the great amount of rejection among families, friends, and the community of HIV and AIDS patients. Ignorance is evident at all levels of living--among employers, in public transportation, as well as funeral parlors overcharging for burials because they claim to be at risk of infection.

I feel it is urgent to bring more forceful education throughout the island to attempt to change the attitudes of panic and rejection suffered by so many patients, to become instead an environment of faith, hope and concern.

Recent medical reports of better medical treatments and great programs and centers which have already begun to function, offer holistic care to persons with HIV and AIDS. All of this, as well as the many professionals serving with dedication in these projects, is enough to cause new hope, enthusiasm and energy to the many persons infected and their families.

The communities which propagate rejection and coldness ought to stop and really listen to one patient who could tell of his or her daily struggle to survive with much luck. We need a campaign of positive messages, of reaching out a helping hand, and eradicating unreasonable fears.

The economic situation of patients in Puerto Rico is a serious problem. The extreme prejudice frequently forces HIV-positive persons, otherwise healthy, to leave their jobs. Others report they are refused jobs even when able to work. Many are from low-income families, or no income. Right now, Social Services pays $64 a month to ill

patients. Many are too young to quality for Social Security and resort to looking for means of survival on the street in undesirable ways.

Many patients have in their pockets an accumulation of prescriptions they cannot afford to buy. We all know the high cost of medicine patients need, and it is as yet an unresolved problem. Medicines are extremely important for the very life of the AIDS patient.

I am working in the City Hospital in Ponce as a volunteer in pastoral care. This hospital, serving 15 rural towns in the south of Puerto Rico, is not easily accessible for people who are ill, timid and fearful of being identified with AIDS or HIV. Therefore, our hospital is often the placed where only the gravely ill appear, seeking help. In our culture, people are poor and proud, preferring to remain silent about their illness, which is felt to be something to be ashamed of and likely to cause them the pain of rejection.

In spite of all our problems here, as an AIDS patient and a volunteer in the pastoral program, I am witness to a Puerto Rican spirit, a special trait of our people, a human warmth which is always evident in crisis. this dynamic spirit permeates also the ever-growing efforts of the

agencies presently dealing with this problem of AIDS. It is obvious in every aspect of the situation.

The response of so many professionals who want to receive information, to be educated concerning the infection, and to really help is an inspiration, a real help to me, personally, and to all the patients. This is so evident at the administrative level of the agencies dealing with AIDS as well as locally in Ponce. We have a wonderful rapport with all the Ponce agencies and administration of the hospital, working together, a truly dedicated network of wonderful collaboration, which energizes me.

Even without the great physical facilities we will soon have, which are still unfinished, patients now have access to doctors in the clinic who are available daily and who really care about us, receive us with love, concern and support.

The potential for what has only begun is tremendous. All the volunteers collaborating with the professionals and other agencies can give testimony to the great heart of compassion of our people. We seek donations for helping in purchase of patient medicines; we ask for beds, sheets, everything to help families care for a patient.

We are overwhelmed with the response of the community. Project Heart is rightly named. We intent to incorporate Proyecto Corazon, the support outreach attempting to reach potential and high-risk persons who are undiagnosed, untreated and possibly spreading infection.

Prepared volunteers in high-risk areas are beginning this project of collaboration with government agencies, reaching out in support and in confidentiality with medical, social, psychological and spiritual support. This Project Heart is nothing else but the formal implementation of the profound Puerto Rican spirit of hospitality, caring and love.

Like all painful crises which stimulate and move our people to unit, to join hands and hearts, this AIDS problem truly drives us toward one another. We will find, as strange as it may seem, that we are a more united people as we continue in faith to deal positively with what we now know to be everybody's problem. We have begun.

We join hand with our forces--government agencies, community organizations and volunteer groups--and we will continue with God's help, more christian than ever before.

Thank you.

[Applause.]

CHAIRMAN OSBORN: Thank you very much.

Are there questions from the Commission?

Dr. Mason?

DR. MASON: I address my question to any member of the panel, and it relates to transmission of AIDS/HIV virus in the Puerto Rican population.

A lot was said about i.v. drug abuse. Not much was said except in the Surgeon General's remarks about heterosexual transmission. I wonder, Dr. Castro or others, whether you could comment about not only how much heterosexual transmission you feel is going on here, and then what you predict will happen in the future.

DR. CASTRO: The number of heterosexual AIDS cases in Puerto Rico, when you consider all adults, adolescents and exclude those who are reported being gay or bisexual, exceeds 70 percent in contrast with about 24 percent in the United States. So the potential is certainly there for transmission.

Furthermore, the fastest-growing group in the epidemic consists of heterosexual i.v. drug abusers, their partners and their children, which also accounts for about 76 percent of all cases--and as I said, it is growing faster than in other groups.

I think it is also very important not to lose sight of the reality that there is indeed homosexual and bisexual transmission, and I believe that there is a lot of collective ignorance in this area. So while the problem seems to be accentuated in the drug-using population that have described themselves as heterosexuals, there is also a potential that many of these males may have described themselves as drug users rather than being bisexual because of the cultural stigma associated with homosexuality. So that potential also exists there.

There is no data to substantiate this. It is sort of the rumor, and is through the grapevine, but as I said before, there is really, unfortunately, no hard data on this subject.

DR. RULLAN: I'd like to comment on our inability to really follow the epidemic because we don't have the proper surveillance system. We are doing AIDS case reporting, which is seven, eight years late and does not let us really see what is happening, although 82-to-18 percent, a 4-to-1 ratio, in Puerto Rico is pretty high compared to the rest of the United States.

If you look at our HIV study that we did in 1988,

the ratio was 3-to-1 male-to-female. Sentinel hospital ratio is 2.5-to-1, and recent family survey is down to 1.7-to-1. So it definitely is happening, but we don't have the sensitivity in our surveillance system because HIV is not reportable in Puerto Rico, because HIV is not really what we measure, that we will not be able to see that impact in black and white for many years.

CHAIRMAN OSBORN: Harlon Dalton, then Don Goldman, then Eunice Diaz.

COMMISSIONER DALTON: I have a brief question for Dr. Castro and then a question for Mr. Maldonado.

Dr. Castro, one of your pie charts showed a dramatic difference between Puerto Rico and the Nation, nationally, with respect to the diagnosis of AIDS, whether it was a presumptive diagnosis based on Wasting syndrome, or a definitive diagnosis. I am wondering what accounted for that dramatic difference, if you know.

DR. CASTRO: What exactly accounts for that, I don't know. It is, however, quite well-established that by virtue of the revision of that case definition in 1987, Puerto Rico was then able to diagnose and report many more cases on this basis.

I think very often I would speculate many of these patients come from areas outside San Juan where the services are perhaps not as available for the appropriate diagnostic procedures, and therefore they get what I would consider to be the default diagnosis. By not having a bronchoscopy done to diagnose that episode of pneumocystis pneumonia, they get reported by virtue of their weight loss and diarrhea, et cetera, or a presumptive diagnosis of pneumocystis. I think that plays a very important role in that, especially outside the San Juan area.

COMMISSIONER DALTON: Thank you.

Mr. Maldonado, I was very struck during your testimony by a number of the contrasts, which of course is the world in which you lived. I think the most common term that you used was "rejection", and you very dramatically described the rejection faced oftentimes by people living with AIDS, but you contrasted that with what you described as the Puerto Rican spirit of love and affection.

I guess I wanted to know how one particular form of that that you described--I was struck by the difference between the doctor you mentioned in the first part of your testimony who, based upon really no examination, told a woman

in front of her mother that she was infected, and you also talked about doctors in emergency rooms who seemed unwilling to deal with opportunistic infections, saying that is just part of the disease. That was the first part of your testimony.

Toward the end, though, you described the situation in the hospital where you volunteer, in which doctors provided quite good care and also very loving care, by your testimony. And I guess I wonder how can you get the second group of doctors to educate the first group of doctors--I mean, how can you bring these two pictures closer together?

MR. MALDONADO: I think it has to with that you do have professionals in the system who don't want any part of it, period; they just don't want to deal with the disease; they live in a state of panic of being infected.

One complaint I have in the hospital that I work with is that there are many conferences and educational programs that the doctors in the hospital are not part of; they are not part of them and are never invited to the many conferences in the area of San Juan. Most of these people, mainly professionals, when they get educated they change their attitudes completely, like many doctors have. You

know, we have many caring doctors who are willing to help once they get educated, once they can be part of education-based conferences.

But you still find people who don't even want to hear about it, they are so afraid, they live in panic. And I am talking about doctors and nurses. I think it is the duty of the government to bring about a program to educate all the professionals on the island.

CHAIRMAN OSBORN: Don Goldman, then Eunice Diaz, and then we'll let Dr. Novello have the last question for this panel.

COMMISSIONER GOLDMAN: Thank you.

I have two questions, the first a specific one. Dr. Rullan, one of the things that you suggest is that the HHS set up a civil rights office here in Puerto Rico. Are there local antidiscrimination offices in Puerto Rico that prohibit discrimination against persons who have AIDS or are infected with HIV under local Puerto Rican law?

DR. RULLAN: If there are, I am not aware of them.

COMMISSIONER GOLDMAN: Okay. Is the issue that the office is needed here, or is it the issue that there is an HHS II regional civil rights office in New York, and have

they just not been responsive to complaints that are made--because I come from New Jersey, and even though obviously it is different being separated from New York by a mere river as opposed to an ocean, sometimes the distance seems as large. And I know how we sometimes feel about the HHS II regional office being in New York, and I am wondering whether the problem is one of response or whether there is a need for a local office.

DR. RULLAN: At the civil rights conference/workshop we had in September, a number of issues came out that a lot of us for the first time started to get educated on. At that conference it was identified that there were a lot of things that we could have been doing through the years, especially with Federal fundings. All of our hospitals have Federal fundings, most of our clinics have Federal fundings, all the private hospitals get involved in Medicare. And I think that if we are going to start dealing with the antidiscrimination clauses that we need, we have to start enforcing it, and we need to know that this office exists. The people in New York were very helpful, and the people in Washington were very helpful, but they cannot be constantly training us. And I think a lot of people who went to that conference opened

their eyes for the first time. I think if we get an office over here, and we have the workshops at the regional level, and we go to the emergency rooms and notify the administrators that they are going to lose their funding unless they have certain clauses, that people are not going to understand what the problem is.

I think it is basically that we have never been exposed to that type of Section 504.

COMMISSIONER GOLDMAN: I have one more question, and any member of the panel can answer it. I have read different numbers throughout the materials in preparation for these sessions, and I was wondering if you might be able to estimate roughly what percentage of those eligible for AZT and PCP, based upon appropriate CDC recommendations, namely, using a 500 CD4 count for AZT and appropriate recommendations for prophylactic PCP, are in fact receiving it in Puerto Rico. Is it 10 percent, 20 percent, 30 percent, 50 percent?

DR. RULLAN: Our needs assessment study in July, which was representative by risk groups and had 339 adults answer, the response rate was 94 percent; we covered the whole island, and our EAS officer was conducting that study.

We found that in the private sector 39 percent of

the people that we surveyed were receiving AZT--

COMMISSIONER GOLDMAN: Thirty-nine percent of those who were eligible, or should have been receiving it, were receiving it.

DR. RULLAN: The problem here, Mr. Goldman, is that the pivot for the whole thing is having a CD4 count. If you don't have a CD4 count, you cannot evaluate the person. And the problem was that most persons did not have a CD4 count. Of those who we asked, 39 percent in the private sector said they had a CD4 count and were on AZT, and 14 percent of those in the public sector had a CD4 count and then subsequently were on AZT.

That was in July. In September, we increased to 1,000 in the public sector. So I estimate that around 20 to 25 percent of people in the public sector are now receiving AZT out of which probably 65 percent of the total should be receiving it. There were probably 45 percent less than what we should do, but right now we are spending $200,000 a month on AZT, and that is as much as our budget can give us.

COMMISSIONER GOLDMAN: Is that reflective of the health care delivery system in general, or is that reflective of specific problems in HIV infection? For example, would a

similar percentage of those persons who have cancer and who are in need of cancer chemotherapy also be being denied cancer chemotherapy in Puerto Rico, or is it a special problem with AIDS and HIV infection?

DR. RULLAN: I think it is a special problem with AIDS and HIV infection because of the fact that it is a new disease; it has taken a while for us to get our infrastructure going, and I think in a year or two, once we can secure our funding, we will have as many people on AZT who are presentative as we have in cancer chemotherapy. I think it is just that it has been difficult to establish an infrastructure. However, we do provide everything free in the public sector, so that 70 percent of our population does not pay for any of the services. In the private sector, people pay, and there have been a lot of physicians who are advertising in the newspaper--anybody HIV-positive, come for pentamidine prophylaxis--and making profits. So we cannot compete with those physicians, but at least we will be providing as we get more funding more people on AZT. The pentamidine, we have just bought for 500 patients the pentamidine prophylaxis, and combined with the Bactrim, we will be able to provide the proper prophylaxis, because we believe that our Pneumocystis

carinni pneumonia is preventable, and we should not have anybody admitted in Puerto Rico into hospitals because of that. So that is the goal that we are trying to reach, and hopefully in the next few months, once we have all the tuberculosis precautions underway and make sure the extractors are there with negative air pressure, those pentamidine clinics will begin and will provide services.

COMMISSIONER GOLDMAN: Thank you very much.

CHAIRMAN OSBORN: Eunice?

T2S1 COMMISSIONER DIAZ: I have two brief questions, one for you, Dr. Rullan, and another one for Dr. Borras.

A number of years ago when I first met you, you were describing to us the general-wide Puerto Rico seroprevalence study that you ably designed with CDC. Could you just tell us if the projections of the numbers at that time in your general seroprevalence Puerto Rico study are still those that you are projecting will be the ultimate impact of this epidemic, or has that changed? I did not hear either of you talk about this, and I think it is such an important piece of information in terms of looking at future projections.

DR. RULLAN: First of all, our seroprevalence study was done with 500 of our workers from the health department,

and we conducted it in two weeks all over the island.

The seroprevalence study found .8 percent, or one out of 125 individuals, infected in the general population, and I believe that was the first time in the world that a general population study was done.

COMMISSIONER DIAZ: What was that number, again?

DR. RULLAN: It was .8 percent, or one in 125.

Subsequently, we then compared it to military recruit data, and our military recruit data was .6, which was not that different, but it was similar.

We then compared it to women and infant/child clinics, and it was one percent in San Juan, which was not a significant difference.

We then compared it with our Red Cross data for people who are donating blood, and because of the clause that high-risk group people should not donate blood, it was lower, but it was .23.

Then came the CDC Family of Surveys, and the neonate dataset is around one percent--that is mostly in San Juan.

And then the sentinel hospitals, two of them in San Juan which had 2 percent; there were two San Juan areas.

So in our seroprevalence study, San Juan had 1.5 percent prevalence; Ponce had .8; Caguas had 1.3 percent; Mayaguez had little; Arecibo had little, Bayamon had .5, and Fajardo had little. But when you have all these Federal fundings that come, they all go to San Juan, so we have to compare San Juan with San Juan. Our prevalence was 1.5 in 1988; the sentinel hospital, which is 6,000 people, in 1989 was 2 percent.

So I think that in San Juan, the prevalence is between 1.5 to 2 percent. I think the rest of the island, the prevalence is around .5 to .6 percent.

COMMISSIONER DIAZ: Which translates into how many numbers of HIV-infected people do you project based on that study?

DR. RULLAN: We projected in April 1988 that there were 40,000 people who were HIV-positive infected.

The 1990 dataset from the sentinel hospitals, which projected 2 percent in San Juan, would mean that there has been an increase of .5 percent, more or less, and I would suspect that right now we must be around 55,000 to 60,000 persons infected.

CHAIRMAN OSBORN: Thank you so much.

Dr. Borras, a real quick question. Should the entire Ryan White Title I moneys not come to San Juan, what would be the impact on that system of care that you have described now is existing and functioning well or relatively well for a large number of people in permitting greater access and also prevention, education and all the other kinds of services you talked about?

DR. BORRAS: I would say that the main impact would be that we would be given no actual state-of-the-art treatment. We would be given supportive treatment just like we have been doing up until now, but no AZT, none of the other state-of-the-art.

COMMISSIONER DIAZ: And the percent of AIDS-infected population in San Juan is what?

DR. BORRAS: The same as Dr. Rullan said; it is growing at that rate.

COMMISSIONER DIAZ: What is the percent of the total AIDS caseload that San Juan SMSA has?

DR. BORRAS: That would get the treatment?

COMMISSIONER DIAZ [Translated from Spanish]: No. What percent of the total AIDS caseload are in the San Juan SMSA?

DR. BORRAS: We spend on AIDS--

VICE-CHAIRMAN ROGERS: I think Ms. Diaz is asking of the estimated 60,000 HIV-positive in Puerto Rico, how many would live in San Juan.

Is that right?

COMMISSIONER DIAZ: Yes, that's correct.

DR. BORRAS: Thirty percent. I mentioned that before--29.4 percent.

DR. RULLAN: Excuse me. Let me add something. That is San Juan City. There are 24 counties in San Juan SMSA out of which San Juan City is one, and we in the Health Department have the other 23. So of the 24 counties in SMSA San Juan, the City of San Juan has one, and the Commonwealth Health Department has the other 23.

CHAIRMAN OSBORN: Dr. Novello has the last question.

SURGEON GENERAL NOVELLO: Just a short question for Ken and for Johnny.

It has been said that in some parts of the United States, women between the ages of 15 and 54 have AIDS as the leading cause of death. In Puerto Rico, would you be able to say that women on the island have AIDS as the leading cause

of death today, or in what projection, and if so, do women know?

DR. RULLAN: The data is that yes, it is the leading cause in women 15 to 44 in Puerto Rico.

SURGEON GENERAL NOVELLO: And the second question is do women know.

DR. RULLAN: My experience has been no. I think the big problem in Puerto Rico--and Dr. Allan Henman [phonetic], when he helped us in formulating our plan--was that in our family of surveys, we have identified 1,500 individuals who were HIV-positive. If there are 40,000 or 60,000 HIV-infected in Puerto Rico, the reality is that 3 or 4 or 5 percent of the people who are infected know; more than 95 percent of the infected people, in my opinion, in Puerto Rico are not aware of their status. That is the killer.

SURGEON GENERAL NOVELLO: Thank you.

CHAIRMAN OSBORN: Let me thank the panel for very helpful and useful introductory testimony. It has been very nice to have you give us such a clear introduction to our task, and we appreciate it very much.

[Applause.]

CHAIRMAN OSBORN: I would appreciate the next panel

coming forward: Laura Torres, Guillermo Otero, and Jaime Rivera-Dueno. Welcome.

While you are getting seated, you probably heard me say before that we are using a little timer here to help us keep our own schedule straight, so I'd appreciate it if you would be brief so we can interact with you afterwards. Thank you.

Ms. Torres?

MS. TORRES: Good morning, Dr. Novello, Dr. Osborn and distinguished members of the National Commission on AIDS.

My name is Laura Torres. I am the Acting Executive Director of the Operational Branch of the Department of Health, better-known as the Health Facilities and Services Administration of the Commonwealth of Puerto Rico, AFASS.

On behalf of the Operational Branch of the Department of Health, I appreciate the opportunity to participate in this hearing to present the financial impact of providing health care services to HIV and AIDS patients in the public health care system of the Commonwealth.

I will also address the issue of the administrative organization that we have developed to expedite the use of the funds available to take care of those patients.

The first patients identified with AIDS diagnosis were admitted to our hospitals during fiscal year 1983-84. Since that year, our hospitals have admitted more than 3,000 HIV and AIDS patients at an approximately cost of $100 million for the whole time.

The average length of stay of these patients is 15 days per admission, and each patient is admitted about three to five times a year. Seventy percent of those patients were intravenous drug abusers; 72 percent between the ages of 20 to 39 years, and 90 percent from 20 to 49 years old, and 60 to 69 percent of those patients died.

We estimate that during fiscal year 1990-91, our hospitals will admit about 1,200 patients, with 18,000 patient-days of care. The cost for the system to take care of those patients will be $16.8 million. Those costs are funded exclusively from the regular operating budget of the agency and represent 13 percent of the Commonwealth budget allocated for inpatient services at the public hospital.

In addition, the public health care system spends between $6 and $7 million annually for treating HIV and AIDS patients at the emergency rooms and OPD clinics of the hospitals.

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It is very important to mention at this moment that the Commonwealth of Puerto Rico receives only $79 million a year from the Medicaid program for the provision of health care services to the more than $1.8 million medically-indigent patients who qualify according to the parameters established by the Medicaid program.

The island's government does not receive additional funds for the increased costs incurred for HIV and AIDS patients. As a result, the costs incurred for treating HIV and AIDS patients in the public hospitals has the effect of reducing the resources available for the treatment of other patients that depend exclusively on the government services.

If the tendency of utilization of the hospital services continue at the same rate of the past five years, by the year 2000 more than 50 percent of the budget available for the public hospitals in Puerto Rico will be dedicated to the attention of HIV and AIDS patients.

Budget for HIV and AIDS patients in ambulatory services. For fiscal year 1990-91, the budget available for HIV and AIDS patient programs for prevention, diagnosis and ambulatory treatment services represents a total amount of $15.2 million. Of that amount, $4.3 million represents

allocation of funds from the Commonwealth of Puerto Rico, and $10.9 million are appropriations from the Federal Government. That amount includes $4.6 million that we expect to receive from the Ryan White legislation.

During the present fiscal year, the Commonwealth of Puerto Rico increased by $3 million the amount of State funds allocated for the development of a comprehensive plan to take care of all the services required by HIV and AIDS patients in the island. By next year, we expect that amount to be duplicated.

With the $4.2 million of State funds and an additional investment of $1 million from the regular operating funds of AFASS, we established seven Regional Centers for the provision of comprehensive health services to those patients. Those centers are part of the network established under the coordination of the Central Office for AIDS Affairs to implement the plan.

During this year, AFASS introduced changes in the organization and procedures of the agency to expedite the use of funds available, in particular the Federal funds.

We decentralized the operations of the program and delegated all the control over the budget and administrative

procedures to the program directors and the regional directors. We developed and implemented a Manual for the Administration of Federal Funds. That document specifies all the procedures that have to be performed to implement a Federal program. It includes procedures to be performed before and after the notice of grant award is received.

Important areas such as budgeting, accounting, creation of positions and recruitment of personnel, purchasing of equipment and supplies, contracting professional and other services, are defined in the manual in detail. It provides for a continuous monitoring of the use of the funds. We designated a Federal Funds Coordinator at the Office of the Executive Director of AFASS who is responsible for monitor and coordinate with the program directors to guarantee the use of 100 percent of the funds available.

As a result of this reorganization, during the present budget period, we are going to expand over 90 percent of the funds available in this project, and this percentage will reach 95-100 percent by next budget period.

The actual organization of the HIV and AIDS programs through the Central Office of AIDS and the Regional Network of HIV and AIDS Centers as well as the development of

a comprehensive plan to take care of all the programs related to this disease will facilitate the performance of the program objectives and the coordination between AFASS and the program.

The cost for providing services to HIV and AIDS patients will continue the increase observed during the past years. Those patients depend upon the governmental system to get the services because most of them cannot afford the cost of the treatment. The health plans and insurance do not provide coverage for all their treatment.

The Commonwealth of Puerto Rico has developed an organization and a comprehensive plan to implement all the programs necessary to take care of HIV and AIDS patients and to prevent and educate the whole population about the disease. The Government is spending more than $25 million in providing services to HIV and AIDS patients in Puerto Rico. We need more funds from the Federal Government. An increase in the Medicaid program for the island and more appropriations for special projects are very important to continue our efforts to provide the best possible health services to the victims of this epidemic disease.

Thank you for permitting me to address you.

[Applause.]

CHAIRMAN OSBORN: Thank you very much.

Dr. Otero?

DR. OTERO: Dr. June Osborn, Chairwoman of the Commission, distinguished members of the National Commission on AIDS, Dr. Antonia Novello, Surgeon General of the United States, Dr. James Mason, Assistant Secretary of Health, it is a great honor and responsibility for me to testify before you on this occasion.

I will take license to tell a personal experience before my formal presentation. I will testify in memory of my first pediatric AIDS patient, who died this year. Xavier was a very poor child, born to an i.v. drug user mother. He died at the age of three. He was receiving intravenous gammaglobulin in one of our programs here in Puerto Rico, and he died this year. I am here testifying in his memory, because for us in the U.S. Public Health Service and I as a primary care physician, AIDS is more than numbers. AIDS is people--people suffering.

If the timer allows me, at the end of my presentation, I will tell you a different Christmas story.

Since the onset of the HIV outbreak, the Federal

Government, especially PHS, has been involved in the funding of a variety of programs in Puerto Rico in order to deal with this disease. The Department of Health and Human Services through its agencies has taken the initiative for surveillance, monitoring, education, research, training and development of health care service programs.

A key role has been played by the U.S. Public Health Service Region II Office and its Regional Health Administrators, the late Dr. Vivian Chang and Mr. Raymond Porfilio in advocacy, consultation and strategic planning to address the serious threat of AIDS.

Region II includes three of the areas in the Nation with the highest rates of HIV infection: New York, New Jersey and Puerto Rico. Region II has appointed a regional AIDS coordinator. This individual is responsible for the coordination of programs for HIV/AIDS patients throughout Region II.

Federal agencies have been offering extensive technical assistance and orientation to the Commonwealth for the establishment of effective programs that are responsive to the needs of the people with AIDS. The CDC, the Food and Drug Administration and other DHHS programs have assigned

staff to Puerto Rico to collaborate with the Commonwealth's AIDS programs. Financial support has been provided to the Commonwealth Department of Health, the Department Against Drug Addiction, the Department of Education, the San Juan City Department of Health and other government agencies, public and private universities, and community-based organizations.

Initially funds were allocated for HIV/AIDS surveillance, the early diagnosis of cases and the education of HIV-infected individuals and those others with high risk behaviors. Other funds were allocated for the education of health professionals and other individuals expected to deal directly with AIDS patients. Later, funds were given for research and to support the delivery of services to AIDS patients and their caretakers.

According to the data available to the U.S. Public Health Service Sub-Regional Office, approximately $34.8 million has been provided for HIV/AIDS programs in Puerto Rico, including $20.3 million for community and migrant health centers programs during FY90. These funds have been awarded by the following PHS agencies: Centers for Disease Control; Alcohol, Drug Abuse and Mental Health Administration;

Health Resources and Services Administration, and NIH.

Of the FY90 funds, 14.6 percent were allocated for prevention and education to the community; 60.5 for health care services, and 16.9 percent for research. I am including the amount for the community and migrant health centers.

In addition, a significant proportion of other resources not earmarked for the provision of services to HIV/AIDS patients are in fact used for such purposes. Among these can be identified Veterans Administration resources, Medicare funds, Medicaid funds, Maternal and Child Health Care Block Grants, family planning funds, Stewart McKinney Act funds for health care services for the homeless, and others.

The amount of resources from these programs used for services for persons with AIDS is definitely considerable.

Medicaid funds. The local Medicaid agency is unable to identify the specific costs that are associated with persons with AIDS in Puerto Rico. The Commonwealth of Puerto Rico has a Medicaid ceiling as compared to the rest of the Nation. For 1989 and subsequent years, the Title XIX ceiling in Puerto Rico is $79 million, to serve 892,984 Medicaid-eligible individuals, which represent more than 27

percent of the population of the island. For fiscal year 1990, estimated Medicaid costs were $386 million, making the Commonwealth's share $309 million.

The Medicaid Agency does not cover costs for AZT or pentamidine for most patients. Persons with AIDS are dependent mostly on a Public Health Service AIDS grant of about $800,000 for 1990 or pay themselves for the medications. At a mid-range yearly AZT cost of $5,000, only 160 persons out of a total of 1,600 would benefit from such funds.

A number of AIDS patients returning to Puerto Rico from the mainland to be with their relatives during the worst part of their disease are faced with a lack of medications that were prescribed in mainland programs and are to be left without any treatment at all on occasions. The Commonwealth has been negotiating for a gradual increase in the Medicaid ceiling for the island for future years. If this is accomplished, surely more Medicaid-eligible HIV/AIDS patients will be able to receive additional services including HIV/AIDS treatment at the Department of Health facilities.

The 15 Community and Migrant Health Centers funded under Sections 330 and 329 of the PHS Act in Puerto Rico received $20.3 million for FY90 to provide comprehensive

primary health care services to the medically indigent population in Puerto Rico. These centers served in 1989 12 percent of the population of Puerto Rico.

Since 1987, goals and objectives directed to HIV/AIDS patients have been incorporated in each center's annual health care plan. In addition, the center staff have been receiving training on AIDS from the University of Puerto Rico AIDS Education and Training Center, a sub-grantee of the New York ETC, and from continuing education activities sponsored by the National Health Service Corps.

Pre- and post-HIV counseling is given to users of the services through an agreement with the Department of Health. Some centers are in the process of participating in clinical trials and research projects for HIV/AIDS patients through the University of Puerto Rico, Ponce School of Medicine, and the Central Office on AIDS. All Community and Migrant Health Centers are involved in a community education plan addressed mainly to the youth.

One of our projects, the Playa de Ponce Diagnostic and Treatment Center, was awarded $500,000 by BHCDA this year for the provision of preventive and primary health services to the HIV patients in their service area. This center will

also receive moneys from the Office of Substance Abuse Prevention for the prevention and treatment of substance abuse and HIV individuals. It is projected that this center will serve more than 100 HIV-infected individuals in the area of Ponce. A new dental clinic that will service AIDS patients will be built soon. The Ponce municipal government is financing this construction.

I must mention that the Puerto Rico Academy of Medical Directors, an organization that includes all the clinical directors from the Community and Migrant Health Centers in Puerto Rico, has developed a clinical protocol for the comprehensive management of HIV infection at the primary care level in Puerto Rico. This document was prepared under the leadership of a distinguished Commission officer, Dr.Rena [phonetic], and a group of other fine clinicians from Puerto Rico. This valuable document, which has been given to the Commission, was published recently by the U.S. Public Health Service Region II Office--

VICE-CHAIRMAN ROGERS: Dr. Otero, may I interrupt you briefly. I have to be the bad guy here. And we are anxious to hear your Christmas story, so we hope you can conclude rather swiftly.

DR. OTERO: Okay. I will skip the rest of my presentation and go to the comments.

The U.S. Public Health Service has been responding to the HIV outbreak in Puerto Rico with fiscal and human resources for the past years, and is committed to continue funding programs. Occasionally, programs have not effectively used some of the funds during the prescribed period, and as a result subsequent funding levels have decreased, and the unobligated Federal balance was applied to offset new grant awards.

It is therefore necessary that the best stewardship be executed for the administration of the limited resources available from the Commonwealth, the municipalities, the U.S. Public Health Service and the community.

Coordination of services is important in order to avoid duplication of efforts and to promote an efficient networking with community organizations.

The Commonwealth and the local agencies need further technical assistance in the preparation of grant applications that can compete more favorably with those from other areas of the country. Whenever possible assistance during the pre-application phase should be requested from

Federal agencies. In this way, funds will be awarded to areas of greatest need and not to places that can put on a good application. It is a matter of need, not a matter of literary experience.

Any efforts to obtain a raise in the Medicaid ceiling should be continued. And it is of utmost importance to continue prevention services.

Finally, the spread of AIDS among Latino, Hispanic and Puerto Rican women and children in Puerto Rico is of great concern to all of us. It is important to prepare and plan additional materials and focused programs for these populations. Specific educational strategies aimed at the prevention of HIV infection among young people is necessary, and we must increase the services for the prevention and treatment of substance abuse among the Puerto Ricans.

Later I will tell you the Christmas story.

VICE-CHAIRMAN ROGERS: We'll get your Christmas story during the questions.

Thank you..

Dr. Rivera-Dueno?

DR. RIVERA-DUENO: Good morning, Dr. Mason, Dr. Novello, Dr. Osborn, distinguished members of the panel,

thank you so very much for being in Puerto Rico and listening to our problems. Thank you once again.

For the sake of saving time, I will use some transparencies which we can go through very quickly.

[SLIDES]

As an overview, here represented to you is the statistical data of the cases reported in San Juan. I am talking about San Juan City only, because that's where our program is.

The statistical data shows that in 1987 the cumulative cases of AIDS were 369. It increases cumulatively speaking to 582 in 1988, and right now, up to October 31, 1990, the number of actual AIDS patients was 981. Then, the HIV plus the ARC cases gave us a total of 2,502 cases reported in San Juan, with a mortality rate of 54 percent.

At present, 30 percent of all AIDS cases reported in Puerto Rico have been reported in San Juan, and over 50 percent of them have been reported in the Statistical Metropolitan Area of San Juan, and most of these patients come to our services.

Putting it in a more summarized way, up until October 31, 1990, in the Statistical Metropolitan Area, we

had a rate of 69.3, which was the fourth in the United States for metropolitan areas.

The cumulative cases, as I have said, were 981; cases between 20 and 39 years old, 73 percent; the percentage of i.v. drug users, 71; the community pediatric cases, 42, and 88 percent were pediatric cases associated with i.v. drug users. As you can see, our pediatric problem is a big one here in Puerto Rico, and according to statistics is the second after Washington, D.C.

Because of this particular situation, in 1987 there was a need to put together the public sector and the private sector to try to deal with this situation in San Juan. So the San Juan AIDS Institute was created at that time, and the objective basically was to develop and implement a comprehensive system of health care for AIDS patients in San Juan, Puerto Rico to substitute for the existing traditional system based on inpatient care; to emphasize prevention, education, surveillance, early detection, and alternative types of service such as home care and hospice care as well as inpatient care and some research activities; and also to develop a cost-effective system for health care delivery in San Juan. Those were our main objectives.

Then, immediately we started to work trying to put together what was needed to come forward with these services that we had committed ourselves to. As you can see, this is a qualitative evolution of services of the San Juan AIDS Institute. In 1977 what we had was basically just hospitalization services, inpatient care, mainly in an open ward with regular personnel. Let me tell you that lots of fear and prejudice obviously accompanied this type of delivery of care because everybody was afraid of the disease.

Eighty-six percent of the cases were hospitalized, and 14 percent were treated at emergency rooms and medical centers. There was no actual outpatient delivery of care.

In our first year of inpatient services, 1988, immediately an exclusive AIDS ward was created, with 12 beds and trained personnel. The emergency room was expanded to have another emergency room at the Rio Piedras Diagnostic and Treatment Center, and an outpatient ward was established there, where pre and post counseling was offered, case management on a limited basis, and education was also offered. A unit of epidemiology was also started in that very first year. An extended care facility was started at one complex here in San Juan with five beds.

In the second year, 1989, our inpatient ward was increased from 12 beds to 20 beds exclusively for AIDS patients. All require medical specialists--pneumologists, gastroenterologists and so on were on hand. And isolation rooms were established because, as was represented before by Dr. Castro, we had a tuberculosis problem here, so isolation rooms were established with the adequate equipment required for that.

Mental health services were provided through psychiatrists and psychologists, and rotating residents were paid by the San Juan AIDS Institute to assure us that we would have physicians rotating through these particular wards.

A brand new pediatric unit was established, providing ambulatory services. It has an infusion unit, established a health education program for families and also for the schools in the San Juan area, and case management was started as well.

The outpatient facility at Rio Piedras was expanded, and we now have followup cases, mental health services, hematology services, infectology, and a detoxification clinic for some of our patients. Also, the services for ambulatory care were expanded to six more Diagnostic and Treatment

Centers aside from the one in Rio Piedras in that particular second year, 1989. At these particular sites, which were distributed throughout the city, we had outreach services, seroprevalence services, health education, pre and post counseling, STD clinics, risk reduction services, and case management. Besides that, we also continue to provide preventive services, and at least some efforts at the shooting galleries and different schools.

We started with a new magazine called "SIDA Vances" [phonetic]. Also, we established laboratory services, day care, home care, and we also established relations with the Catholic Church for a hospice here in San Juan, and a fullblown Department of Epidemiology was started.

In the fourth year of this qualitative evolution that I'm trying to describe to you, this particular year, aside from everything that you have seen in the first and second year, we added in the third year clinical trial units. At this moment, we have two going on for adults and two for pediatrics. The outpatient clinic has been expanded from six to nine to cover all Diagnostic and Treatment Centers throughout the city, and on December 1st we will start the first AIDS treatment and care center at our facility in the

has been reduced from 22.3 in 1987 to 11.9 in 1989. Remember that most of the activity in 1987 was basically hospitalization, inpatient care. And the number of beds, as I already said, increased from 12 to 20.

The cost per day of hospitalization or inpatient services was $348 in 1987; it has increased to $452, but we have added lots of other specialists and other types of services.

As far as the outpatient services, as you remember, in 1987 there was practically nothing except for some clinics at the medical center, and the outpatient visits at that time were 358. It has increased to 15,378 in 1989. Visits per patient have increased from 4 to almost 9, and the cost per visit has been reduced from $246 to $128.

Home health services were not in existence in 1987, and we have been able to put in place a home health care program in 1989 which served 1,460 for a cost of $150 per visit.

Let me mention that a sample was taken--

VICE-CHAIRMAN ROGERS: Dr. Rivera, you'll have to close fairly shortly, but go ahead.

DR. RIVERA-DUENO: The cost per patient has been

reduced from $16,000 to $12,000, and the municipal appropriation has been $3.2 million for these past three years.

Finally, these are the plans for the future--you have already heard Dr. Borras mention it. I just want to conclude by saying that the San Juan AIDS Institute, a not-for-profit corporation, making use of all available mechanisms like case management, early detection and so forth, has demonstrated that with a good infrastructure, an effective administration and a comprehensive ambulatory setup, we could provide for an effective cost containment effort.

There is still a lot to do, and we hope to get there.

Thank you so very much.

[Applause.]

T2S2 CHAIRMAN OSBORN: Thank you all, and thank you for being willing to live within the time constraints that are too short, always.

Harlon, I guess you had a question, and then Ron.

COMMISSIONER DALTON: Actually, I have two questions. The first has to do with technical assistance and the second with funding for medications and drugs.

I am confused on the question of technical assis-

tance. One of the panelists on the first panel indicated that the HRSA money that had been received here in the Commonwealth has not included so far any technical assistance funds. One of the current panelists urged that technical assistance be provided to help people at a minimum qualify for other grants. And I have heard it said that there is at least some question about whether or not Ryan White funds will be made available because of the fact that in fact agencies here on the island have not in the past taken advantage of technical assistance.

So could someone please clarify this issue for me?

DR. OTERO: Technical assistance has been provided by HRSA to local programs to the Commonwealth and the city. Perhaps more intense technical assistance is needed. And as I mentioned in my presentation, when one comes to competing applications, and you are not dealing with entitlement programs, and you have to submit an application, the Puerto Rico programs on occasion are not able to submit the best applications.

What is perhaps needed locally is staff--and perhaps it can be a full-time person or a person who comes here more frequently--to assist local government and programs

to review the applications before they are submitted in order to review the guidances so that funding will be available.

Of course, Puerto Rico does not have funds to pay for a grant writer, which in other programs in other areas of the Nation, there are professional grant writers who will write the grants for the universities or the departments of health.

COMMISSIONER DALTON: And who are you suggesting should pay for this grant writer--which I agree is a terrific idea.

DR. OTERO: Well, I'm not saying a grant writer, because PHS officials cannot pay for a grant writer. But we can provide technical assistance.

MS. TORRES: Within the Department of Health, we need technical assistance for HRSA at the same level of CDC. CDC designates technical assistance directly to our programs, and those people help us in the development of the proposals and some meetings on the proposals, and also technical assistance in the performance of the programs and projects within the budget period.

We need the same type of assistance for the HRSA projects also.

COMMISSIONER DALTON: So then in fact are you two in agreement that HRSA should earmark more money for technical assistance which could be used for the purposes that you were describing?

DR. OTERO: Yes, I agree that additional technical assistance should be requested.

DR. RIVERA-DUENO: I just want to mention that I wouldn't mind having people from HRSA here, because obviously they can help a lot, but I also have to be fair, and they have been helping us a lot in trying to put things together.

COMMISSIONER DALTON: And now with respect to medicines and drugs, let me see if I understand the picture. Medicaid provides virtually no money in Puerto Rico for AZT, pentamidine and other drugs because of the cap. The Commonwealth provides--if I understand the testimony--no money for AZT, pentamidine. The City of San Juan provides no money. The AIDS Institute heretofore--if I understand your written testimony--has provided no AZT because it is not in your contract.

So that the only money that is being provided for AZT and, I take it, for pentamidine--tell me if I am wrong--is the 900 or so million dollars that has been special

Federal appropriations which, if I understand your testimony, would cover maybe 160 people when in fact there are ten times that many people who would qualify for AZT. If I understand your testimony, 38 percent of the people you serve might well qualify for AZT, but in fact you are not in a position to give any of them AZT.

If I am right about that, what is going to happen? I mean, is the Ryan White bill the only hope for paying for AZT and pentamidine, let alone other drugs to deal with opportunistic infections and other manifestations of the disease?

DR. OTERO: In my presentation I mention that some HRSA funds will be used for the treatment of patients, in this case for the people in the Ponce area, some NIH funds that are used for research, some patients are already receiving other treatment.

Ryan White will bring some hope to Puerto Rico both for San Juan City and for the rest of the island. And if the Medicaid ceiling is raised and there is the commitment of Secretary Sullivan to assist in the raising of the cap, perhaps more hope will come, and things will be better in the near future.

COMMISSIONER DALTON: Although as I understand your testimony, the negotiation is for a gradual raising of the Medicaid cap--

DR. OTERO: Yes, yes.

COMMISSIONER DALTON: --so we are not talking about a dramatic increase, I gather, even if you are successful in these negotiations.

CHAIRMAN OSBORN: Mr. Jarrell--let me take an opportunity to thank Ron Jarrell for sitting in for Belinda Mason at this meeting. We are very glad that you could join us, and you get the next question. After that, Dr. Novello, Dr. Rogers, Diane Ahrens, and then we are going to need to move fairly promptly.

MR. JARRELL: I'll make my question real fast. It is again also on the technical assistance from HRSA related to the Ryan White bill.

My concern as a person living with AIDS directing a community-based organization is that the plan that the Government of Puerto Rico has outlined is very dependent on the community-based organizations, and I am concerned as to what assistance the government has given the community-based organizations in seeking the technical assistance from HRSA

for funding from the Ryan White bill.

MS. TORRES: From the Ryan White appropriations, we are planning to use about $2.3 million for community-based organizations and $2.3 million for drugs and medicines, and in addition, from the State funds we are using now, some assistance to community organizations, not in the amount they need, but we will bring some assistance to them according to the funds that we have right now.

In addition we have about half a million dollars for drugs from the State funds during this year, but we need more than $3 or $4 million for drugs and medicines. So we need the funds from Ryan White and also an increase in Medicaid in order to have the funds available for the whole treatment that our patients need on the island.

MR. JARRELL: But basically the main question I was trying to get at, and maybe I was unclear, was the government assistance to the community-based organizations in competing for these funds from the Care Bill.

MS. TORRES: From Ryan White, $2.3 million will be used for community-based organizations.

CHAIRMAN OSBORN: Before proceeding in the order I stated, Dr. Mason suggested it might be important to qualify

some technical matters about the cap.

DR. MASON: As you said, a point of clarification. The Medicaid cap for the Commonwealth of Puerto Rico was placed there by Congress, and Secretary Louis Sullivan after his visit here several weeks ago went back and said he would strongly support raising that cap so that more money could become available, but that would require Congressional action and not action that the Secretary or President Bush could take.

With regard to Medicaid and AZT and pentamidine, again they are both licensed drugs and can be provided under Medicaid under Federal law, but this is a local decision not to provide them, I would guess, because of the limited amount of money that is available.

CHAIRMAN OSBORN: Dr. Novello?

SURGEON GENERAL NOVELLO: Just one question, and that is in the gay community it has been well-established that prevention has been key in lowering the prevalence and the incidence, and this is a wonderful finding.

It is also known that if you really do good prevention, then your cases of AIDS can be diminished from 30 to 50 percent.

From your budget, your prevention moneys, do you think they are enough to utilize the prevention message out there for the people today so that in Puerto Rico we can have a lowering of the incidence? And if you do think it is enough, are we using it accordingly--is it scientifically accurate, sensitive to the needs of the people, and in the places where they go to find it?

[Applause.]

DR. RIVERA-DUENO: Well, I think you have addressed the key point of the whole morning for me, which is prevention education.

Unfortunately, we have been so busy working with the little amount of money, trying to reach the patients to provide them with care, that we have practically nothing left for such a very important issue.

At the Institute, we have been trying to get other alternatives like the Robert Wood Johnson Foundation and other foundations to help us, and even though they have been very responsive, unfortunately the amount of money we are getting is not enough to really get into the areas. You have to remember that our main population is i.v. drug users, and those are not the best ones to utilize the classical way of

education, so we have to go a different route which is more costly and almost on a one-to-one basis.

CHAIRMAN OSBORN: Diane, then David Rogers, and then we'll have to break.

COMMISSIONER AHRENS: I am back to the AZT issue. I was recently at Burroughs-Wellcome in North Carolina and was told by the epidemiologists there that they had a program which would offer free of charge AZT to any person with AIDS who needed it and could not get it. And this was done through the primary care physician making a request to Burroughs-Wellcome.

Now, it may be that everyone is aware of that; it may be that people do not believe that. But I am wondering if that has ever been tested here and whether anyone has found that to be an effective way of receiving the AZT that is needed.

DR. RIVERA-DUENO: As far as I know, this is the first time I have heard about that particular offer, and we will be there at their door, knocking, as soon as possible.

We have been receiving some grant money--let's call it that--for a clinical trial unit with Burroughs-Wellcome here in Puerto Rico, but this is for just a specific patient

who meets certain standards for the trial that we are doing there. But the way you have mentioned it, I don't know of anything here in Puerto Rico.

COMMISSIONER AHRENS: Thank you.

VICE-CHAIRMAN ROGERS: Because our time is short, I will forego questioning but just thank all three of you for some eloquent testimony. We have learned much this morning, and we will learn more during our next two days. It is powerful, and it is impressive, and I congratulate you on what you are trying to do.

Thank you.

[Applause.]

[Break.]

CHAIRMAN OSBORN: Let's get started because we already late in a very important segment of the program.

I think since Jorge is here and willing to start, we'll be very happy to hear from you. Thank you for joining us. I am sure you have heard me say that we have a timer so we can try to stay within some constraints of time, so if you hear it go off, that means about a minute left. We appreciate everyone's willingness to put up with that constraint so that we have a chance to interact with you.

Jorge Irizarry.

MR. IRIZARRY: ACT UP is a government watchdog organization and its achievements very well attest to this fact. ACT UP Puerto Rico has a place in these hearings among the other organizations, and I strongly resent having to use my HIV status to get a place.

[Applause.]

Making it clear that I am speaking as an activist for ACT UP, I will proceed.

CHAIRMAN OSBORN: Excuse me. Let me just express my regret for not having represented you the way you intended. I think the staff felt that you were represented as you wished when they put this together, but there was no intention to misrepresent you.

MR. IRIZARRY: Ten years after the AIDS crisis started and four long years after the Interagency Commission was created, just recently was put in action the most erroneous, shortsighted, insensitive and unrealistic plan possible in order to deal with this crisis. Meanwhile, Puerto Rico has one of the highest incidence rates in the Nation.

There is an urgent need for education--education at

all levels and angles; education toward prevention at all levels of school and available to people out of school, i.v. users, sex workers, and to all the communities in general.

The government should reach into the community, inform them, and let them do their own teaching among peers. This concept of peer education has been highly successful in the gay community, Latin community, and other communities in the United States.

But the OCAS public information I see every day in the newspapers is highly misleading and vague. It tells people to protect themselves but doesn't tell them how, and it gives the false and dangerous idea that somehow you can identify people who are HIV-positive or with AIDS.

Education toward living with the virus or living with AIDS is nonexistent, and the system does not see it as an alternative.

There is no primary care for PWAs--people with AIDS. One would say that without this prophylaxis and acute treatment, medicines wouldn't warrant full benefits, but these last two are available to some privileged ones, mostly to those so-called "innocent victims".

Is the list of priorities of our dysfunctional

Health Department ruled by prejudice, homophobia, and other ill-conceived judgments?

Prioritizing the definitive list of problems to be soled must be humbly resolved. A comprehensive disaster management master plan must be developed that addresses all of the problems currently affecting the AIDS crisis in Puerto Rico. Within a call of a state of emergency, interim crisis management must be implemented not in a void, but in a clear and pragmatic observation of a long-term reconstructive plan.

It is time for cures for this dysfunctional system--no more shortsighted remedies. I am sorry to say Dr. Rullan does not seem up to this task. Even the Mayor of San Juan, the city with the highest incidence in Puerto Rico, has publicly said the government response to this crisis has been one of denial and highly ineffective.

OCAS asks people who think they are at risk to get tested. Well, after being tested and knowing my status, what is next? Right now, there is nothing but to leave my family, my friends and my house and go to the mainland, in search of treatments available there.

I see nothing for me here but ignorance and indifference, and the same goes for people with AIDS. If I

had to take AZT, the government refuses to buy it with Medicaid funds. If I were rich and could afford it and then it failed, there is no expanded access that I know of for DDI or DDC on this so-called tropical island.

The case for providing DDI and DDC with new drug application status and approving both for marketing has been masterfully laid out by both in the Consensus Statement on DDI and DDC Licensure, approved by over 40 organizations, investigators and physicians, and in Project Inform Perspective No. 9 of October 1990. Access to advanced forms of treatment is inherently improved when new drugs become available on a prescription basis.

In the case of Puerto Rico, as witnessed in the murderous Medicaid coverage and AZT availability scandals currently being perpetrated against the people of Puerto Rico, marketing approval is meaningless in the face of an explosive pandemic like AIDS. Three years after its licensure and prescription availability, AZT, the only approved therapy to combat destructive HIV progression, remains available to only 315 adults and 70 children. The Commonwealth admits that over 20,000 adults already enrolled in Medicaid are currently eligible to receive the therapy but cannot.

Before AZT as a monotherapy becomes available on the island--by the way, the same island where it is manufactured--it may be obsolete.

So when considering access issues in Puerto Rico, the inevitable approval of DDI and DDC will widen the gap between prolonging the life expectancies and expediting death. While the more privileged patients of the mainland will be extending their life expectancies, inversely, the relative death rate in Puerto Rico will skyrocket. As life expectancies are extended with the privilege of access to anti-HIV and anti-opportunistic infections drugs we, the second-class citizens in Puerto Rico, will be riding a steady and constant decline in comparative life expectancies.

(Opportunistic infections specific to people living in the tropical climates are not being studied at the same rate as those opportunistic infections of white men.) Puerto Rico must take the initiative and start a real aggressive part, promoting the experimental clinical trials.

In Puerto Rico, the lack of access to primary health care is the greatest obstacle to the start of these trials. Clinical trials can only be seen in the context of health care. A sustained lack of health care means a person

will not be well enough to enter a clinical trial.

The needs of AIDS and HIV clinical trial participants include primary health care, chemical dependency treatment, social services, child care and respite care. I do not see Dr. Rullan working to reach these goals. Instead, the government imposes on us a plan that seems to be modelled after the action plan in Hawaii, which has one of the lowest incidence rates per capita in the Nation, has a different culture and different social problems.

The government provides a system doomed to failure where, for example, Fajardo has 122 patients eligible for AZT treatment, but only 38 receive it, giving the infectologist the right to choose who will receive it and who won't. Arecibo's center is not functioning at all. CLETS has been practically dismantled. Caguas and Ponce--the city with the second highest incidence in Puerto Rico--submitted protocols badly needed and were denied any allocations for it.

Here, I have two receipts for a patient at the district hospital in Ponce who was prescribed pentamidine. That person had to buy it with his own money--the hospital doesn't supply it--and he spent two days looking for somebody to administer it because the doctor does not know how to

administer it. By the way, all of a sudden, the patient was released last night. I guess you are visiting that hospital today.

Also, $2.3 million assigned to Puerto Rico specifically for home care has yet to show any benefits. To our knowledge, there is no home care at all in Puerto Rico.

Dr. Rullan should be held accountable for this doomed-to-fail government plan, lack of vision, leadership and sensitivity, should recognize his inadequacy for this job and step aside, give up his three or four salaries, and leave, so somebody with more qualifications can do the job.

The basic issue here is securing access in Puerto Rico to life-prolonging treatment in order that patients with this life-threatening illness have the opportunity to make their own informed decisions as to what their course of treatment will and will not be, while requiring absolute access to the latest treatments that modern research may bear.

I will now conclude this with three major points to be addressed.

First, Medicaid coverage of medically necessary treatments until all applicable existing laws are respected and adhered to which require the Commonwealth Government to

supply any and all medically necessary treatment to those people enrolled in Medicaid.

Second, access to clinical trials of experimental agents. Ethically designed and scientifically sound clinical studies of experimental treatments for all HIV-related conditions must be established in Puerto Rico. In doing so, drugs will be tested in the very people for whom they are intended before they make it to the market, while at the same time offering people with a life-threatening illness an opportunity to try a potential treatment that they may not otherwise ever have the chance to have.

Third, socioeconomically and culturally appropriate education--for that matter, in Puerto Rico, education at all. Both of the aforementioned strategies have inherent in them the absolute necessity for education that takes into account historical, cultural, social and economic barriers. Such education is a dynamic and consuming effort that cannot cease and, sadly to say, has not started.

Thank you.

CHAIRMAN OSBORN: Thank you very much, and thank you for being willing to be brief. We appreciate it.

[Applause.]

CHAIRMAN OSBORN: We'll have an opportunity to interact after we have heard from the other witnesses on this panel.

Dr. Ramirez-Ronda, welcome.

DR. RAMIREZ-RONDA: Good morning, Dr. Novello, Dr. Mason, Dr. Osborn, distinguished members of the Commission.

I want to thank the Commission for allowing me to present my data and my presentation this morning.

In Puerto Rico, the cumulative number of AIDS cases by November 1990 was over 5,000, and the estimates of HIV-infected persons ranged from 35,000 to 200,000, depending on the database, risk group projections or others. And we heard this morning Dr. Rullan's revision of 55,000 people infected.

Irrespective of the numbers of the impact of HIV disease on an island of 3.2 to 3.7 million, depending on which census data we look at, is enormous.

The patient with HIV disease requires intervention once his seropositive status is known at different stages. First, just close followup at intervals and then, when the illness progresses, there are therapeutic alternatives. It is accepted that patients infected with HIV benefit from therapeutic interventions once their lymphocyte T-4 count is

500 or less. At this stage it is recommended that patients who are willing and able to take medicine can be given zidovudine in a dose of 500 mg/day. Recent studies show that even 300 mg/day are effective.

At this stage of illness the availability of treatment in Puerto Rico is variable. Patients at the San Juan VA Medical Center are able to receive any and all medication. The treatment is also available for patients with economic resources through private physicians and/or with their private health insurance plans.

The availability of this early treatment to indigent patients is limited by the resources available in the public sector. A few patients in San Juan, Ponce and Mayaguez also receive the medication, and this has been expanded recently to Bayamon, Caguas and Fajardo specifically in the last two months.

Persons infected with HIV disease, once their T-4 cell counts fall below 200 or less, are candidates to receive prophylaxis against infections by Pneumocystis carinni.

There is medical evidence that oral prophylaxis with trimethoprim-sulfamethoxazole, dapsone and sulfadoxine/-pyrimethamine is as effective as aerosolized pentamidine.

The availability of the oral prophylactic regimes should be widespread and without difficulty. The availability of aerosolized pentamidine is limited to the private patients, the San Juan Va Hospital patients, and a few cases in the San Juan AIDS Institute.

There is a new effort in the Department of Health with regionalization of services in which this may be provided. I want to mention that aerosolized pentamidine, while needed for a few patients, is not better than other more cost-effective regimes and that the widespread implementation of this modality of prevention without specific guidelines must be studied and weighed.

Patients with HIV disease and T-4 counts below 200 are also subject to many complications, opportunistic infections, lymph node tumors like lymphomas, malignancies like Kaposis sarcomas, and others. Many of these patients end up in the public sector for the management of the complications.

Treatment is available for pneumocystis infections, tuberculosis and toxoplasmosis. Fiscal restrictions, lack of funds or restricted funds impose great difficulties to administered agents like ganciclovir and interferon in the

public sector with the exception of the VA.

In the public sector, the DBA is committed to provide these patients with all their medical needs if indicated. The availability of medications to treat AIDS patients in Puerto Rico with antiretrovirals and other specific expensive agents is limited not by the lack of interest or knowledge, but by fiscal restraints.

The availability of the newer experimental drugs in Puerto Rico was, until about a year ago, limited or nonexistent. When the ACTU network was established in the U.S., Puerto Rico was left out probably because of 1) ignorance from the organizers that AIDS was a problem in Puerto Rico and that there are qualified persons on this island, well-trained, and with expertise and experience; 2) apathy from our side to get involved, or 3) misconceptions by some of the drug manufacturers and their research departments of what Puerto Rico really is.

In August 1989, at the initiative of the San Juan AIDS Institute, a group of health care professionals from the San Juan AIDS Institute, the San Juan City Hospital, the University of Puerto Rico School of Medicine, and the San Juan VA Hospital joined efforts, and with the help of

personnel from the ACTU Unit at Massachusetts General Hospital prepared and submitted an unsolicited proposal to the National Institute of Allergies and Infectious Disease to establish an ACTU in Puerto Rico. The proposal was returned and not funded. The interest to establish the unit continued, but not as a freestanding unit, but as a satellite unit of the MGH. This approach was fruitful and productive. The present infrastructure was fortified and brushed up. But because of budgetary difficulties, it was not possible to have another satellite unit in Puerto Rico having the MGH one at San Juan City Hospital.

In San Juan, we have the outpatient facilities, the trained clinicians, the trained data handlers, laboratory personnel and, most important, the patients--a population of a large number of persons with HIV disease that can benefit from medications, including newer medications. This prompted the San Juan AIDS Institute to establish a Division or Department of Clinical Studies with an operational infrastructure.

At the same time, the efforts of the Infectious Diseases Research Laboratory of the San Juan VA Medical Center were effective in obtaining protocols to use new

experimental agents in VA patients with HIV disease.

The Division of Clinical Studies at the San Juan AIDS Institute became a reality when the first protocol to study antiretroviral agents was established October 1, 1990 and with a second protocol to study a new antipneumocystis agent that will start December 1, 1990.

Clinical studies and trials offer alternatives to treatment but are not the way to supply the treatment needs of the population of HIV-infected people in Puerto Rico.

In the spring of 1990, the National Institute of Allergies and Infectious Disease requested proposals from minority institutions to established the infrastructure for ACTUs at those places. The medical sciences campus of the University of Puerto Rico School of Medicine submitted a proposal for establishment of an infrastructure for an ACTU at the University of Puerto Rico School of Medicine. This grant was approved and funded. Hopefully in three years the school of medicine at the University and the University Hospital will have the infrastructure that will allow the institution compete as a site for an ACTU.

In Puerto Rico, the availability of some newer antiretroviral agents has been limited. Of course, most

trials of DDI were by the ACTU group, which by design, Puerto Rico was excluded from. There have been few trials and little interest in the local epidemiology of HIV disease by the manufacturers of DDC. Still, a few patients have received the experimental agents under the parallel tract development program. This has been limited to highly educated, well-to-do individuals, whose physicians accept the responsibility of filling out all the paperwork. The rate-limiting step in this has been the large paperwork requirements of any experimental protocol. You need qualified people to fill accurately the forms. Once again, experimental drugs are important, but not the solution for the needs of treatment of many patients who have never received one dose of any antiretroviral drugs.

At the present time we have in Puerto Rico several experimental protocols at the San Juan VA Medical Center and at the San Juan AIDS Institute. There are early studies on the dose effectiveness of d4T which ceased enrollment--just 15 patients were studied. A study comparing zidovudine in the regular dose, 600 mg/day, versus the same dose twice a day is underway at both of these institutions.

In a third study in which the pneumonia caused by

Pneumocystis carinii and with mild to moderate manifestations, a new agent 566C80, is compared to the usual treatment of trimethoprim-sulfamethoxazole.

There are two other studies under implementation--the use of DDI in patients on AZT without significant improvement of their illness, and the use of 566C80 as prophylaxis against PCP compared to another regime.

The interest of the pharmaceutical companies in Puerto Rico related to HIV disease has improved. Bristol-Myers-Squibb has at present one study and going on further studies as well as additional agents. Burroughs-Wellcome initiated studies here and have at present to protocols.

Of course, the potential for studies with other products exist since the trained people and the infrastructure exist.

In Puerto Rico, there are also studies carried out by the University Children's Hospital, San Juan City Hospital Department of Pediatrics, and the University Hospital at Bayaman on i.v. gammaglobulin in children in collaboration with the NIH, and a few pediatric patients receive AZT.

A recommendation which I would like to suggest is that the efforts to establish clinical trials in Puerto Rico

be coordinated. We cannot have, or probably cannot afford to have, three or four units with separate infrastructures. A time to join efforts is here, and there is little or no need to have in San Juan three separate, individual units planned for clinical studies on AIDS. The best that can happen is solid funding of the infrastructure and well-paid personnel that will dedicate all their time to the efforts and not have to share private practice interest with the interest of the unit.

AIDS in Puerto Rico is epidemiologically different from that reported by the consolidated report of CDC for USA, but similar--

VICE-CHAIRMAN ROGERS: Dr. Ramirez, we'll have to ask you to close fairly swiftly. I am pleased that we have your written testimony, so you might want to just give us your final punch lines.

DR. RAMIREZ-RONDA: Yes, I'll conclude, since you probably have copies--not of the revised version, but of the original version.

What I would like to conclude with is there is no question that AIDS is a very important illness in Puerto Rico, that it has impacted us, and that the future essentially

projects that the number of cases is going to keep on increasing and that it is going to compromise tremendously the financial resources.

The availability of antiretroviral treatment is very limited at the present time. Clinical trials is a solution for the prevention of the abuse that some of these patients get by offering cures when there are none; organized clinical trials will prevent this and will offer these people alternatives of treatment, but they are not the solution for the treatment of the vast majority of patients. Clinical trials are limited by design and are not the solution for the treatment of the mass of people who are infected.

Thank you.

[Applause.]

CHAIRMAN OSBORN: Thank you very much.

I want to have a chance for the Commissioners to interact, but let me make a couple of summary comments about our place on the program. We are at the moment half an hour behind and have seven people who are scheduled to speak before a rather fixed 12:45 press conference. So with that in mind, I regretfully ask that people who have questions and comments be exceptionally brief.

Ron Jarrell, please.

MR. JARRELL: You speak very openly, and I appreciate you being here to give your testimony. Do people like yourself who speak up against the government plan and the agencies incur any kind of retaliation, since you are HIV-infected, in your care or in other forms of discrimination?

MR. IRIZARRY: Speaking for myself, on a personal basis, which I didn't want to do, I can afford private treatment. I am speaking for the other 20,000 people infected who cannot have medical treatment, so I cannot relate to your question.

No, I don't think they will retaliate against me. Sometimes I feel like my family is bogged down by paranoia.

MR. JARRELL: Thank you.

COMMISSIONER GOLDMAN: Dr. Ramirez, are there any opportunistic infections that are more common in Puerto Rico because of its tropical setting than in the United States that deserve special research in this setting?

DR. RAMIREZ-RONDA: Well, I think that when we look at the frequency of opportunistic infections here, Microbacterium tuberculosis is quite frequently higher than in the

nationally reported data. But if you look specifically at some subgroups within the States, we approach those. But in CNS manifestations, toxoplasmosis of the central nervous system is extremely frequent here--actually, it is the most frequent CNS manifestation that we have here--which is much higher than that seen in the United States. Of course, it is lower than in other places like in France, where the infection rate is much higher. Histoplasmosis and disseminated histoplasmosis is quite frequent here; also, it is an endemic condition here.

The type of opportunistic infection depends a lot on the epidemiologic environment. And of course, toxoplasmosis is prevalent here, the same as histoplasmosis, so we see them on a higher frequency.

Of course, there is opportunity to do research in those areas, but it depends on a lot of resources and interest of specific people in those diseases.

CHAIRMAN OSBORN: Harlon, I'll give you the last question.

COMMISSIONER DALTON: Actually, I just wanted to thank both panelists, and I have a question. Dr. Ramirez-Ronda, your testimony was really terrific. It was put

together with a lot of care, and we do have it.

I wrote Irwin Pernick a note earlier, saying that I sort of wished the VA was running the country sometimes, and listening to you talk certainly has reinforced that--except for a few minor things like mandatory testing, et cetera.

Mr. Irizarry, you had many wonderful things to say, including reminding us that clinical trials cannot be thought about except in the context of provision of basic health care. In that connection among other things, you mentioned home care as an important component. I just wanted to be clear--did you say that as you understand it there is no organized program available on the island for home care?

MR. IRIZARRY: There was a proposal requesting $2.3 million for home care, and it was played around with and around with until just recently, and they appropriated the money, and basically it is going to be used only for terminal cases, which I don't think is the real purpose of home care.

T3S1 COMMISSIONER DALTON: Are there currently organizations, either public or private, to provide care to people who are not terminal?

MR. IRIZARRY: Government sponsored, I know of none.

CHAIRMAN OSBORN: Thank you both very much for your

patience with our being somewhat late and for your important testimony.

MR. IRIZARRY: We appreciate your hearing us.

[Applause.]

CHAIRMAN OSBORN: Welcome, and thank you also for your patience.

I would like to ask the honorable Isabel Suliveres de Martinez to start off, please.

MS. SULIVERES: Dr. Osborn, Dr. Novello, members of the Commission, as you know I am the Secretary of the Department of Anti-Addiction Services, which covers the entire island and deals with both addicts and alcoholics.

In 1973 the Government of Puerto Rico, faced with an increasing use of heroin and marijuana on the island, particularly on the part of returning veterans and returning migrants from New York City and other large metropolitan areas in the U.S., created the Department of Anti-Addiction Services, headed by a Cabinet-level secretary.

The Department has responsibility for all governmental prevention and treatment services for both drugs and alcohol. It also licenses physicians, pharmacies, and all other controlled substance providers in order to avoid

deviation of these substances to nonmedical use and licenses all private and nonprofit prevention and treatment centers on the island.

In a Department-sponsored research study published in 1989, Garcia and Colon estimated the addicted population on the island as numbering 37,595 addicts. Prior to the publication of this "Estimation of Drug Abuse in Puerto Rico", the number of addicts reported by the media and some official records was around 100,000, but we have found no scientific data available to validate this estimation.

Garcia and Colon estimate that for the year 1978, Puerto Rico had 13,703 addicts. By 1981, the number had risen to 28,388; by 1984, there was an increase to 33,795; and by the year 1986, the number of addicts reached 37,595. Thus an annual increase of addicts at the rate of 11 percent was reported by these researchers. According to Garcia and Colon, this rate of increase in drug abusers in the island during this period was 13 times greater than the population increase.

It is of interest to note that heroin addiction showed a slight decrease for the first time in Puerto Rico in the period between 1984 and 1986, according to our study--

from 5,685 to 4,127 addicts.

Marijuana abuse also decreased during the same period of time, from 28,100 to 18,140. This downward trend, however, was upset by the sudden increase in cocaine abuse. By 1986, cocaine abusers reached 15,328 in Puerto Rico. In prior years, the low number of cocaine addicts on the island made it impossible to successfully estimate cocaine use or abuse.

Up to the present, Puerto Rico has been spared the crack epidemic which has plagued large cities in the United States. However, crack is beginning to enter the island as shown by recent police drug incitations, and most treatment programs are beginning to treat a few crack addicts who have returned from the United States. This greatly troubles us because were this initial trend to continue, we may be faced with a real problem in the not so distant future.

Once again, returning migrants may create a market in Puerto Rico for a most undesirable drug and place our youth in great jeopardy.

I.V. drug use has created a serious problem of HIV infection in Puerto Rico. The Latin American Center for Transmissible Diseases, known as CLETS, reported in 1990 that

60 percent of all persons diagnosed with AIDS in Puerto Rico informed of previous i.v. drug use. No other State or Territory has reported such a large concentration of i.v. drug users among AIDS cases.

Moreover, Puerto Ricans in the mainland show a larger concentration of i.v. drug users among AIDS cases when compared to whites, blacks, or any other Hispanic group.

As is well-known, CDC data reports that Puerto Rico occupies second place after Washington, D.C. in AIDS infection rates in the Nation.

Concerned with this reality, DAAs researchers, Robles and Colon, applied and received NIDA funding for a demonstration project known as the Puerto Rico AIDS Prevention Project in the Metropolitan San Juan Area. The goal is to reach 2,000 i.v. drug users in high-risk areas and follow them for a period of six months to learn about their drug use patterns, risk behaviors for HIV transmission, state of health, lifestyles and sociodemographic statistics.

We have submitted to the Commission a document--we sent it yesterday, and we hope you received it--which summarizes the various findings of this study. I trust that this information will help you to get a better view and

understanding of the addictive AIDS patients in Puerto Rico.

Up to the present, with 1,800 cases identified in this study, 45 percent have tested HIV-positive. However, in interpreting this data, it must be remembered that this population was selected in areas surrounding shooting galleries. Obviously, you are going to have a higher percentage of infection.

Robles et al. considers that the most important factors associated with this seropositive are the number of years of i.v. drug use and a history of prior incarceration.

An analysis of the identified 1,800 cases by Colon et al. shows that 66 percent of the addicts had at one time or another been enrolled in a treatment program but that they had entered treatment at an advanced condition of severity, with ten years of drug addiction behind them, with a criminal record, and suffering from a variety of health conditions. Thus, treatment programs are having access to this high-risk population when already considerable deterioration has occurred, obviously affecting positive outcome.

An interesting result of this demonstration project is the fact that a large number of the identified addicts expressed interest and were referred to drug treatment. This

study has revealed that 64.3 percent of the addicts in the study use shooting galleries regularly, a percentage higher than in similar groups in the U.S., but share needles less than similar groups in the U.S. It is easier to get needles in Puerto Rico.

It is possible that this high percentage of shooting gallery use is at least partly due to the fact that many of our subjects, much more than in the U.S., live with their parents who are traditionally the only relatives who are willing to receive them in their homes, and despite the addicts' deterioration--and this is a deteriorated group--the strong cultural trait of respect for the mother does not allow the addict to inject drugs in the mother's home, thus increasing the use of shooting galleries and the risk of HIV infection.

Because of our concern with the delay of i.v. users to seek early treatment, DAAS has established mobile clinics in the metropolitan area to reach out to addicts who are not prone to seek help on their own. In addition, we requested and received waiting list reduction funds from OTI to accelerated treatment availability. With target cities recent funding we expect to further improve treatment

availability for i.v. drug users in San Juan.

Last fiscal year 1990-91--I want to apologize because they gave you the 1989-90 figures--DAAS offered treatment to over 22,000 drug addicts last year, to over 10,000 alcoholics and to over 9,000 drunk drivers. In addition the Department carried out a vast prevention program covering public and private schools, housing projects, and the community-at-large. DAAS runs a variety of treatment alternatives--detoxification, drug-free residential, out-patient treatment, methadone maintenance and acupuncture treatment.

In the penal system we operate four detoxification clinics and expect to open two additional ones soon. We also offer psychosocial treatment in a number of closed penal institutions, but this is an area where treatment expansion is badly needed.

Despite consistent efforts on the part of the Commonwealth and Federal Governments to increase DAAS' budget during the past five years--it has increased by about 70 percent--treatment slots continue to be below the level of need. If we want to be effective in AIDS prevention and treatment, we must vigorously reach out for i.v. drug users

and provide them with immediate treatment, and offer them effective followup when they abandon treatment or when they successfully terminate treatment to avoid relapse. To do so would require additional allocation of funds.

DAAS has developed an educational model for AIDS education of all its drug patients. Additional funding will allow for the assignment of full-time specialized staff to this endeavor. We run 55 drug treatment centers and four satellite clinics, and three mobile clinics serving the entire island population. We also run 18 centers for treatment of alcoholics and 12 prevention centers.

All our patients who are to be tested for AIDS are referred for testing when they enter treatment. The Department of Health does the testing. Throughout treatment, cases needing testing or treatment for AIDS are referred to the Department of Health. We always tell people AIDS is not an addiction. (My department has to do with treating addictions, not AIDS.) However, we are concerned because it is our population, the ones that are testing most frequently positive with the disease.

The Department of Anti-Addiction Services provides drug treatment for HIV-positive patients and AIDS patients

and refers to special care to nonprofit groups the treatment of those who require hospice care.

In addition to the Puerto Rico AIDS Prevention Project already mentioned, DAAS operates three additional AIDS-related programs. "Tu, Mujer"--meaning "You, Woman"--aims at educating the sexual partners of addicts in high-risk communities, funded by NIDA, at three testing sites on a voluntary basis referral. The "Tu, Mujer" project has revealed 6.7 percent seropositivity in addicts' sexual partners and 43 percent seropositivity in sexual partners who are also prostitutes and i.v. drug users. Although multiple sex partners was found not to be prevalent behavior among the Puerto Rican women in this study, this is prevalent in the United States, multiple sexual partners. Here, we found that changing partners frequently was more prevalent than multiple partners.

The methadone maintenance AIDS testing projects funded by CDC are too new for results to be significant, but one project housed in our largest detoxification center--

VICE-CHAIRMAN ROGERS: Secretary Suliveres, let me interject. You are going to have to finish up fairly quickly. As you know, we have your written testimony.

MS. SULIVERES: I know, I know. It should be pointed out, however, that the rate of 45 percent seropositivity of our clientele is biased because we refer cases that we suspect may be infected with AIDS.

Someone asked me the other day as to why i.v. drug use is so prevalent among Puerto Rican addicts. No study has been done on this subject matter, but I will share with you two possible variables: First, the strong cultural tradition to favor injections as a means of taking medication. It is interesting to note that our addicts call the shooting galleries "little hospitals" or "hospitalillos", and the process of injection, "the cure" or "la cura".

Second, the first hard drug which entered Puerto Rico was heroin, and at that time the only way to use the drug was through i.v. injection.

Thank you very much.

CHAIRMAN OSBORN: Thank you very much.

Welcome, Lydia Santiago. You are the next speaker.

MS. SANTIAGO [Interpreted from Spanish]: Good afternoon. My name is Lydia Santiago. I am a resident of Hogar Crea las Americas Posada de la Esperanza. I will speak a little bit about myself.

I acquired my HIV about a year and a half ago. I was living in an abandoned building on Fortaleza Street in San Juan. This was a dilapidated building, a place where no one would ever think that a human being would be living.

About a year and a half ago also, some people arrived at this building with an ambulance in search of people who were living there. They heard about us through telephone calls--I don't even know how--but they arrived at the building, and they took us out to give us a better place to be nourished, to give us a bed because we were sleeping on the floor. This is how I arrived at Hogar Crea.

Before that I had visited many hospitals, but they did not want to give me any attention because of the condition of my legs; I had ulcers, and they were diagnosing that my leg had to be amputated. At Hogar Crea, I was cured day by day of the ulcer. They would take me to the hospital day after day because I had no other place to do it. At the moment that I arrived at the hospital, I learned that I was a patient of AIDS. They had not told me before that. They had not given me any pre counseling or post counseling which is now being given at Hogar Crea las Americas.

This is my testimony.

CHAIRMAN OSBORN: Thank you very much.

Mr. Bodhwell?

MR. BODHWELL: Good morning. I am not used to using five minutes. My name is Henry Bodhwell. I am a dependent of an English family. When the Americans arrived in Puerto Rico, my great-grandfather came to Puerto Rico, and I am a Puerto Rican.

When I was addicted to drugs in 1965, I was in New York--I am going to be brief--I was under all the Federal and State programs. Also, this is a sequence of behavior, of conduct. I was in all the institutions, in every institution--I don't want to mention each one of them, but in all institutions--in New York State. In my adolescence, I was in reform schools. I had trouble and disorder in my life.

I arrived at Hogar Crea in 1981 as a convenience. I was tired. I am very aware that when you reach a place and you are not known, as much as you get to know the place, at this Hogar Crea I saw a program that was structured in such a way that I could not manipulate the program. It was a unique program.

The addict as I understand always wants to change but has a personality or character disorder that cannot leave

him because he has not acquired maturity. At Hogar Crea, as I became aware of my own life and my own reality, I was re-educated.

I am now a counselor of HIV testing. I am prepared to deal with addicts today at Hogar Crea las Americas. I assist female colleagues. I also lived this life, and I know how to give affection and love. And we speak of money, but I believe it is important to have affection and love and to find doctors who touch--who touch. We can then be successful, because it is all for the good.

I was eight years in a methadone program, but it goes beyond your control, and I am saying this so that it does not go out of control, because in 1985 another illness touched me, HIV. But since I had received my self love, I accepted it.

We wish to contribute on behalf of Hogar Crea. Our facilities exist, and we ask that you give us help in the medical--I am not a psychiatrist or a psychologist, but I went through 30 years of addiction. In Attica, I was using drugs in prison; in Federal prison, I was using drugs.

So we have been re-educated. We are tired of seeing all of this disorder. We wish to organize and to give

of ourselves. I am representing many. I was in the daily newspaper, in The Journal, in all newspapers because they were all looking for me; but I no longer appear in the newspapers. That is the difference now. I am a married man, happy, and my wife and I are both growing.

But I want to give you my thanks for this opportunity on behalf of Hogar Crea. We are available; we have no fear. We want to help so that you can continue to help us. At Hogar Crea, we have 67, and we touched the problem in 1985 when we tested, and we had HIV here, another epidemic illness. But we shall go forward.

Thank you for your attention.

[Applause.]

CHAIRMAN OSBORN: We have time for one or two questions.

Dr. Novello?

SURGEON GENERAL NOVELLO [Interpreted from Spanish]: These are moments when we feel that everything is worthwhile.

[In English]: It is worth everything to get you here. So many times, we have spoken about the fact that we needed places where you could be detoxified.

[Interpreted from Spanish]: What is the rate of

employment of the addicts who are reformed? Once these persons are cured, how do we re-integrate them into the community? There is prejudice in returning back to employment.

MR. BODHWELL: Yes. I have been an addict for so many years. I felt that the best place was to continue helping Hogar Crea. We have a program which rehabilitates and helps. We have fellows from good families who have been addicted, and they have not finished their education at the university. We help them to go back to the university. We have had lawyers, international criminal lawyers, who have returned to their professions. In the negative aspect of my life, I became a barber, stylist, mechanic. At Hogar Crea, I feel that I am more useful in what I am doing. That is my personal decision in going forward with Hogar Crea.

CHAIRMAN OSBORN: Eunice?

COMMISSIONER DIAZ: I have a question for Dr. Suliveres and a comment for Lydia.

Dr. Suliveres, this year, I understand that with the Government programs here, you were engaging some assistance I guess through CDC and NIDA for street outreach efforts to i.v. users.h

MS. SULIVERES: That's right.

COMMISSIONER DIAZ: Could you describe that a bit, because I would like to be able to contrast how those examples of training programs that are sometimes working on behalf of our populations elsewhere may be useful here, and if there was anything that you particularly remember was very significant about that.

MS. SULIVERES: Well, the CDC projects are relatively new, and that is why I did not go into them, because we don't have enough data coming out of them yet. But there is one thing that runs through--the Puerto Rican addict, like most Puerto Ricans as human beings, wants personal contact. You have to know how to contact them on a personal basis, and you have to be very careful not to be too push or too demanding because you will lose the patient; he's not going to come back. You have to work at their speed, and with a great deal of understanding and a great deal of respect, not matter how deteriorated they are, because if you do not do that you are going to end up without patients.

COMMISSIONER DIAZ [Interpreted from Spanish]: Lydia, I wanted to ask you, Lydia, when you spoke of your experience, why were you in that building, originally--

because you had no place to live, or because of other circumstances, the use of drugs?

MS. SANTIAGO [Interpreted from Spanish]: When I was a drug addict, my family rejected me, and I had to abandon my home, not because they did not love me, but they did not accept my behavior. That is why I was in that building.

In addition to that I want to say that I found love and support at Crea. I learned to value things. Even the relationship with my family improved. There is no better place than that place. That is my personal opinion.

COMMISSIONER DIAZ: I am glad that you were welcome there.

CHAIRMAN OSBORN: Let me thank you all for that very important testimony. We appreciate you being here.

[Applause.]

CHAIRMAN OSBORN: I am pleased to welcome the honorable Hector Luis Acevedo, Mayor of San Juan.

Thank you for putting up with our tardiness; we are very pleased that you could join us.

MAYOR ACEVEDO: Good afternoon, members of the National Commission on AIDS. We are especially proud to have

a Puerto Rican woman on the Commission.

With me today is Mrs. Janecito Major [phonetic], the Executive Director of the San Juan Institute on AIDS; and Dr. Borras, our Medical Director in the City of San Juan.

I will not waste your time by going back to the statistics about the AIDS problem in San Juan. I will try first to review in two minutes what we call the basis for our statement.

First is the impact that we are going to have in San Juan if we continue the way we are in the next years. As you will notice, the AIDS problem in San Juan is duplicating itself almost every 18 months. What this means is that in a year and a half, we will have detected double the cases of AIDS in San Juan. If you put that into the future, this city will not be able to survive if we do not stop the AIDS epidemic.

It is due time that our society begins to look at this problem not as a problem of drug addicts or homosexuals or promiscuous people; this is a problem of all the people of San Juan and Puerto Rico.

If we put in place a good prevention program, we should be able to stabilize the amount of new cases and

decrease the amount of new cases in the future.

Dr. Borras testified this morning--and I will not take up your time on it, but just commend the good efforts that the private groups and the government groups have been making throughout these years, creating a private/public entity at the San Juan AIDS Institute, which I think you will visit this afternoon. We have dedicated 20 beds in the municipal hospital. We have a Harvard group of advisors. We have contacted the best professionals we can possibly have in our society here in Puerto Rico.

But I must say with all sincerity that these good efforts have provided a real start in the fight against AIDS, but we are losing the war as of this date. We have today a situation where we have ambulatory care, which I think has done an outstanding job; we have diminished the number of days in bed for an HIV patient from 22 to 11 in Puerto Rico. We have extended the care to the home, and we are looking to outreach efforts, clinical tests, and all that have been recommended to us.

As of this date, I would like to bring to your attention what I think is the most important priority in terms of public policy, and to this I would like to devote my

ten minutes.

First, I think in general terms we are on the wrong track. We are looking at AIDS as treating AIDS patients. I would invite every member of this Commission to look with me at the Ryan White bill and find a line specifying education in that bill. There is not a single line.

If we keep looking at this problem as a way to treat the patient, and we do not look at the statistics, we are going in the wrong direction. I will advise--and this is the policy that I am advising--a change in public policy in terms of the priorities, to put prevention as the first priority.

When I reviewed the budget of the AIDS program in San Juan, I did not approve it this year because most of the money goes to treatment, and a little of the money goes to prevention. If we do not change that policy, we will not be able to treat the patients in the next five to ten years, and I think this Commission can be instrumental in regard to the need for a change of priorities in the fight against AIDS.

We need to put prevention and education as of this moment, along with research, first, because if we do not stop people from getting into the problem, we won't be able in the

next years to treat the number of people, and we will be in a situation like "Sophie's Choice"--whom do you deny beds in San Juan, and in New York and in San Francisco?

In Puerto Rico, as you all know, intravenous drug abuse remains the major cause of the epidemic and must be, in terms of our efforts, the primary prevention target. As drug abuse does not advertise itself on TV, it is sometimes doubtful that we reach this population in general education efforts. We should devise--and we are working on this in San Juan--a special program to target the people in the drug abuse community, which is the main group spreading AIDS in San Juan. This is not the situation in Africa, as you know, where it is a promiscuous way of spreading, or in San Francisco, but it is in San Juan.

Other high-risk groups demanding urgent attention include prisoners, which in Puerto Rico have a direct relationship with the drug problem. So in terms of priorities in testing and in education, we should hit first the prisoners and the families of the prisoners because they are normally the most related group to drugs and to AIDS in Puerto Rico.

We should accelerate adolescent prevention and education efforts. We are planning to bring young people with

AIDS to the schools in San Juan so that they can offer their testimony. We have been present when people from Casa Crea or other programs have brought people with the problem, and these testimonials are sometimes the most effective way of changing the lives of young people.

We have a problem here in Puerto Rico, and I know in most of the States, that is what I call the denial mentality. This is a problem that historically has been associated with drug users and homosexuals. We have in the general mentality that says, well, since I am not a drug user or a homosexual, this is not my problem.

I would say that the first priority we have here in Puerto Rico in the next months is to change that denial mentality because that is the one that is going to provide the open door that we need to attack this problem. We have to change the mentality that "This is not my problem" because this is all of society's problem. If not, when we have to deny beds to people who do not have AIDS in our hospitals, then we know what will happen.

Let me tell you from the standpoint of a mayor, if we do not stop the spread of AIDS in this city, there is not going to be any decision on the budget of Puerto Rico nor of

the city because all the money in the next ten-year budget will have to go to treatment of AIDS.

What I am trying to convey to you is that if we do not put forth a very disciplined effort, a strong educational effort, the pressure of the treatment will take all the money in the future.

So this is the time that we need a very strong public policy, putting prevention first, because if not, the pressure, the political and the human pressure, of treatment will take most of the funds.

One of the things that we can do in public positions is to see the future and try to prevent the worst consequences if we do not act now.

We need laws, and we need a coherent vision of the rights of the AIDS patients. We have here cases in which they are fired from their jobs, they are denied health insurance. We should put as public policy that an AIDS patient is a patient like any other patient, and if you want to do business in this country, you cannot cancel health insurance because one of the clients has a health problem.

VICE-CHAIRMAN ROGERS: Mayor Acevedo, we're going to have to ask you to close. Your time is up. We are

pleased to have your impressive testimony, but could you wrap it up fairly fast?

MAYOR ACEVEDO: Yes, sir. I am circulating to you the main points of my statement, but I would like to say that one other big issue is that here in Puerto Rico and in the United States, AIDS has been looked at as a legal problem. The Secretary of Health came to this country for a civil rights seminar about AIDS. I would like to see the public health community take the leadership in this issue, with the lawyers following, helping them. This is not a civil rights issue. This is a public health issue with civil rights consequences, and sometimes we are looking at the problem the other way.

I believe we should expand the availability of HIV testing; we should support the ambulatory and home care strategy. And I must say that here on Saturday, people from the Caribbean and Latin America will meet to establish one of the first organizations for the prevention of AIDS in the Hemisphere.

AIDS does not respect frontiers, and if the problem does not respect frontiers, the solution should try to unit all in the fight against AIDS.

Thank you.

VICE-CHAIRMAN ROGERS: Thank you very much.

[Applause.]

CHAIRMAN OSBORN: Dr. Lanier--and let me while I call on you also thank you for sitting in for Secretary Mendez.

DR. LANIER: Thank you, and I'll be very brief.

I was struck by your testimony in which you said that if we don't stop this epidemic of AIDS, disaster will strike. You also said that you failed to approve the budget this year because there was too much money targeted for the treatment and not enough for prevention.

My question of you is what do you believe the leadership of the City of San Juan should be in terms of bringing together the institutions of the community such as businesses, the churches, schools and other leaders in order to deal with the kinds of problems that you see that we have with the AIDS epidemic?

MAYOR ACEVEDO: Thank you very much for that question. I must say that I believe in joining efforts. There is no way the government can solve this problem. The leadership of the community has been a key in the treatment

of AIDS in San Juan.

When the young lady who testified before me said that she was picked up, she was picked up by an ambulance of the Municipality of San Juan and was delivered to Casa Crea, which is a private institution.

There is no way to solve this problem if we do not unite.

I went to the U.S. Congress and fought for the funds in the Ryan White bill, and I think that goes to treatment; but in terms of prevention, if you look at the schools in Puerto Rico, if you look at the churches in Puerto Rico, you need obviously to unite the efforts with a common denominator, which is that the people who care most for the needy people and the people who have the potential of AIDS are the private groups. That is why I think it is crucial that we put together a community effort, joining the organizations, of different strategies, because each one has its own priorities, every institution has its own priorities, but there is a common bond, and if we have the resources and we have the personnel to deal with that, the only way is to join those efforts and not to repeat ourselves every time we have a problem. If not, we will have government programs and

private programs doing the same things in the same places, and in other places, neither one doing anything.

DR. LANIER: Thank you.

CHAIRMAN OSBORN: Eunice?

COMMISSIONER DIAZ [Interpreted from Spanish]: I wanted to ask you, Mr. Mayor, the Ryan White bill is specifically directed to the cities, one of which you are Mayor. What is the state of preparedness of the City of San Juan to receive those funds, since the bill emphasizes cooperation between public and private groups, especially with community organizations? What are you doing to be ready for the implementation of this bill?

MAYOR ACEVEDO [Interpreted from Spanish]: We went to the Senate and the House of Representatives to fight for those funds because in terms of our strategy, they are indispensable for the Municipal Government to function, for us to provide the basic elements of modern medicine, such as AZT, to all patients. But what happens is that some of these patients are going to New York to receive the AZT because the State provides it, and then they come to die in Puerto Rico. We need those funds now. We have been preparing the infrastructure to take care of this with the medical staff that

we have in the AIDS Institute, as well as volunteers who are working, as well as organizations. We do have the infrastructure to administer these funds.

The major problem was that we didn't have sufficient inpatient beds for detoxification programs for the drug addicts; we didn't have one, single bed in San Juan. We are a target city in the Health Department program, and next year we are going to receive funds so that the government and the city in a joint program can treat these patients.

We have been seeking funds for the infrastructure that we already have. We have the physicians, but if we don't have the money to buy the AZT in Puerto Rico--now, with the Ryan White bill, we are hoping to have the means to get the AZT in Puerto Rico.

CHAIRMAN OSBORN: I regret having to interrupt the dialogue now, but we are far past our time, and with some six commitments coming up, that I think we will thank you very much for telling us your thoughts and proceed to the next panel.

Thank you very much.

[Applause.]

VICE-CHAIRMAN ROGERS: I'd like to welcome this

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panel. We want to give you as much time as we possibly can--as you know, we are running short. I would point out to you that we do have your written testimony, and we all do our homework carefully; we will read it with care. If it is possible for you to make your remarks even shorter so that we have a chance to interact, I think that would be much appreciated by the Commission. If that is difficult for you, I understand; if you can simply speak from the heart, so do it.

With that, welcome, and please proceed in whatever order you have decided upon.

MS. PLATON: Good morning, honorable members of the Commission.

I am here to represent Norma Perez-Giraud, the Ombudsperson for the Disabled, and I hope this answers a question somebody posed to the first panel this morning--there are antidiscrimination statutes; there is an office that can handle these complaints.

Our office was created on September 25, 1986, pursuant to Law No. 2., to protect and advocate for the rights of people with disabilities. The office is ascribed to the Executive Branch of the Commonwealth, that is, the

Office of the Governor, and in addition to implementing this local law it also houses three Federal programs. I am not going to explain them to you, but I am just going to go over them briefly.

There is Protection and Advocacy for the Mentally Ill, Protection and Advocacy for the Developmentally Disabled, and a program called Client Assistance Program that helps in conflicts with the program of Vocational Rehabilitation of the Social Services Department.

There is also a program called "Ayuda para los Imperdido"[phonetic], which means "Help to the Disabled", which works as a referral orientation program and which can also provide legal representation in cases of discrimination, in architectonic barriers, employment, housing and health services.

The framework that provided for these laws I think you are all probably familiar with. They are the Rehabilitation Act of 1973, the Fair Housing Act of 1988, and as of July 1990, the Americans with Disabilities Act.

In light of the issues at the onset of the AIDS crisis, the application of existing legislation was the resource that most readily answered many of the questions

that face the nation, thus, the inclusion of HIV infection as a handicap.

The Rehabilitation Act, specifically Section 504, defines persons with handicaps in the following manner: "persons having a physical or mental impairment that substantially limits one or more major life activity; persons having a record of such an impairment, or persons regarded as having that impairment". Other infectious diseases are thus included because the infectious nature of the disease cannot be separated from the disease itself; it is just a manifestation.

So including these diseases in that sector helps to protect people from the stereotypes created by disease and disability that permit discrimination and don't grant equal opportunity to all citizens. Our office, as guarantors of this Act, has problems concerning the legal ramifications of asymptomatic HIV infection. A lot of people come to us and say "but they are not disabled, they are not in a wheelchair, they don't have any kind of disability". But in the Americans with Disabilities Act, this was defined perhaps in a better way, saying that it does impair a major life activity, being procreation and intimate sexual relationships. And both

these acts again prohibit discrimination against disabled individuals who are otherwise qualified for the benefits or services at issue.

If the person with HIV or AIDS is otherwise qualified, they shouldn't under this Act be segregated because of risk of transmission, because in public settings we have come through research to learn that it is insignificant. And if a significant risk is found, the employers or educators, whatever the setting be, should consider what reasonable accommodation could reduce that risk. And it is our responsibility as the office of the ombudsman to make sure that these reasonable accommodations are reached.

In Puerto Rico, the problem we have is that, yes, these are Federal laws, and we can implement them, and the only really local legislation we have is Law No. 44, which is an antidiscrimination law. But because of the ignorance around the ~~disease and the cultural tabus~~ that we have created around it and now, I notice, the lack of information between ~~service providers ourselves~~--because why did OCAS not know of the existence of our office, et cetera--it is troubling that perhaps HIV-specific legislation is the only way that we are going to be able to work together, at least

to prevent discrimination.

So after establishing that, I wanted to address, because it is very important to our agency, that as advocates for mentally ill individuals and the developmentally disabled, we also have to think about these people who are living in institutions where infection is widespread and less care is taken in counseling because perhaps they believe the mentally ill do not understand. The same goes for developmentally disabled children; all pediatric AIDS cases are considered developmentally disabled.

We are also concerned with the implications that the infection has to the central nervous system, meaning that a lot of our psychiatric institutions could be burdened with patients who were not before mental patients, but in the later stages of the disease if they are suffering from dementia, they will have to be admitted.

Today our psychiatric institutions are not equipped to deal with secondary medical factors that the disease presents, and you can be denied admission if you have hepatitis, if you have AIDS, because they are not medically equipped. But then in the same way, our hospitals, our primary care clinics, aren't prepared to deal with the mental

diagnosis of the patient. So we have to find some sort of agreement between how are they going to get treatment for their medical problem and not neglect the fact that they are mental patients.

Again, concerning children with AIDS, they are sometimes born with other impairing conditions, other handicaps, such as speech or hearing impairments, encephalopathy, microcephalia, and a condition that resembles cerebral palsy. Sometimes in the service that we provide today, we are not including them as part of the already developmentally disabled population.

So we must consider all these factors, such as what are we going to do about foster homes, behavior modification in institutions, more adequate drug rehabilitation programs, and the availability of psychological/emotional support groups.

I think all I have left to say is that as an advocate for rights of people with disabilities and as representative of the ombudsperson who protects those rights, I believe that only through some specific HIV legislation or amendments to the existing statutes will we be able to readily solve the complaints in our office if those who have

already arrived and those that I hope in the future will seek help for their discrimination; nor can we recommend without this legislative support that residential facilities, psychiatric, correctional or for the developmentally disabled take a stand and create public policy aggressive enough to provide fair treatment to all individuals.

Thank you.

[Applause.]

VICE-CHAIRMAN ROGERS: Thank you very much, Ms. Platon; nicely done.

Yes, Ms. Vargas.

MS. VARGAS: Good afternoon already. On behalf of the Sabana Litigation and the AIDS Civil Rights Project and on my own behalf, I would like to thank you for allowing us the space to share your concerns, our views, our evaluation and thoughts on the AIDS epidemic in Puerto Rico and civil rights.

It is a well-documented fact that the Commonwealth of Puerto Rico is facing an AIDS epidemic which at this time is challenging most governmental agencies and private for profit and nonprofit organizations as well. AIDS affects all facets of everyday living. AIDS is of health care, employment, housing and public service concern and affects all

community institutions.

Puerto Rico's epidemic is placed second to Washington, D.C. These jurisdictions have in common certain things, such as the high concentration of poverty and the severe drug abuse problem.

According to studies done by Legal Services Corporation, approximately 70 percent of the population in Puerto Rico would qualify for legal services, which places them therefore well below the Federal poverty line. The most recent surveillance report states that 68 percent of the HIV cases reported are intravenous drug users, men and women; 18 percent gay men; 10 percent bisexual i.v. drug users, and the remaining are women, children and hemophiliacs.

It is said and generally accepted that 90 percent or more persons living with AIDS in Puerto Rico are medically indigent, are Medicaid recipients or qualify for Medicaid coverage.

Puerto Rico in fact participates in the Medicaid program and has elected to provide other optional medical services such as prescription drugs. Nevertheless, as has been the testimony of prior officials and admitted to by the officials here in Puerto Rico, Puerto Rico Medicaid program

does not pay for prescription drugs medically necessary in the treatment of AIDS, such as AZT and aerosolized pentamidine.

As in other instances, the government asserts as a justification for not providing such treatment a lack of funds. In fact, Puerto Rico receives different treatment in receiving less benefits from the Federal Medicaid program because of its political status--which, by the way, is the status advocated by the present Puerto Rico Government.

As of June 1990, approximately 250 people were receiving AZT of approximately 5,000 people who were diagnosed and medically eligible for receiving AZT.

The AZT treatment that is in fact being provided is done so through the clinical trial programs and other not-for-profit organizations. While in other jurisdictions--this is a sad statement--the battle is geared to getting Medicaid to pay for experimental drugs, Puerto Ricans have yet won the right to payment of basic, medically accepted, life-sustaining treatment.

Puerto Rico has yet to issue an adequate public policy statement with regard to AIDS. There have been several drafts proposed by the Government of Puerto Rico, and

they have all been shunned or rejected by the groups who advocate for people with AIDS.

The Sabana Litigation and AIDS Civil Rights Project believes that discrimination is a major obstacle in the battle against AIDS. Without strong civil rights protection, the battle will most certainly be lost. Discrimination breeds on fear of being identified, rejection, segregation, loss of family, loss of dignity.

If we take fear of discrimination and add fear of death, there is no motivation for any person to voluntarily seek testing.

We ask you, why should any Puerto Rican or resident of Puerto Rico submit to HIV testing? When the test results are known, a person living with AIDs can expect no treatment, discrimination, stigmatization and segregation. Where is the motivator?

Fear of discrimination and the knowledge that the majority of persons diagnosed with the virus will go untreated, results in people running underground. This is bad public health policy. At the very best, Puerto Rico has no public policy, and that in fact is the government's policy--to do nothing.

I'd like to share with you some instances of discrimination that have come to our attention in view of the work that we are involved doing, from the services requests that have been made to our offices.

In employment specifically, a potential employer requires an applicant on the application to divulge his or her HIV status. An employer fires, demotes or denies the promotion of an employee upon learning his or her HIV-positive status--even though he or she is able and willing to do the work.

Discrimination in access to health care is devastating. For example, a patient is denied medical treatment--not treatment for AIDS, but orthopedic surgery--upon learning that he is a person living with AIDS. Not only is he not receiving treatment for his AIDS condition, but he is being denied general medical treatment.

We believe the denial by Puerto Rico's Medicaid program of the payment of prescription drugs which are medically necessary for the treatment of AIDS is another instance of discrimination by this government.

Private laboratory refuses to make general blood work tests upon information that patient has AIDS. These are

but a few examples of discrimination in access to health care.

Regarding housing, here we can cite a recent housing discrimination case which is filed before the Federal Court for the District of Puerto Rico, AFASS v. Arbe [phonetic]. This is a case where a government agency, the agency which is responsible for issuing a use permit, denied several persons living with AIDS and a group of friends and relatives of persons living with AIDS a use permit to operate a hospice. The denial was based exclusively and solely on discrimination factors. The agency succumbed and became a part of the community which was full of fear, which was ignorant as to AIDS and the causes of AIDS, and they became a participant in that discrimination. This is a government agency--not the ignorant people of Luquillo, which is how it was presented by Arbe--but it was the ignorant community of Luquillo and not Arbe who had anything to do with the discrimination.

VICE-CHAIRMAN ROGERS: Ms. Vargas, we are running out of time. I know you have some powerful recommendations. Would you like to give us those?

MS. VARGAS: Yes, we do. There is one issue that

we must address even though you have pointed out to me the very short time that I have left, and that is that we believe that the government's focus is misplaced. The government, in order to deal with the AIDS epidemic, regarding legislation they are signalling to mandatory testing. Mr. Acevedo sat here and said that prevention must be attended to, must be given a priority. What he did not say here today, but is in fact being recommended by his administration, is that they are considering mandatory testing for all citizens of Puerto Rico. That is Mr. Acevedo's recommendation, and it is now being studied.

Sabana Litigation Project understands that mandatory testing would not pass constitutional scrutiny, either under the Constitution of Puerto Rico or the Constitution of the United States, and even if it did, even if it did, the fact is it is very bad public health policy.

[Applause.]

Our recommendations. We believe there is a need for strong local antidiscrimination laws and enforcement mechanisms. I disagree with what Lydia pointed out, that in fact there is a local law that prohibits discrimination and protects people with AIDS as a group; it is not that way.

The definition provided in that law for handicapped is that a handicapped person is one who either has a mental disorder or a motor disability, and handicap would not fit under either of the two terms included in that law.

VICE-CHAIRMAN ROGERS: Ms. Vargas, you are going to have to finish up pretty quickly.

MS. VARGAS: I think generally, my strongest recommendation would be to take a look at what you are doing and what you are suggesting as public policy and refocus it, and think about strong local antidiscrimination laws.

Thank you.

VICE-CHAIRMAN ROGERS: Thank you very much.

[Applause.]

VICE-CHAIRMAN ROGERS: Mr. Villalobos?

MR. VILLALOBOS: Good afternoon, dear members of the Commission, especially to our Surgeon General, Dr. Novello.

My name is Dr. Raul Villalobos. I am the Executive Director of the Correctional Health Services Program of the Commonwealth Department of Health. The Correctional Health Services Program is the branch of the Department of Health of the Commonwealth of Puerto which has the responsibility to

provide and coordinate all the medical services for the inmates.

The health policy of the Correctional Health Services Program is within the health policy for the general population in Puerto Rico. This means that the same health services are available for both the general population and the penal population.

The Correctional Health Services Program provides health services to 25 medical units across the island within every penal institution. Services include medical, dental, nursing, pharmacy and educational. Also, some secondary and tertiary medical services are offered.

The Correctional Health Services Program provides services in two phases--outpatient and inpatient. The outpatient phase is offered through all the medical units, and the inpatient phase is provided only through the regional intake centers at the State Penitentiary in Rio Piedras, Bayamon Regional Center, the Vega Alta Center, the Southern Regional Center, and in a few weeks, at the Western Regional Center in Mayaguez. The State Penitentiary also offers some tertiary medical services.

Those services which are not provided by the

Correctional Health Services Program are offered by the public hospitals of the Health Department.

AIDS and HIV infection is a worldwide problem that requires worldwide efforts. In Puerto Rico, the epidemiological trends show a marked relation between drug addiction and the infection. The other means of transmission are present, but in lesser proportions. This is also seen in the Hispanic population throughout the Nation.

By June 30, 1990 the penal population was 9,177 inmates, with a 96 percent male representation. Most of them have a drug addiction history, and their crimes are related to it.

Each of the regional intake facilities provide enhanced health care services. These include medical screening, physical examination and laboratory tests, and at this moment, the process of individual information and orientation about AIDS and its prevention has begun.

The standard operating procedures have been established for the management of medical conditions including HIV infection and AIDS. The symptomatic patients are seen weekly by the medical staff of the institutions and monthly by the internist assigned to that region of the institution;

the asymptomatic patients are seen monthly by the medical staff in the institutions.

Inmates with AIDS, ARC, or advanced HIV infection who need other specialized services are referred to the public hospitals of the Department of Health. The ones who need extended care services are maintained in the skilled nursing facilities through the intake regional centers of our institutions. The mild symptomatic are localized in the medical dormitories which are housing units within the penal institutions.

HIV testing and counseling is available at all medical units on a voluntary basis for all those interested in knowing their HIV status. With each test, and individual pre and post counseling session is required and is provided by the same professional in our institutions.

Recently, the government through its Central Office for AIDS Affairs, OCAS, has established regional offices to provide services, and as part of the program center will be established soon within the State Penitentiary in Rio Piedras where AZT and inhaled pentamidine will be used.

Our program keeps close coordination with the services provided to AIDS patients in the general community

so that once the inmates are released, they may be referred to the same programs available at the community level.

Let me continue in Spanish, please.

[Interpreted from Spanish]: The emphasis of our program in the past year has been directed to the education and prevention areas of AIDS and the transmission of HIV. As you all know, our population in a great percentage is part of a high-risk group, especially for the use of intravenous drugs, and a large percentage of these are penal population.

This brings us together to the epidemic of AIDS that is affecting the entire Nation, but particularly affecting our penal system. Our work plan has as a priority the AIDS administration, and to that effect we work closely with the Central Office for AIDS Affairs directed by Dr. Rullan, and we are working hand-in-hand with the new treatment program that OCAS has obtained, and particularly strengthening our programs of education and prevention.

Thank you for permitting us to express our thoughts before you.

[Applause.]

VICE-CHAIRMAN ROGERS: Dr. Rivera?

DR. RIVERA: Distinguished National Commission on

AIDS, and audience, my presentation is divided into three parts. The first part, you have; it is an analysis. The first part is what we analyzed as the perspectives and issues related to HIV services for prisoners with HIV infection and AIDS. I will make a summary as best as I can within my time.

VICE-CHAIRMAN ROGERS: Thank you.

DR. RIVERA: The second part is Appendix A, which you have here, which is the direct voice of the prisoners of Puerto Rico--I think they are patients, the ones who signed this memo.

The last part includes press releases which are related to the topic that you chose for us. Prisoners at this time are the last part of today's work, but not the least, because they come from their families, and they return to their families, so we are speaking of the same population, anyway.

My introduction is an advocacy for human and constitutional rights in Puerto Rico. I know you may be amazed at some of my conclusions here, but the evidence is available if any of you wish to know more about it.

In Puerto Rico, prisoners with HIV infection and AIDS are a nonsegregated part of the penal population, which

is over 10,000 inmates in 32 institutions at an annual cost of $14,333 per capita and over. It is much more. Thus they must be considered in the context of the penal crisis in Puerto Rico.

Statistics on the extent of the number of patients are unavailable and/or contradictory. Figures range from 80 to 85 percent drug addiction-related prisoners, that is, 8,000 to 8,500, to 60 to 80 percent as HIV-infected and AIDS patients in its various phases.

Advocacy for these patients suffer the same hazards and dangers as for any other person. Advocacy for human and civil rights in Puerto Rico is a most difficult, controversial and dangerous citizen activity which may end you, as it did with us, and with over 130,000 Puerto Ricans, in a police and Justice Department Special Investigations Bureau, the NIE, on a list of "subversive and separatists" whereby you, your relatives, friends, are persecuted, abused, banned from jobs, imprisoned, assassinated. The Federal Government was and is involved in these violations with the State authorities.

During this decade, advocacy for prisoners and their families' rights encounters at least three huge difficulties; first, the correctional system's retaliation

practices against the latter and the advocates; second, the Corrections Administration sub-human prison life conditions described by the Federal judge as "inhuman, cruel, horrifying" in 1979, and 11 years later, the same judge said that he is reaffirming what he found in 1979. The third serious difficulty is the Commonwealth public policy since 1985, which has been limiting the system to construction of super-giant, super-prisons, super-warehouses for human beings, lacking treatment, rehabilitation, and overall adequate services in 15 new prisons, which amount now to 32, at a cost of over $200 million.

Retaliation practices are included here, and you may read them, but I would point out the discrimination, abusive corporal, moral and psychological punishment, solitary, indefinite confinement, arbitrary mass interinstitutional transfers in Puerto Rico and to Federal prisons abroad, last moment cancellation of relatives' visits, women visitors stripped from their clothes, and most of all, lack of recognition of the right to dignity, self-respect, and intimacy. There are gang fights among them, and the transfers very seldom take that into consideration, or do not.

We acknowledge the effort that is being made, but

we are going to bring to you the other side of the picture, the hidden truth, as I call it.

You have here the purposes and sources of information, but in all the information what points out as the most difficult thing is the secrecy involved in the information that is given to citizens like us, who are really concerned and working voluntarily on all the problems that the State also faces. But most of all, besides the secrecy is the controversy that we find that must be reviewed between confidentiality and intimacy and the right to know--the families, the patients, and citizens who, after all, are the ones who pay for these services.

The crucial correctional patients and relatives crossroads that I have analyzed here for you has at least five or six very important areas for you to consider.

Since 1988, we have been petitioning the Governor of Puerto Rico and the legislature and its agencies to declare AIDS in prisons a national emergency, and that patients at least in the terminal phase of the disease should be returned to their relatives who can take care of them and are willing, or to any other alternative shelter or "crea", whatever facility is available.

There are laws which permit the administrator to put this into practice. The secrecy which I was referring to before can be singled out here. We have been asking the administrator to please let us know the results of these laws so that one can move ahead in terms of the relatives, but as of today, we have not received any information.

Now, the other important figures are the following. And here, although one is very careful, and one is trying to be as--I won't use the word "scientific"--but as adequate as possible, these are the figures on the penal situation with relatives.

VICE-CHAIRMAN ROGERS: Dr. Rivera, I want to warn you that your time has expired, but please finish up for us.

DR. RIVERA: Well, I would petition respectfully that since I have been here, I have heard people take much more time, 15, 20 minutes.

VICE-CHAIRMAN ROGERS: Absolutely.

DR. RIVERA: I would petition you to at least let me finish the most important parts of the summary. I will try to reduce the time as much as I can, but the prisoners' dilemma is maybe the most important one the island is facing at this moment, because it is not only the AIDS patients in

prison--

CHAIRMAN OSBORN: We are eager to hear your conclusions. As you can hear, we have pressures on us, too, so why don't you finish as quickly as you can?

DR. RIVERA: Of course. But such a big and important issue cannot be--especially in English. If it were in Spanish, maybe so.

Anyway, the figures for the penal and relative population are really worrisome. Annually, through the prisons of Puerto Rico, 40-45,000 prisoners--as made public by Corrections--go through 32 facilities. This represents annually about one-quarter million or 250,000 relatives. If you take into consideration the ones in the daily population, the annual population, those on parole, those who may have been a short time in prison, but they have been there anyway, all other Puerto Ricans or individuals who may have gone through the penal system, that means that one out of every 12 Puerto Ricans are related to the penal situation. That is really an emergency.

Now, how much information do they have? Who is educating them? Maybe the minimum experience, they are going through with correctional help. But even those these figures

may be reduced, definitely the highest population risk lies in the penal population and their immediate families because in Puerto Rico, crime is increasing, drug addiction is increasing; all related dangers are part of this situation.

I cannot go without telling you part of the hidden truth. This is: Last October 23rd, a young AIDS patient calling for his parents in desperation being scolded by a sociopenal worker because his chains were loose, died in a medical center, chained to his bed--although he had never been a violent nor an escapee risk. His parents were never notified of the situation. For days he had been pouring water on his face from the toilet bowl in his cell to lower his fever. At times, a kind guard had brought him a can of water. The administrator and other staff had denied his condition to his immediate relatives even when he was dying. He had been working in the prison's kitchen, cooking and serving meals to inmates, washing dishes. His parents, in despair, left Puerto Rico.

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Another inmate died chained to his medical center bed for four months, the Corrections Administration policies insensible to his human and constitutional right to die with dignity.

Like in a warehouse, you can see terminal AIDS patients lying in the most miserable beds in some institutions, in halls, masks or not over their faces, all eyes, almost and/or speechless, dying corpses.

Visiting hours for relatives relate in a similar ways. For a few days, the patient is brought down, walking on his own; then, held by somebody else, until they disappear.

Massive, arbitrary transfers cannot be left out because the records do not move along with the prisoners when they are moved from one institution to another. Relatives keep coming to us for help in having their patient returned to their home, and there is always the lack of adequate information.

Mental health is part of this gruesome picture, and the chaos in the Health Department in Puerto Rico, especially this last year, as evidenced in all public information, makes it more difficult for these patients and for the prisoners and even the staff.

Conclusions and five recommendations. It is with deep grief that this analysis of perspectives is brought to your attention. I do not come for help. I am a social worker, but stopped using the word "help" a long time ago. I

come from each one of us to assume responsibility for what we must do.

The crisis of the penal institutions in Puerto Rico worsens as the public policy concentrates on the construction of these huge prisons-warehouses.

Although you may visit some and be impressed by the new facilities, you must look underneath, because underneath it all lies the absence of even a minimum balance of security, protection, treatment, rehabilitation, post-institutional supervision, as ordered by the laws of Puerto Rico, and the violation of the Constitution of Puerto Rico, which you will find on page 7, and of the Human Rights International Charter.

The prisoners--

VICE-CHAIRMAN ROGERS: Dr. Rivera, I will have to ask you to close. We will, of course, read your testimony.

DR. RIVERA: Just one minute, one minute.d

VICE-CHAIRMAN ROGERS: One minute.

DR. RIVERA: The prisoners are complying with the laws. They are in prison. Now, when is Corrections going to begin to comply with theirs?

The five recommendations: Study the "decriminalization" of drug patients, and make it a medical problem, which

in Puerto Rico should result in reducing the large number of drug addicts, at the same time with detoxification.

Increase substantially the funds for the DESCA program, with detoxification and psychosocial services increased in the penal institutions, which in the long run will reduce the risk numbers in those facilities.

Supervise the Federal funds and whatever funds are available because the largest figures stay up in the highest administrative structure, and only 10-15 cents or less may come to the direct services to the patient.

Liberalize the interpretation of "confidentiality" versus "intimacy" and the rights of the patient, of the family, and of the citizens to know.

Develop the professional participation of community volunteers as ours. Because we criticize, we are excluded from many very important things, and that is why we thank you at this time.

We have faith that all efforts shall be for the better, and I agree with this saying, to end. Jose Arsenio Torres, a professor at the University of Puerto Rico, wrote the other day: "The crisis which people live"--referring to the Government of Puerto Rico--"is of government and vision;

it is of a definition of public policies relevant to its problems, and of will power, commitment and dedication to carry them out."

And Mathilde Krims and other specialists on AIDS said: "murderers, murderers in large letters with capitals, with an exclamation point around those who hide information for the saving of patients with AIDS on time."

VICE-CHAIRMAN ROGERS: Dr. Rivera, your passion becomes you.

I am afraid we won't have time for questions, but I am going to ask individual commissioners as we break if you will stay; I think some of them will want to query you further.

We are grateful to you all for your eloquent testimony. Thank you very much.

DR. RIVERA: Thank you, and let me tell you--truth is passionate.

[Applause.]

[Whereupon, at 1:20 p.m., the proceedings were adjourned, to reconvene at 8:30 a.m. on Wednesday, November 18, 1990.]