NATIONAL COMMISSION ON

ACQUIRED IMMUNE DEFICIENCY SYNDROME

Wednesday, November 28, 1990

8:30 a.m.

Gold Room

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P R O C E E D I N G S

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CHAIRMAN OSBORN: Good morning. We are running a bit late and have another busy morning scheduled, so I think we should get underway.

I am particularly delighted to welcome our first witness, Eunice Diaz, for whom there is no introduction needed either to the Commission or I think to the audience. She is a very important person in having put together our entire visit, for which we are quite grateful.

Eunice, I'll turn the floor over to you.

COMMISSIONER DIAZ: Good morning.

Thank you, June. I would like to mention something that I always mention when I come to Puerto Rico and stay on this part of the island, and that is that I think today probably I have two uniquenesses, and that is that of the fellow Commissioners I come the farthest distance away, from Los Angeles, California, and I don't think that any Commissioner can look out of the hotel window and see the exact place of their birth, in San Juan.

Having said that, it is always a pleasure to return here, particularly on this very important occasion where we are accompanied by such distinguished individuals as my

friend, Surgeon General Antonia Novello, Dr. Mason and others.

I would like to take this opportunity to share one main thought with you today and a few brief recommendations--and I definitely plan, Dave Rogers, to stay within the time so you don't have to say, "Ms. Diaz, would you look at us and tell us what you have to say really fast."

As a matter of background let me remind you that I, like Dr. Kenneth Castro said to you yesterday, am a Puerto Rican living on the island during the first ten years of the HIV epidemic, so I come before you today with an intense feeling of emotion, passion, pain and devotion to an issue which has been discussed yesterday and which many of you have been reading about and preparing for this hearing.

Little did I realize ten years ago when I first got involved in AIDS, long before it was even called an HIV epidemic, that Hispanics would be so disproportionately impacted by HIV and that among the Hispanic subgroups, Puerto Ricans would become the group most severely impacted.

Approximately three years ago I began to work extensively and intensively with others across the Nation to identify and bring together interested and involved Latino professionals and particularly Puerto Rican professionals who

had knowledge and expertise that could be brought together to discuss issues related to the rapid progression of HIV among Hispanics and Puerto Ricans and to look at alternative responses to this epidemic.

Toward this end we organized a First National Conference on Latinos and AIDS in Los Angeles in early 1987, with over 100 health professionals participating both from the mainland and Puerto Rico, discussing areas such as prevention and education, service, organization and delivery of care, legal advocacy issues, and the need to communicate to our population via the most expeditious manner and the most effective strategy.

Participants worked in multidisciplinary teams for two days and developed specific agendas that could be responded to at local, regional and Federal levels. Perhaps the greatest value of that meeting in Los Angeles three years ago, which a number of people in this audience attended--I can think of Dave Petty [phonetic] from the University of Puerto Rico and also Mr. Donald Babb, president of Fundacion SIDA--that perhaps the greatest value of that meeting was the cross-fertilization and sharing of ideas, programs, model interventions, and evaluation strategies among us as profes-

sionals, different representatives from agencies, and peers.

At that time I convened a small group of people, primarily Puerto Rican professionals, both from the island and the mainland to discuss the need to engage in a more intensive discussion on issues related to HIV in Puerto Rico and among Puerto Ricans living on the mainland. With help and support of individuals such as Dr. Mason, Dr. Jim Allen and Dr. Samuel Metheny, we were able to sponsor and hold a think tank for more intensive discussion of those issues in August of 1989.

Our chairman, June Osborn, was able to be with us for part of that meeting, and we had the following objectives: to better understand the factors contributing to the rapid progression of HIV among Puerto Rican populations both on the island and the mainland; to provide a forum for the sharing of knowledge, expertise and experience in dealing with this epidemic; to develop ongoing networks, communications and collaborations among the participations, and lastly, to explore the need for further collaboration in the development of a comprehensive and coordinated system of AIDS care.

I will not summarize all of the points of that forum because I think for the Commissioners those were

presented in our briefing packets and I hope for the audience, if you don't have it, "AIDS in Puerto Rico", a report of that first think tank, which is very, very well done, and was done with the help of the National Council of La Raza, and it summarizes what came forth from discussion on that occasion.

This past August, just a few months ago, found us here, celebrating Think Tank No. 2 in Puerto Rico, focusing in more detail on care and treatment issues and the organization and delivery of AIDS care both on the island and affecting Puerto Rican populations on the mainland. Over 130 professionals attended and developed a set core of recommendations as a result of this experience. From this, we then had the driving force to continue further collaboration and communication amongst us as professionals.

But in fact these three experiences--the Latino meeting in Los Angeles and the two think tanks--provided for us a discussion point for looking forward to what has to be developed on behalf of our people.

I will say that HRSA has been extremely cooperative and valuable to us in being able to look to some of these issues that relate to care and treatment and provided perhaps the most staff support as far as any of the Federal agencies,

together with NAPO, the office that Jim Allen heads.

We wanted to look not only at the impact of this epidemic on the island, but very clearly define the inter-relationship with this on Puerto Rican populations living on the mainland and those who travel back and forth--what we have been calling the "air bridge"--whether these people live in New York, New Jersey, Connecticut, Florida, or Illinois.

I respectfully submit that as a result of all those experiences I have one major observation and a series of recommendations to make to this august body. My observation and statement in being able to in some way pool together the experiences of all of those forums, and what I have heard from many of the distinguished people who have testified before you and who are in the audience, is the following.

The tremendous challenge of AIDS in Puerto Rico can never be successfully dealt with without the corresponding attention given to how this epidemic is affecting Puerto Rican populations on the mainland. It is not possible to fully address the AIDS epidemic among Puerto Ricans unless the implications of the "air bridge" and circular migration patterns and the effect that these have on each other and the ease with which people travel are fully and clearly under-

stood.

We have to realize that in fact Puerto Rico is unique in this historical pattern of population migrations between the island and the United States. By 1970, 1.5 million Puerto Rican-born residents and their descendants were living on the U.S. mainland, then about one-third of the total number of Puerto Ricans.

Also, another thing that has not been discussed fully in this hearing so far and I hope may come out today is the "coming home" phenomenon, and that may be more pronounced and greater here in Puerto Rico than anywhere else in the United States. This may be due to many sociological factors and individual and family and cultural characteristics.

The following will represent in a nutshell what I offer to you, my fellow Commissioners, from my perspective and my work of working within these issues for the last ten years.

I recommend strongly that this Commission urge that Congress direct a study to include a comprehensive view of the organization and delivery of health care in Puerto Rico in light of what we have heard, with the unique and current situation and the impact of the HIV epidemic, as well as

looking into the health status of major Puerto Rican populations who migrate back and forth between the island and the mainland.

The uniqueness of the political status of Puerto Rico, the patterns of migration of our people and the rapid spread in modes of transmission of HIV and the ability and limitations of Federal, State and local health care systems to respond to this serious problem demand that this special attention be given at this time.

I would say that is the one cardinal recommendation I have for this body, and I hope that we will consider it seriously. There is a precedent for such. In 1982, Senator Daniel Inouye from Hawaii suggested that the same type of study be done for the Hawaiian Islands and later presented a total report to the Congress, which was then dealt with in pieces in looking at how those islands may be helped in terms of the AIDS crisis in the health care system.

I would say that based on that precedent we can at this time consider asking that some specific attention be given to the health care system, with particular emphasis on how this epidemic will impact our total health care delivery.

My further recommendations are that there needs to

be developed a clear statement by the Government of Puerto Rico of what exactly is required or desired in terms of Federal technical assistance. We heard a lot of differing opinions yesterday, and that is healthy, but I submit to you that this may mean a different kind of assistance, packaged in a different way, different individuals assisting, and perhaps it might be that we need more in vivo assistance, or even some form of looking at ways in which telephone communications between several agencies and the island of Puerto Rico and the health care delivery system here can be on a regular basis communicating with each other.

The third recommendation is that we need to continue toward a broadening agenda of inclusion and involvement and collaboration, a true partnership with churches, private sector, pharmaceutical companies, voluntary organizations, and most of all, the community-based effort. It is urgent that the community-based organizations and response be an integral part and an important voice through planning and implementing any system of AIDS delivery care on this island.

My next recommendation deals with developing supportive efforts from this Commission that will enhance the continued dialogue between island and mainland professionals,

peers, organizations and agencies.

The fifth recommendation is that I feel there needs to be a prioritization of the development of a pilot system of case management linking the island and the mainland and certain Northeast cities to emphasize the continuity of care and appropriate patient and family and significant other follow-up and referral.

Lastly--and I give this perhaps the utmost priority--I think that at this time we need to devote on this island and with the help of friends on the mainland the highest priority to developing the infrastructure that will be needed immediately to have Puerto Rico become competitively eligible for as much of the Ryan White moneys as can be available to this island.

It is my sincere recommendation to the various entities involved on this island, and a plea to you, that a clear demonstration to ourselves and others of new, creative and truly collaborative efforts that perhaps have never been tried before need to proceed in good faith at this critical time and that that can be far more productive and of most benefit to those for whom the legislation is designed if we can perhaps bring this to a table, negotiate in good faith,

and develop it for the benefit of the people of Puerto Rico.

I am proud to be a partner with you in these efforts, and with my help and interest in what is going on here in Puerto Rico and among Puerto Rican populations in the mainland, I share with you the feeling that I know we can do it on this island. We have faced adversity, and we have faced problems with dignity, respect and tremendous valor. We are a people of pride. We need this Commission's help. We need the help of Congress. We absolutely plead with you at this time that every effort be made to bring a sense of unity and devotion to the task at hand.

Let us keep in mind that we are fighting a major enemy, and that is the virus, not each other. I thank each one of you and hope that perhaps through these hearings we have served some purpose in voicing some of the things that perhaps we believe in so strongly and that I think this Commission in coming here has been able to bring together in a forum of helping us to look at a way of inspired efforts, continued support, and continuing involvement in this epidemic.

Thank you.

[Applause.]

CHAIRMAN OSBORN: Thank you very much, Eunice.

Does anyone have questions for Eunice? Dave?

VICE-CHAIRMAN ROGERS: Ms. Diaz, yesterday I said to a fine woman in front of us that I appreciated her passion. I wish there were more people of passion, and you have just stated eloquently some of the problems, and it has been a privilege to hear you.

Thank you.

COMMISSIONER DIAZ: Thank you very much.

CHAIRMAN OSBORN: Our next panel will deal with the topic of human and social services. We invite you to the table.

Thank you for joining us this morning, and I'll ask you to proceed in the order that you have agreed to go, and introduce yourselves as you go. Thank you..

DR. ALTIERI: Good morning. I am Dr. Altieri, from the Department of Social Services of Puerto Rico was created by Act 161 of June 30th, 1968. Its objective is the strengthening, development and protection of the Puerto Rican family so it might reach its maximum integration and participation in all social and economic processes.

The Department of Social Services performs its

responsibilities through the following programs: Family Services, which includes services to families with children; Public Assistance, which includes nutrition and economic assistance; Vocational Rehabilitation; Child Support Enforcement; Disability Determination; Economic and Social Rehabilitation for Families in Extreme Poverty, and Residential Facilities for Children.

The agency has a nondiscriminatory policy and provides services to all children, adults and elderly citizens and families that because of economic, social, physical or mental reasons need assistance to be able to participate fully in the economic and social progress of our island.

Over 1,600,000 Puerto Ricans were served by the Department during last fiscal year.

In the fight against AIDS, the Department of Social Services serves as a support agency to those agencies like the Department of Health whose primary responsibility is to provide direct medical treatment to patients with AIDS. All services offered by the Department of Social Services are available to persons with HIV or AIDS.

Services to children. For those children with AIDS

whose parents are not capable of caring for them, the agency provides foster care. This is considered the best alternative since it allows a child to satisfy his emotional and effective needs in a warm home environment. Twenty children last year received specialized care in foster homes. For the foster parents of these children, the services of a homemaker several days a week are available to ease up the burden that the care of these children can cause.

Eleven children could not be placed in foster homes so the Department contracted the services of Proyecto Amore, a private sector for the care of children with AIDS. This shelter is the closest there is to foster home care. Over $117,000 was expended during the past fiscal year for the purchase of these services.

In addition, all day care centers administered by the Department of Social Services are open to children with HIV or AIDS.

Services to adults and families. Foster care services are also available for adult patients. Last year, only one adult with AIDS was placed in a foster home. Recently, the Department entered into an agreement with the AIDS Central Office of the Puerto Rico Department of Health

to provide home care services to terminal patients receiving medical treatment at home. These patients have no family, or their family is incapable of providing for them. The homemakers will provide various services including preparation of meals, maintaining the area clean, shopping for groceries, among other things.

This project will begin with 100 homemakers throughout the Department of Social Services' ten regions.

In addition, patients with AIDS can benefit from the Department's public assistance program, which includes economic and nutritional assistance. They can also benefit from the emergency assistance fund to cover such things as medicines and laboratory test expenses.

The services of the vocational rehabilitation program are also available to persons with HIV or AIDS. This program can provide specialized medical and rehabilitative treatment, but most of all it can make the patient feel productive when placed in school or a job or a business of his or her own. This not only helps with the emotional aspect, but also economically, since the patient will be able to support himself as long as he or she feels strong enough to continue with their activities.

To help the homeless with AIDS, the Department of Social Services participates in an interagency committee that provides funding and technical assistance to Hogar Crea las Americas, a shelter for homeless people with AIDS. Also the Department provides support services to this shelter, including social work intervention, clothing, articles of personal hygiene and recreational activities, among others.

The Department of Social Services will continue with its nondiscrimination policy so that all its support services can reach all those in need. We are strongly committed to the fight against AIDS and will remain so.

Thank you.

CHAIRMAN OSBORN: Thank you very much. I think we'll hold questions until we have heard a chance to hear from everybody on the panel, and that will give us a chance to interact. We appreciate your testimony.

DR. NUNEZ-LOPEZ: Good morning, Commissioners, Commission President, honorable Antonia Novello, fellow health workers here today, persons with AIDS and HIV, and all other persons interested in this public health problem, this serious public health problem.

I have given a copy of my formal presentation

written in English to the Commissioners, so I will ask for the opportunity to do my ten minutes of talking in Spanish. I think it would be more effective and efficient if I do that, and I appreciate the opportunity to speak in Spanish.

[Interpreted from Spanish]: Good morning. I am Jose Antonio Nunez-Lopez, Assistant Secretary for Mental Health in Puerto Rico.

I want to summarize my presentation of ten minutes. It can be summarized in ten minutes by talking about our responsibility for mental health in Puerto Rico, our limitations to fill this public need. I think we need to comply with new needs. And I do not know much about AIDS, but with your visit here, I have realized that this problem is very serious, and as public servants we need compassion and involvement. We must first learn the seriousness of the problem.

I appreciate your inviting me here today because I have been able to recognize the seriousness of the problem. What have we done up to now to seek help to face this new challenge of making the services available to people with AIDS in Puerto Rico--mental health services? The Assistant Secretary for Mental Health has responsibility to offer

services to any patient that requires these services, but mainly indigent people.

We have 55,000 patients. This is 15 percent of 600,000 people who need services. These services are offered through three State hospitals with 600 beds. We have 12 Community Mental Health Centers throughout Puerto Rico, and we have 1,000 rehabilitation spaces in the community. We have 3,400 employees. We have a budget of $74 million, which is $3 million less than what we need to continue the same services.

As Mental Health Assistant Secretary, I devoted about 60 percent of my time in the last five months to the two Federal cases that we have. One of them is the Navarro case and another case is the Feliciano case, which requires helping 10,000 prisoners in the correctional system of Puerto Rico. Out of these convicts, we have made evaluations for mental needs and services, and 60 of these 10,000 inmates need services.

I have been in service in the Assistant Secretary's office for five months, and I found that the Secretariat has had five administrators in the last five years. At present, we have been five months without being able to recruit an

administrator. For three years, there was no personnel chief. We don't have a person for the planning work, we don't have an epidemiologist, we do not have a system for management information, and in the last three months we have tried to solve these main problems.

What is the system that we have available for services? Well, in the Mental Health Centers throughout the island, there is difficulty to give services because of scarce resources. They don't have psychiatrists in some places. Today I had to cancel a visit to Caguas where I was going to interview a psychiatrist who was going to offer services in that area. In some places, we don't have psychologists or social workers, and in many cases, it is two to three months waiting.

We must implement Public Law 99-660. We are the poorest State, and last year because we didn't have the technical assistance, the plan was not approved, and we were penalized with a $14,000 fine.

Furthermore, we have had to pay a $70,000 fine in the case of Navarro Ayala in the psychiatric hospital, and we are expecting some fines in the case of Morales Feliciano.

What are we offering to the HIV-positive or AIDS

patients? At present the only thing we can offer to any new patient who has a mental dysfunction is they would have to go into the Community Mental Health Center system with the limitations that we have--we do not have help in the psychiatric hospitals to treat people with AIDS.

What do we need in order to assume this responsibility, which is not only serious, but is a great burden. Dr. Rullan told me that in Puerto Rico in three more years there will be 30,000 people with AIDS, which is a tremendously high proportion. These people will be suffering mental problems, and just to think about this figure is awesome.

What can we do to assume new responsibilities? We need to at least identify and define the problem, what is the need for mental health services for these people with AIDS and who are HIV-positive. We know they must be very high because we are dealing not only with a terminal condition, but with people who are being rejected by the community, sometimes by the system itself, and sometimes they are even self-rejecting.

I do not know anyone personally, but I know that we must have the resources. We must establish a system of information to give follow-up to this problem once it has

been designed, to manage it according to resources, in coordination with the Central AIDS Office.

We also need a professional who is interested in this, who lives this and who feels the problem because it is essential to develop this program. This professional must have leadership in the field of psychiatry or psychology and must be responsible for preparing, coordinating and following up the training of our resources so that these patients are provided services in a human and efficient manner. This person must generate questions that must be answered by the information system that we establish in order to evaluate our work and to plan for the needs that could be predicted through the information system.

We also need staff to establish quality measures of services, to develop protocols for management of patients and for specific situations, to monitor difficulties in coordination of services with the AIDS Central Office, and to prevent problems in the collaborative work.

We will need staff for the evaluation of the system that we are able to establish and to use more efficiently the limited resources that we have and also to develop proposals, which I know if we involve ourselves, there will be ideas

that will help us to clarify the problem and will perhaps help us establish a model for better services.

What have we done up to now to face this challenge?

In August we talked to the AIDS Central Office and we asked to be assigned some resources. We were told that in October perhaps they would have an idea of the funds available.

I met two weeks ago with Dr. Rullan and the staff of the Psychiatric Hospital in Rio Piedras, which is under Federal management, to ask for help in the management of AIDS patients in the Psychiatric Hospital. It was very productive. We reached some conclusions, and we are working on this agreement.

At that meeting we were told that the person in charge of the program could speak with the people in the Central Office to see if we could obtain these minimum resources, and we are trying to prepare a proposal. We have not been able to establish a contact.

I believe that this summarizes the position of the Assistant Secretary's Office for Mental Health. In Puerto Rico, we have a history of many years that the Government provides direct services to the people, and for these

patients, who are not only indigent--because according to how expensive the cost of treatment is, it could go beyond 80 percent--they may need the development of a system to answer their needs, and we feel that we need help to do that.

Thank you very much.

[Applause.]

CHAIRMAN OSBORN: Thank you very much.

DR. FERNANDEZ-DUMONT: Thank you very much, members of the National Commission on AIDS, distinguished guests, ladies and gentlemen.

My name is Joaquin Fernandez Dumont. Under Dr. Johnny V. Rullan and the AIDS Central Office for the Commonwealth of Puerto Rico, I am the Coordinator for Inter-Agency and Community-Based Organizations Affairs.

Although prevention and control of HIV infection and AIDS are paramount objectives of our organization, it is my primary function as a member of the AIDS Central Office team to address the roles of the private sector and local government agencies in the prevention of AIDS, and treatment and hospice administration for HIV-positive and AIDS patients.

This is an area where in the past, let say up to some point in 1989, it appears that we had made limited

progress island-wide.

Before moving ahead, however, I believe it is important to mention that it is probably desirable that we do not assess CBOs in Puerto Rico utilizing criteria normally used in the U.S. mainland. All local CBOs serve a culturally homogenous population of Puerto Ricans who have, generally speaking, a common, principal characteristic of being part of a socioeconomically bypassed population. Within them, there are HIV high-risk groups that are found internationally. These CBOs, particularly throughout the island, outside the metro area, need various types of assistance including in the organizational process so that they may request and receive adequate assistance, including economic, both Federal and from the local government. Perhaps this is the fundamental reason for the position I occupy in OCAS.

From personal initial field contact with various CBOs throughout the island, CBOs of proven leadership in the area of social and health-related community services, it seems that there existed lack of demonstrated awareness of the nature and magnitude of the problem within pertinent local government agencies.

As the president of one CBO stated, "the HIV

situation was buried dead" in the day-to-day affairs of the government.

From these talks, some factors bearing on the problem arose. It appears no one wanted to accept that AIDS was a serious problem in the island. As a result, a lack of awareness existed in the Puerto Rican population.

Effective communication and leadership from government agencies, particularly those providing health and welfare services, were perceived to be nonexistent.

Effective networking among CBOs and particularly between CBOs and government agencies was marginal at best.

Some significant CBOs did not perceive the government as a partner or potential partner in dealing with the problem.

And generally speaking, CBOs need government assistance in the following and other areas: In the economic area, for technical personnel, medical equipment, medicines, transportation, burials, et cetera, in the operation and maintenance of a minimum of critically needed hospices, at least one per Health Department region; for training of community volunteers as HIV educators and members of the staff of the CBOs; for transportation; for the production of

and distribution of literature; for developing community networks of HIV social workers; for nutrition, and for home care services.

Finally, CBOs demand participation in the decision-making process. CBOs see effective participation by their organizations in the decisionmaking process as a critical strategy in the effective undertaking of the problem, particularly in partnership with local public services departments and other CBOs.

The question now in front of us is: What action have we taken and/or will we be taking to deal with the HIV situation, ensuring roles for the public sector.

The answer to the question is that the AIDS Central Office has taken some critical steps during the last several months to assure its proper leadership role in promoting and facilitating CBO roles in dealing with the problem as follows: 1) recently appointing an interagency and community-based organizations coordinator; 2) outlining and implementing an aggressive plan to promote complementary private sector participation and networking directly as a field-based operation. The plan was based on a needs assessment survey done among HIV-infected individuals during 1990. And 3)

establish an island-wide policy under the guidelines of the Ryan White Comprehensive AIDS Resources Emergency Act of 1990 to ensure ample participation for CBOs in the decisionmaking process.

The AIDS Central Office is in the process of recommending to the Governor of the Commonwealth of Puerto Rico the appointment of a CBO-based AIDS consortia that will have the authority to call for proposals for economic or other assistance from local CBOs, establish evaluation criteria, and evaluate and assign the State-allocated moneys to CBOs in an efficient and effective manner.

We have commenced to develop a CBO database which is badly needed. And finally, OCAS has recently established a regional network of HIV specialized clinics where the technical assistance suggested and required by CBOs, from education through HIV testing and counseling to hospitalization and case management are provided in a complementary or partnership manner, utilizing the medical psychosocial model.

Before concluding my presentation, I feel it is necessary to highlight the fact that we are aware of shortcomings in the past, but we look to the future and your deliberations in assisting us in reaching our goal in prevention of

HIV and control of AIDS.

This concludes my presentation. Thank you very much.

[Applause.]

CHAIRMAN OSBORN: Thank you very much.

DR. TORO: Good morning, Dr. Novello, Dr. Osborn, members of the National Commission on AIDS.

Initially, I want to welcome the Mental Health Department to the fight against AIDS; and to the Social Services Department, I was expecting to see the Secretary--obviously, she might be too busy.

I would like to make my presentation in Spanish, please.

[Interpreted from Spanish]: My name is Jose Toro. I am a clinical psychologist and Executive Director of the AIDS Foundation of Puerto Rico. I represent the personnel of the offices, a large group of volunteers who generously give their time to contribute to this effort, and more than 900 people with AIDS who at one time or another in the last three years have received services from our organization.

The AIDS Foundation is a community office initiated in 1983 to offer support and education to persons infected by

the HIV virus, their families, and significant others. Since that time, from a group of just volunteers, we have 12 employees, more than 80 volunteers, and 10 programs in progress.

T1S2 We have a support group for emotional problems, case management, direct services, a prevention program for the gay community, services to children with HIV, support groups, a home for homeless people, a program for research and experimental treatment, and a series of publications and pamphlets which are distributed throughout the community.

In the year 1989, the Foundation offered $38,000 for emergency aid. This year, in September of 1990, we have offered $33,400, a total of 487 active clients.

This aid is directed for medication, transportation, housing and medical equipment at home. We also provide loans for [inaudible] so that the people can receive the treatment, aerosolized pentamidine, at home, for those patients who can pay when they get raises or who are able to obtain this medication at a low cost. In direct help, we also provide things such as items that are donated by the community.

During the year 1989, the volunteers contributed a total of 11,217 hours of service which represented the

equivalent of $139,000, 35 percent of the total budget of the agency for that year. This data was provided in the Sixth International Conference on AIDS in the summer of this year.

The sources for funds for the Foundation come from the community. We have fund gatherings, and we have other financing contributors, the CDC, the [inaudible] Institute. In spite of a limited budget of $340,000 for this year, the Foundation has made a tremendous effort to offer as many services as possible.

There are many calls that we have for help and for information, for pamphlets, educational seminars, workshops; we are asked to form parts of different committees and to offer our views in different professional fora. We accept referrals from different government agencies of private professionals and family members and others who receive services.

However, notwithstanding how much we have received, we always have more to do. There is always something left to be done.

There is need for the community with AIDS to join efforts to surpass our needs with our limited resources. There are many areas that require attention in Puerto Rico,

and the way in which we approach these areas will determine the efficiency and the rapidity with which we can fight this epidemic. This will be the moment in which we will be able to develop new strategies directed toward eradicating the pain of an entire community that has lost and is losing its best resources--the young people.

In Puerto Rico, we have conducted studies of seroprevalence that will give us the level of dissemination of HIV in our community. We know that the number of reported cases are only the tip of the iceberg. We know that in the next few years, the development of HIV in Puerto Rico may be terrific and will create a total collapse of government and private services. The cost of primary services and hospitalization will make these services prohibitive for the majority of the population.

In the absence of a vaccine, and if it is not available to the entire population, we only have prevention as a tool. Efforts must be directed in this direction. Up until now, a majority of the efforts have been directed toward development of clinical tests, and we are opening the door for the population to have this testing.

In a local town, they called the Mayor of San Juan

so that they would study the constitutional implications of conducting nationwide testing. Apparently, testing is used as a prevention tool. New campaigns that offer alternatives, the use of condoms and the prevention campaign must be directed to young people, in massive campaigns where they don't cause fear and repression, but to invite the young people to develop skills to make their own decisions and select that prevention method that satisfies their needs.

We also need aggressive campaigns directed to specific populations where we know that the national conferences do not reach them. People in the community must serve as guides to develop these campaigns--people of the drug using community and the sexual community, and young people must participate and direct these campaigns for the particular populations.

In the area of services, the early detection of the disease makes no sense if we don't have access to treatment. Lack of access, limited to antiviral medication for opportunistic disease in Puerto Rico makes this most difficult. We do not have in the Health Department at this time a center for management of aerosolized pentamidine. The AZT distribution is very limited, and the interventions recommended, such

as the common interventions, become a major task. To place a single hidden demonstration of [inaudible] for prevention of blindness for the [inaudible] becomes a serious problem. The medical staff are reluctant to perform surgery on HIV-positive patients.

Recently, private laboratories in the city have refused to give blood tests to a patient who was HIV-positive.

The lack of knowledge by professionals in health services in Puerto Rico is not sufficient to modify their attitude toward infected patients.

We could spend hours here if we were to tell you the problems that these AIDS patients in Puerto Rico have to suffer in relation to services. Nothing would be new to you; I am sure that in prior situations or in other places, you probably have heard the same.

HIV has impacted all people--from prejudice and rejection to the most incredible situations, such as finding people dead in their apartments because of lack of resources for food, housing and medical services. It is appalling.

I am convinced that you have seen many cases like this in other places. The difference in Puerto Rico is that we have refused to acknowledge and have refused the help of

the community in this process. The government feels that it is their sole responsibility to offer services, and they refuse to receive the aid from the community in areas of services, prevention and treatment.

In the last three years, leaders of community agencies in Puerto Rico have met on many occasions with government agencies, without being able to obtain any results. However, the community requires and demands participation in the decisionmaking for the local and Federal funds in the prevention areas and treatment areas. Community-based organizations do not feel that we are in competition with the government agencies; we feel that we are a complement to the services the government offers. The only difference is the little sense of urgency that the Federal or government agencies show.

Probably in these two days you will hear testimony which is contradictory from AIDS patients and government and state representatives. We will testify as to the lack of adequate services, about the magnitude of the social and financial impact on HIV patients in Puerto Rico, on our women, our children, and our young people, drug users. The representatives of the government agencies will testify about

plans--

VICE-CHAIRMAN ROGERS: Dr. Toro, let me alert you that your time is coming to a close, so if you could just give us your main points in conclusion.

DR. TORO: --with these claims and promises, people are dying. Thousands of people are afflicted with AIDS in Puerto Rico, and this is not solved by political campaigns or magic solutions and promises.

Together with the community and government agencies, we will guarantee access for adequate prevention, detoxification programs for drug users, detoxification for women, housing, housekeepers, health care at home, access to experimental treatment, access to standard treatment such as AZT and aerosolized pentamidine, and the guarantee of civil rights to infected people. When we have all these, we will solve the problem.

Thank you very much.

[Applause.]

CHAIRMAN OSBORN: Thank you.

REVEREND GARCIA [Interpreted from Spanish]: Honorable members of the Commission and friends, my name is Francisco Garcia. I am a Catholic priest.

My profound appreciation for allowing me to share my experiences and difficulties, those that have been very sour and those that have been hopeful in the fight against AIDS.

I do not believe any sector of our society was prepared for the impact of AIDS--not the Department of Health, nor the churches, nor families, nor the community.

It is my conviction that each one of us according to our capacity and our creativity can make a difference in this situation that AIDS presents in our society.

If we do not have the cure, we do have the capacity to serve and to love. Love cures all--not only those who receive it, but those who give it.

In November 1984, I began to visit patients with AIDS in the Regional Hospital of Ponce and share with them their anxieties and preoccupations.

After three years, in March 1988, I took the initiative to respond to several desperate patients who were discharged with no place to go. I took them to the parish and prepared the parish hall to accommodate them and so began a hospice. In promises, we are richer than the Rockefellers, but the truth is another thing.

I organized volunteer groups to treat the patients and to nourish them on a daily basis. At Albergue La Providencia in Adjuntas, people visited us and gave us services and donated furniture. Radio and the press visited us, and television, and as soon as there was knowledge, calls from all over the island were received to include patients.

In 1989, I was confronted by my superiors that I had to select between the parish and the patients, and I opted for the patients and resigned as the parish priest. They gave me permission to dedicate myself full-time, and I transferred to Ponce.

Because of lack of education and knowledge of AIDS in some of the community sectors and, sadly, professionally, I have had to confront the rejection in use of ambulances to transport AIDS patients. Because of the many cases of this sad experience, I added a siren to my car, and I transport patients myself to the hospital or to their homes.

Equally, many funeral homes profit because of the pain of people without resources. A friend builds the coffins, and another takes the dead to the municipal cemetery where we have been given a small plot to bury the dead.

Also, with the Department of Prisons, I have been

able to get for the terminal patients that we may assist them in the hospice with the dignity they so deserve.

We visit patients in their homes daily, and we try to make easier their pain, not only to them, but also to their relatives; counseling the families, counseling the communities and schools; giving short speeches, educational lectures on prevention through education.

Churches, community entities and religious entities join efforts and give us support. We have had activities to gather funds--they give us pajamas, towels, sheets, nourishment, et cetera.

We thank the Department of Health, not only to the past Secretary Enrique Mendez but the Acting Secretary, Dr. Soler-Zapata, and the Health Director in this town, Dr. Giordano San Antonio [phonetic], and the Ponce Hospital Administrator, who in February of this year gave us the facilities of the former health unit in the Regional Hospital in Ponce for the hospice, La Providencia, that will serve the 15 towns that are part of the southern area. And according to the November statistics, more than 1,000 cases have been reported.

I appreciate the Social Services Department for the

economic assistance through HUD funds for the remodelling and repair of the physical plant that we have achieved.

At the present time, we trust the services of Dr. Rullan in the clinics, treatment, medication and professional assistance that will commence to give services in new facilities in the Regional Hospital in Ponce and of which the hospice will benefit.

At this time, we need economic assistance in order to pay for the nurses and the personnel to be available 24 hours a day in the hospice and, at the same time, for the cost of medication.

There is one historical reality with respect to AIDS in Puerto Rico, and that is that the more or less that we have toward our brethren has been through the initiative of people, individuals or groups of citizens or religious entities, and these have put pressure on the government that not only is a fighting struggle, but also for services. Thank God, the government seems to be aware of the reality, and the moment is here when we have to join efforts and good motives and desires.

The government without the contribution of the community cannot do it, and the community without the help of

the government cannot go anywhere.

In the desire to serve not only on the part of the government, but also on the part of groups and entities, there are tensions and struggles and differences. I do not think we should lose the vision and the perspective that there are some brothers and sisters who are suffering and who are waiting for our assistance.

I trust the honorable Commission will give us the support to give collective services to our patients and a good educational campaign. Talent, volunteers, creativity, hands--all of that, we have in Puerto Rico. I hope this Commission will channel the resources, the means, the economic resources, and that these will be distributed equitably according to services and programs not only of the government, but also of the groups that we have given of ourselves to help, with dignity and heart, our brothers and sisters with AIDS.

Sadly, in Puerto Rico everything is done within politics. Proof of this is the money that has been contributed for Hugo, the last hurricane, that still has not reached its destiny, and there are still families waiting for these funds.

Humbly, I suggest that we have an integral committee

of government representatives and community representatives for the equitable distribution and supervision of the use of the funds, in that way to avoid any controversy, political controversy, favoritism, so that the funds will go to the purposes for which they have been contributed.

I have witnessed the talent and the professionalism and the interest and the preoccupation and nobility and integrity which are characteristics of the people of Puerto Rico.

Again, my respect and appreciation to all of you. God bless you all.

[Applause.]

CHAIRMAN OSBORN: Thank you, Reverend Garcia. It is a privilege to know of your work. We appreciate it.

What we will do now is take some time for questions of the group that we have heard from so far, after which there will be a family joining us to present some testimony. In anticipation of that let me ask that no photographs be taken in or outside of the hearing room in that context.

And as a technical note, I want to remind people that there are translation services available if they desire them.

With that introductory comment, are there questions?

Larry Kessler, please.

COMMISSIONER KESSLER: This question is for Dr. Dumont.

Perhaps you can help me understand. You used a phrase that I have heard several times now in the last two days that I don't quite understand. You said that the criteria for the local community-based organizations should not be held up against the criteria of CBOs in the States, on the mainland. And it has been said that way, various variations on that theme. Could you explain what you mean by that?

MR. FERNANDEZ: Yes. There is not a definite line in this statement that I have made, but it appears when one talks with people who are doing most of their work in the States that when they talk about CBOs, you get the impression that they might be thinking of a definition that includes minority groups such as are defined in the States.

In Puerto Rico, we could speak of a minority group in terms of those definitions if we consider the entire island to be a minority group--in other words, we are a homogenous population, homogenous in terms of culture. We do

have a common denominator which is that most of the people who are having the worst part of this problem are people who are socioeconomically bypassed, and with all the things that are involved in that definition.

COMMISSIONER KESSLER: I thank you for that clarification, and I would like to issue an invitation to you particularly because of your role, working with CBOs--and the Commission office I am sure will be able to help you--if you can find the money and the time, I would love to see you come to the States to look at several models there that I think you will find invaluable in terms of the partnership that can exist and that does exist between CBOs, the Health Departments, the States, the cities, and the business and corporate community, and that when that partnership is developed and enhanced by adequate funds and so on, and all the human resources that volunteers provide, et cetera, you can build an incredible network of services. Should you desire that help, technical assistance, whatever, the Commission can help, and individuals here on the panel will be happy to help you.

I would love to see a stronger level of participation--not just the CBOs seeing the government as a partner,

but the government seeing the CBOs as a partner as well--because then I think you will overcome some of the problems we have been hearing about, or at least make progress--I am not sure you will overcome them, but you will make some substantial progress that will benefit people with AIDS tremendously.

MR. FERNANDEZ: Definitely. I think there is a management problem to this thing. In other words, we have a problem but there is a way that we must design to approach and resolve the problem, and I think that networking and CBO involvement, government involvement, leadership is the answer. I'd like to accept your invitation.

COMMISSIONER KESSLER: Thank you.

CHAIRMAN OSBORN: Eunice?

COMMISSIONER DIAZ: I have a question for Father Francisco and another for Joe Toro.

Father, do you think that it is important that the kind of involvement you have within the church in some way be translated to other religious denominations and affiliations, and what might be some of the barriers to doing that, just very quickly?

REVEREND FRANCISCO [Interpreted from Spanish]: My

personal experience has been that not only the Catholic church but the protestant church, Baptist, Methodist, Evangelical, all of us are joining efforts. In El Juntas [phonetic], I had the beautiful experience that pastors and reverends from other denominations came and joined efforts.

My greatest concern is that I feel we have the talent and the desire to help, at least when I have gone to private and public schools for these conferences, the next day they are visiting us at the home, and we are receiving articles. But we are limited in the clinical aspects. People cooperate with money, but medications are very expensive, and this is where we need the financial help to be able to pay for the medications.

In a concrete case, in our home we need nurses 24 hours a day. But I think that all churches are answering, although we can give more.

COMMISSIONER DIAZ: Thank you.

Joe, just a very quick question. I am sure you were involved in the previous three years of the HRSA demonstration project here in Puerto Rico. I had the privilege of being a consultant for a brief time in the design of the noble objectives of such a program. A lot of

that rested on the collaborative participation of government and community-based response in looking at service needs and responding to those needs.

Do you think your organization has learned some very key things that you would like to translate? What can you think of that now has to be put into the mechanism from the CBO response into the planning process and readiness of this island for the Ryan White legislation? What would you say are some of the key things that stand out?

DR. TORO: Within the demonstration projects in Puerto Rico, for example, the dynamics of participation included the presence of case management that were located in different agencies, both government as well as private, which facilitated the recognition process and the development of services, especially in the surpassing of obstacles. I think that the presence of these key staff in the different agencies showed that it was possible to have interagency cooperation, and also the fact that we had group communication and that we were able to surpass the obstacles.

I think in the process of identification and thinking, as in the case of Ryan White, it is important to develop a group--which is part of what many people have

asked--that includes the participation of different community organizations as well as the health departments, both local and State, but with the power to make decisions, with the power of having influence that is translated into public service and public policies.

COMMISSIONER DIAZ: Thank you.

VICE-CHAIRMAN ROGERS: I want to express appreciation to all of the speakers for their excellent remarks. I would like to direct my question to Dr. Altieri, and I apologize if I did not pronounce your name correctly.

About foster care and border babies--in many of our mainland communities, particularly those that are heavily impacted with AIDS and babies born to mothers with AIDS, we have problems with border babies, placing them in the homes. If I understood your presentation correctly, you have a relatively small number of children that need such placement, and you are able to find placement without much difficulty--or did I misunderstand your remarks?

DR. ALTIERI: We placed 20 children, with some difficulties. I can't say that we don't have any difficulties, especially with funding, because we have to pay more for these children in foster care, children of AIDS, than we

do pay for other, for example, abused children. We do have difficulties, and we keep trying.

We had a campaign last year on radio, TV, and newspapers also, asking people to open their homes--literally translated, open their homes--for foster children. It was a very good campaign, but we couldn't keep it for long because we didn't have enough money for it.

We keep trying. We are starting a new campaign soon. We take care of all the children who are referred to us whose parents either died of AIDS, or they cannot take care of them. But those are the ones who have been referred to us.

We do understand that the number is going to grow, and that is one of our biggest worries. They are going to keep coming to the Department, and our resources are less and less every year. So that is something we will have to work out.

CHAIRMAN OSBORN: Harlon?

COMMISSIONER DALTON: My question is also for Dr. Altieri. You mentioned that recently you have entered into a contract to provide home care services to terminally ill patients. My question is whether you have plans to extend

home care to other persons living with AIDS, and also how do you define persons who are terminal under the current program?

DR. ALTIERI: Okay. This agreement is in the first stages. We just sat down and agreed as to what the Department and the Office for AIDS are going to provide. We are going to start as soon as we can.

We didn't define terminal; they did. They are those patients who have all the symptoms but who can be taken care of in their homes; they are bedridden. They are going to receive the services of nurses, but they can be at home. In case they really need the hospital, they can go back, but really, the purpose of this is that those who can be taken care of at home do so because then the hospitals will have more beds for those who need special care in the hospital.

I don't know if I answered your whole question.

COMMISSIONER DALTON: Briefly, are there any plans for extending home care service to persons who are not terminal but who can benefit from having care in the home?

DR. ALTIERI: Yes. That depends on how much funding we get. The home care services in the Department of Social Services is right now in a very serious crisis. Because of shortages in funding, we have to start cutting

services of home care. But in this agreement with the Central Office for AIDS, we plan to extend the service if we have enough funding for it because the Department doesn't have the money for it.

CHAIRMAN OSBORN: Dr. Novello?

SURGEON GENERAL NOVELLO [Interpreted from Spanish]: I am glad that we have spoken about foster care. I am very concerned about foster care. I am concerned because, as you stated, in the year 2000 we are going to have 10 million orphans throughout the world, and in Puerto Rico we said yesterday that we are going to have 125 children with AIDS. The prevention campaign that we have lets people know that AIDS in children is not contagious.

DR. ALTIERI [Interpreted from Spanish]: The campaign for us was not for prevention--it was to ask people to accept children in their homes. We don't have enough foster homes for children--not just children with AIDS, but for all types of children. So we want to inform people that children do not transmit AIDS. They are aware of that lack of foster homes not just for children for AIDS, but for all children, unfortunately.

SURGEON GENERAL NOVELLO: The program in Puerto

Rico is not different from the United States, but we did something in the United States through the NIH, the Department of Defense, and HRSA in which we used funds--we had a training program in which we used members of the community to become adoptive parents. And at the same time, regardless of whether they are members of this family, you pay them the same as you would pay an outside person. But we have found that many of these mothers cannot die in peace because they don't know who is going to take care of their children. When they are introduced to the person who is going to take care of the child, the peace, the tranquility, the peace of mind that you see in their faces is remarkable.

This is a new program, but it is expanding. You must use the community and tell them that children do not transmit AIDS, and that these children need homes. But you can tell them that they can also be foster parents. Whether this exists or not in their community, it will function, and I am sure that something similar could be used in Puerto Rico at the Federal and State level and at the community level with the tremendous emotional capacity that these homes have. Mothers refuse to die, and you see the desperation of a mother who is dying and knows she is going to leave her

children alone.

DR. ALTIERI [Interpreted from Spanish]: You are entirely right, and I am going to transmit that message because we can derive great use from this suggestion. Thank you.

SURGEON GENERAL NOVELLO [Interpreted from Spanish]: Thank you very much.

CHAIRMAN OSBORN: Thank you, and let me thank all of you on the panel for your important testimony. We appreciate the time you have taken to share with us.

As I have mentioned before, I hope everyone will observe our request not to take photographs inside or outside of this room as we hear from a family living with HIV.

[Pause.]

MRS. _____ [Interpreted from Spanish]: We are a family who, sadly, have the AIDS syndrome. We are infected, my husband and two of my children and others who are not determined yet.

We are here so that you can ask us the necessary questions in order that it be of assistance to all of us and to all the other patients.

We are under the Institute of AIDS, through the

Hospice of Amistad and the Pediatric Hospital for my children. We are accompanied by our social worker, Ms. Maria Aponti [phonetic], and the pediatric social worker, Mr. Rivera, and we are available to respond to any questions that you deem appropriate.

COMMISSIONER DIAZ [Interpreted from Spanish]: We appreciate all of you, as a family, that you have come here to collaborate and participate in this important hearing we are having in Puerto Rico. It was our wish to get to know you and to know the entirety of your needs and your perspective as parents, having children, and being infected by this problem.

I would like to ask the gentleman if he can tell us his experience in terms of how you see that it has impacted your family and what has been your experience?

MR. _____ [Interpreted from Spanish]: Well, before anything, good morning to all. My experience on this basis is that we have gone through a lot of hard times and many problems, and in fact, through the help of God and the help of the Institute of AIDS, we have been able to overcome all of these problems.

My experience--well, what can I think when you know

that you are going to die? Practically, I am a man of a few words; I do not talk a lot. What I hope is, with the help of God and with your help, to be able to go ahead.

That is all I have to say.

COMMISSIONER DIAZ [Interpreted from Spanish]: Could you give us your age and how you were infected, if you can say so?

MR. _____ [Interpreted from Spanish]: Yes. I am 25 years old. My wife is 24 years. I have five children--Xavier, my son, is four years old; the oldest is six, and the other one is three; and I have two others who are at home, a one-year-old, and the other is seven months old. That is my family.

I contracted the virus through drugs. I was an addict before, and I had the disgrace of contracting the virus through drug addiction, and that is all.

XAVIER _____ [Interpreted from Spanish]: Thank you very much.

SURGEON GENERAL NOVELLO [Interpreted from Spanish]: A question. How long since you were diagnosed as positive?

MRS. _____ [Interpreted from Spanish]: Could I answer because he doesn't have much information. Two years

ago. Two years ago the virus was diagnosed.

SURGEON GENERAL NOVELLO [Interpreted from Spanish]: And are any of the children positive?

MRS. _____ [Interpreted from Spanish]: We have the four-year-old child who is undetermined, but with a very positive outlook. He has been the one who has been ill, but through prevention, thanks to God, he was admitted into the Pediatric Hospital. I was very concerned because--I have to say this, I have to say it--the place where we are supposed to take the children, when they heard of the condition, the doctors would not touch the children for the checkup. I get there, and they just ask "What do they have?" If it is a cold, I have to tell them. And the fact that they are admitted into the Pediatric Hospital whenever I have an emergency, in addition to the fact that they are checked every month, I have the opportunity of taking them there and protecting them against any illness.

COMMISSIONER DIAZ [Interpreted from Spanish]: Did you have any idea that you could be at risk before you went to the test?

MRS. _____ [Interpreted from Spanish]: No. You always think that that happens to other people, not to you.

It is not going to happen to me; that cannot touch us. It was very traumatic, at least for me, and also for them when we knew. He got ill, and a test was recommended. He did submit himself to the test, and it was positive. I was pregnant at the time, so it was very difficult to accept it because we had many misconceptions about the illness, things that you hear in the street, where you shouldn't hear them. But then we were rightly advised in the Institute of AIDS, and we were able to digest it and accept that we would have to live with it.

COMMISSIONER DIAZ [Interpreted from Spanish]: What type of support do you receive from your respective relatives and families?

MRS. _____ [Interpreted from Spanish]: Our relatives, at least my family, have been very strong, or my mother--my family is my mother. The others, I have not told them, because I know there is going to be rejection. They are not prepared for this. But my mother is always with us. She has been with us, helps us in everything.

His parents have also accepted it a little more apart, but at least they do not reject us; we do not feel the rejection.

But we have left it there--father, mother--because the rest of the family may not understand, not because of us, but because we want to avoid the rejection of our children, that they will not be allowed to play with the cousins. So we decided that no one should know.

COMMISSIONER DIAZ [Interpreted from Spanish]: Are the children in school, any of them?

MRS. _____ [Interpreted from Spanish]: Yes, three of them are in school; two of them are in private school, another one is in Head Start. In the school, they are not aware of the condition because I am afraid they might be thrown out of school. In Head Start, yes, the social workers there know of the condition. They recommended that the teachers or anyone else in the center should not be told, and not even in the records of the child is it written.

COMMISSIONER DIAZ [Interpreted from Spanish]: Are all of those who have been found positive under treatment?

MRS. _____ [Interpreted from Spanish]: No. It has not been necessary to make use of it because in spite of the fact that the young boy has been the most impacted, it has not been needed to use any special medication, nor my husband either, because he has felt symptoms, but it is not so far

advanced.

No, none of us receive anything. On one occasion, we thought about AZT for him, but we were told that, no, we could hold on because sometimes--how do you say it--it has secondary effects, and since he is not that ill, it is best that he maintain himself as now.

So we handle the illness at the moment that it comes out.

COMMISSIONER DIAZ [Interpreted from Spanish]: The two children were born after?

T2S1 MRS. _____ [Interpreted from Spanish]: I was pregnant when he was found positive. That has been determined, and even with the use of condoms, I became pregnant, and this child is negative, but he has had multiple illnesses of the condition. Also, he has been included in the Pediatric Hospital in order to avoid any risk with him.

So I was pregnant again after I knew of the condition. The truth is that it is a very positive possibility.

COMMISSIONER DIAZ [Interpreted from Spanish]: Can you recommend any type of service or social support which is needed for a family such as yours in Puerto Rico?

MRS. _____ [Interpreted from Spanish]: Well, it is sad to say that the economic assistance we have is poor. We receive a small economic assistance from the Department of Social Services, and the food stamps, and really, this is on scales that are according to costs that are if you pay rent or not. We do not pay rent, so we receive the minimum amount, and it is not enough.

COMMISSIONER DIAZ [Interpreted from Spanish]: How much are you getting?

MRS. _____ [Interpreted from Spanish]: One hundred seventy-six dollars per month of economic assistance to pay for the needs of the children and us, and also in food stamps, we get $170 bimonthly, and there we are able to balance the budget--but we have five children, and it is not enough--the milk, the Pampers--every month we have to go to the social worker to try to get milk and Pampers. And those who give once do not want to give twice. So we need support.

The social worker gives us a great deal of support. She goes to the Lions Club, anywhere--but once you ask, there are those who do not want to give twice. We need the milk, we need juices, and sometimes there are no Pampers. Food, we always have, because if not, my mother will provide it. She

is disabled, and I have to deal with that, but she is not well-off economically.

There is no specific place where you can go for assistance. The only place that gives economic assistance is the AIDS Foundation, but they do not have enough funds, and sometimes they cannot give more because there are many, many people, and you have to understand.

But the money is not enough. If you have to buy medication, then it is worse. The money is not enough for the basic needs let alone for anything in addition to that.

With respect to doctors, the Institute of AIDS is well-staffed. We have good doctors. Many times we find with the medications that sometimes we have to wait a week or two, but we get them.

Although with the Pediatric Hospital, yes, sometimes the medications are not available, are very expensive, you cannot find them. But sometimes you ask, and they say, "Well, you have to wait one month, two months, three months. It is being ordered, but I don't know when it will arrive."

But at least the place that we go, the medical attention is wonderful.

Another problem that I want to bring before you is

the WIC Program. I have problems with the WIC Program. My children were removed from this program, and even with that program I have to buy additional milk because they drink a lot of milk. They were removed from participation in the WIC Program. They were asking for a lot of things, and you get there, you bring them, and they continue to ask for more and more information, and I do not understand why--why? In other places, it is not the same. Why does it have to be that way for the WIC Program? They are highest risk, they are anemic because they have very low hemoglobin, and I do not understand why this has to happen. I don't know what is happening.

In housing also, we have problems, many problems. If we do not go to the Porta Lesa, the Governor's house--we threatened to move into the Porta Lesa, the Governor's house. The place that we have now--first we were placed in a residential project, and we continued to fight. Then we found under Title XIII a house, and that is where we are, thanks to God. We waited two years. We lived in my parents' house, he lived in his parents' house and I lived in my parents' house, separated, because we could not be in one place since we were so many. And now we have achieved the objective of having our own house, and at least we do not

bother anyone. But we need a lot of help, too much help. There are too many children, not only mine--I know there are some others who are worse off than us.

VICE-CHAIRMAN ROGERS: I would like to ask the father whether he has ever had drug treatment services and if during that treatment services whether he has been counseled about transmitting the AIDS virus to other drug abusers, or at any point in his treatment whether he received counseling to prevent the spread of the disease to other people.

MRS. _____ [Interpreted from Spanish]: I would like to--

COMMISSIONER DIAZ [Interpreted from Spanish]: He is asking whether at any moment you were in treatment for drug addiction and whether, within this treatment, you had an opportunity to receive, besides counseling with respect to AIDS and how it was transmitted, in order not to infect other persons?

MR. _____ [Interpreted from Spanish]: Yes. Thanks to the help of Dr. Soler [phonetic] in the AIDS Institute in San Juan, I was able to come out of drug addiction. He helped me the great deal on the basis of a treatment that I followed, and thanks to him, I appreciate his help a great

deal.

What is the other thing he asked?

COMMISSIONER DIAZ [Interpreted from Spanish]: How long ago was the treatment?

MR. _____ [Interpreted from Spanish]: About two years treatment.

COMMISSIONER DIAZ [Interpreted from Spanish]: And he also wanted to know whether under this treatment you also received counseling with respect to the transmission and protection in transmitting AIDS.

MR. _____ [Interpreted from Spanish]: Yes. They advised me, they counseled me, they explained to me how it was transmitted, what to do in order not to infect other persons. They explained everything in terms of what I had to do since I had the virus, and I have withdrawn from drug addiction. They explained everything.

MRS. _____ [Interpreted from Spanish]: I wanted to add something. That is that he was under all programs existing in Puerto Rico for drug addiction, and none of the programs were effective. There were many, many years where we were trying to bring him out of drugs. The only one is Dr. Soler, and thanks to God, it has been the Institute of

AIDS, completely free of charge, who has given us this treatment. This is free of cost, but the help of the government for drug addiction here simply does not work--all of them. He tried all of them, from Christian programs, the Hogar Crea, DESCA [phonetic], acupuncture--everything, everything, everything. Nothing worked; only the aid and assistance of this doctor. I would say this treatment was sent directly from God, and it is very important.

VICE-CHAIRMAN ROGERS: Thank you.

CHAIRMAN OSBORN: Thank you very much. We appreciate hearing from you, and it is very helpful to us.

Thank you.

[Pause.]

VICE-CHAIRMAN ROGERS: Dr. Osborn has asked me to welcome this distinguished group. Let me make one comment before you start. I am pleased that all of you were here to hear that powerful family testimony.

You are dealing with some issues that are very close to our hearts. I would point out to you that we do have your written testimony from each of you. I also know how terribly hard all of you have worked on that. You are obviously free to read it if you wish, but we do our homework

rather carefully, and if you would like to just punch home the points that you would most like the Commission to go away with so that we can interact with you, the more time we have I think in back-and-forth, the more we carry away with us. And we will indeed read your testimony, and I know you are working across a langauge barrier, too, so that may be hard, and if you want to say, "I'd rather read it," fine, but if you would just like to punch some of it home, I think you will get our full attention.

Thank you.

DR. FELICIANO: Good morning, Dr. Osborn, Dr. Mason, Dr. Novello, distinguished members of the National AIDS Commission.

Thank you for the privilege and unique opportunity to testify at this hearing and to share with your our problems in our health system for patients with AIDS and some recommendations to address the issue of women with HIV infection and AIDS.

Due to the shortage of time, you have heard a lot of statistics, and you have the written document. I want to recall only a few things. Twenty-nine percent of the cases in Puerto Rico are from the City of San Juan, and from those,

66 percent were diagnosed through our health system and through the AIDS Institute, and of course, a much higher percentage are being treated in our system.

Twenty percent of the cases diagnosed through the AIDS Institute are female. Thirty percent of our cases are less than 30 years old, and of the female cases, 45 percent are less than 30 years old. Seventy-two percent are related to i.v. drug users, and 10.5 percent are heterosexual. Of those, 7 percent are females who get their infections through heterosexual contact not related to drug addiction.

In the Sentinel Seroprevalence Study, in the o.b. cases we had in 1988-89 1.87 percent positivity and now, in 1989-90, we have a 3.86 percent positivity.

You have heard our system. It is through Health Alliance that we contracted the AIDS Institute to avoid the usual governmental bureaucracy and to assure the best utilization of scarce funds and to contract the most efficient persons who were really interested to deal with the AIDS issue.

Aware of the importance of prevention, early diagnosis and treatment geared to the female population, our Department has incorporated several services and programs for

them. At each of our nine Diagnostic and Treatment Centers, we have readily available confidential, cost-free, voluntary HIV testing services. These services are offered by a multidisciplinary team. Pre and post counseling is mandatory and represents an educational session for patients. Voluntary sexual partner notification and contact tracing activities are stimulated.

We have promoted and enforced these services through intensive educational and outreach activities geared to adolescents, pregnant women, child-bearing female population, drug addicts and their partners, as well as the general population, and we have gone to shooting galleries in order to deal closely with these populations.

Educational material has been prepared, mainly geared to children, adolescents and females. Primary ambulatory clinics have been organized at six out of the nine Diagnostic and Treatment Centers for the follow-up of HIV-positive asymptomatic cases. A team is composed of a doctor, nurse, counselor and health educator. A specialized referral service for the ARC and AIDS cases is localized at the Rio Piedras Diagnostic and Treatment Center, all these services through the AIDS Institute, offered by a multidisciplinary

team.

Pregnant HIV-positive patients are referred to a specialized obstetric clinic, and the Pediatric AIDS Demonstration Project at the San Juan Municipal Hospital participates in the follow-up of these patients. So all our prenatal HIV-positive patients are followed up at the San Juan Municipal Hospital in a joint effort between the o.b. department our Pediatric AIDS Demonstration Project and the personnel assigned through the AIDS Institute of Pediatrics.

We have started education of our professionals including an emphasis on the o.b. and pediatricians at all our Diagnostic and Treatment Centers, and very soon we will start our primary follow-up pediatric clinics at our CDTs to avoid one thing stated by the family--that nobody wants to take care of a common cold and a mild fever. So we hope that very soon, by January, we will start these clinics.

A Pediatric AIDS Program is available which offers ambulatory and hospitalized care for HIV-positive babies, their parents and families. The program is located in the Municipal Hospital. We have a multidisciplinary team, and they offer medical service, education, counseling, case management, respite care and drug clinical trials in order to

meet emotional, social and physical needs of our patients.

We have to say that all our pediatric cases that merit AZT and gammaglobulin are receiving them through clinical trials or through moneys from the AIDS Institute program.

Coordination with the community, including participation in "Pastorale de SIDA", which includes clergymen, religious and civic groups, helps us to fill other specific needs of our families.

Family planning services are offered at our Diagnostic and Treatment Centers through the UPR Medical Science Campus Program.

Sterilization services are offered at the San Juan Municipal Hospital. No abortion services are offered through our health system.

Pretty soon we will be remodelling our ambulatory centers which will include aerosolized pentamidine and other specific drugs.

Recommendations. At this point, I want to acknowledge the support that Federal agencies such as HRSA, CDC, and NIDA have offered to the City of San Juan. As past Director of the San Juan Health Department, their intervention

was crucial to make available Federal funds to our system.

Every day, the cost of the AIDS epidemic increases. We have limited economic resources--we have seen that--to deal with the multiple demands for services. For this reason it is important to continue an aggressive preventive program including specific educational activities geared to help young populations to develop healthier life styles and modify risky behaviors of the general population. This should include, and we are including, safer sex and use of condoms.

Puerto Rico has a Medicaid cap. This represents a great fiscal load to our system with the onset and impact of the AIDS epidemic. It is mandatory to analyze alternatives to obtain more funds through Medicaid.

It is unfair to Puerto Ricans, as U.S. citizens, to have one of the highest rates of AIDS cases and not have the fiscal resources to deal with the other epidemic as other States and cities in the mainland. If we are going to be fair, we have to recognize the efforts of many Federal officials and more specifically the Honorable Louis Sullivan for their efforts, and we expect that you will join us as the National Commission to be part of this effort.

Community involvement should be further stimulated

to include industry, commerce, mass media communication and other prominent private enterprises that can help us in cofinancing the cost of the epidemic, and they have not done such.

The continuation and expansion of services for counseling and voluntary, cost-free, confidential HIV testing is deemed necessary. We must expand family planning services to make them more readily available. Abortion is not a solution, since we would probably be killing two healthy people for each infected one.

The establishment of foster homes and day care centers for HIV-infected children should be a priority and should include services for HIV-negative children of infected mothers. Proyecto Amore should serve as an excellent model for many others to be established, and it is a pity that Proyecto Amore will not participate in this hearing to share with you the valuable services they are offering.

Day care centers to improve the quality of life of our patients should be expanded. At present there is only one in Puerto Rico, administered by the San Juan AIDS Institute. Due to the high percent of i.v. drug use as a risk factor in AIDS, expansion of services in prevention,

treatment and rehabilitation is a must.

Recently, a grant to develop a primary care center to reach this goal was approved for San Juan City through DESCA. This will include transportation. It is planned to develop these activities in close coordination with our AIDS program and to enforce the rehabilitation of drug addicts, the program that we have through the AIDS Institute.

Emphasis should be made--

VICE-CHAIRMAN ROGERS: I should warn you that your time has run. Thank you.

DR. FELICIANO: We have to expand home care, skilled nursing. The use of AZT and other specialized drugs should be pursued. This should be established as public policy and must be a priority in the utilization of any additional funds available.

In a Latin country as ours, where the male supremacy has prevailed, and the "macho" figure is predominant, we have to strongly consider the empowerment of the female to deal with her sexual partner, sexual conduct, and her whole life. It is an issue of economic survival versus protection, and that was more or less that Dr. Novello said.

Women have faced a system designed and run by men

for men. Family programs have been successful in Puerto Rico because of initiative and active involvement of the females. The same is urgent in the fight against this disease.

Women have to give away their passiveness and assume a leading role at this historical moment in order to ensure their futures, save their lives and those most loved by them--their children.

Let us assume positions and develop programs that will help them to reach this goal.

We should remember the importance of the impact of women in the whole society and in keeping the integrity of our families as principal caregivers. Above all, let us set aside our fears, our prejudices. On our small island, let us set up the most cost-effective system that will enable and warrant good quality of care, in a sensitive way and taking into consideration that patients with AIDS are our brothers, needing our support, our understanding, our services, but above all, our Christian love.

Thank you.

[Applause.]

VICE-CHAIRMAN ROGERS: Thank you very much, Dr. Feliciano.

Dr. Zorilla.

DR. ZORILLA: Good morning. Since you have my written comments, I will emphasize the challenges of being a woman in the era of AIDS; I will describe some aspects of the population that we follow, and I will include our most recent ethical dilemma as researchers, the identification of medical problems without sufficient access to treatment and services.

As you can see, these are the most recent Puerto Rico mortality statistics. If you exclude accidents and homicides, AIDS is the leading cause of death in both sexes from 20-39 years old in Puerto Rico, and that was three years ago.

This is a graph showing the cases of AIDS in Puerto Rico by sex, and as you can see, this current year--and that is up to this month--females comprised 21 percent of AIDS cases in Puerto Rico.

As you can see, the AIDS cases in females in Puerto Rico by risk transmission, we can notice a significant increase in transmission by sexual contact, and it has been increasing at a rate of 5 percent every two years, so we can easily expect that by 1992, heterosexual transmission of AIDS will be the leading cause of AIDS in women in Puerto Rico.

I will then describe the population that we have followed. In 1986 we started a prenatal screening program. The HIV test was universally offered to women attending prenatal clinics at five towns in Puerto Rico. Most of them got counseling and written consent, and our seroprevalence has fluctuated between 1.4 and 1.7 percent.

The post-test counseling was given at the Medical Center, and these women were followed at our clinics. We decided to keep these women in the Puerto Rico Medical Center because they come from small towns, and if we send the reports back to their towns, everybody would know of their results. So to ensure confidentiality, we just follow them.

We continue following them not only through their pregnancy but afterwards, because we have some limitations in getting services for them.

We have also a group of sero-negatives from the same population for the basis of comparison.

As you know, they are young women; most of them live in relationships of stable union, like consensual union or legal marriages, although most of the positives have consensual unions and not legal marriages. This is an example of how asking for an HIV test for a marriage license

would not identify the population at risk.

Most of these patients acquire the infection through the sexual route. Sixty-five percent of them were partners of drug users; 6 percent were partners of men who were positive but denied drug use; 6 percent had multiple sex partners; only 18 percent of them had a history of drug use; and 15 percent of them had no risk factors upon interview. And this is what worries me about AIDS, heterosexual transmission and women because we don't know what our partners are doing or were doing in the past.

Talking about sexual partners' history, most of the partners of the HIV-positives gave a history of drug use, and not only most of the current partners but also the previous partners, as compared to the HIV-negatives. So the risk factors for them were the men whom they chose to live with.

Regarding sexual practices, we have also found high-risk sexual practices among the poor Puerto Rican women, and this is a very limited segment of our population. I cannot make generalizations for the Puerto Rican population, but anal intercourse was significantly higher in the HIV-positive population, and it is still frequent in the HIV-negative population.

Regarding the clinical status of these women, as you can see, 50 percent of them have CD4 levels less than 500, which is the crucial level for therapy initiation, and about 50 percent of them also have symptoms of AIDS; only 17 percent of currently receiving zidovudine versus 60 percent of their children, who are receiving zidovudine.

I just want to finish by saying that it is sad for me as a researcher to study these women, study them deeply, getting CD4 results, HIV vital cultures, all kinds of studies, and then to not have access to the minimum treatment that these women deserve.

[Applause.]

VICE-CHAIRMAN ROGERS: Thank you very much.

Dr. Diaz.

DR. DIAZ: I'd like to add that I am the pediatric counterpart of this o.b./pediatric union that has existed at the medical school now since 1986. We have followed children since early in the epidemic. The program is a tertiary hospital-based program, but it has become both primary, secondary and tertiary care for the children. So far we have seen over 200 children, and I will be very brief.

I have shared much of my experience at the site

visit, and in my written comments there is expansion of numbers and so forth; I think we have had lots of statistics. But I would like to just basically share what we think is important, and above all, access to specific anti-retroviral therapy is extremely important.

We have seen enormous gains in development, in weight gain, in children who are started early on in therapy. So children, who represent a different group from all the others because I think their disease progression is faster, need to have identification early as well as access to specific therapy early.

For those children who already have access to therapy, it will become important to have alternatives, because what we have seen so far is that AZT as the first of the analogs that are useful is not a long-term remedy; it is not effective perhaps in the long-term. We have seen that there will be some immunologic and neurologic deterioration despite AZT, perhaps after the first year of use.

So we need alternatives, and we need to start those alternatives available for children who are on AZT now.

I think that is what I would like to share with you and would much welcome questions and expansion of the

experience we have had in the program.

Thank you.

VICE-CHAIRMAN ROGERS: Thank you very much, Dr. Diaz.

Let's proceed to Dr. Santiago.

DR. SANTIAGO: Good morning to the members of the Commission.

I'd like to point out that I think what is going to happen with the AIDS epidemic--I hope what is going to happen with the AIDS epidemic--is similar to what has happened in the last two or three days in Puerto Rico: rain and rain for a couple of days, and a beautiful sunshine today.

I also want to take a little bit of my time, and I will be brief in my statement, to truly appreciate Dr. Novello and Eunice Diaz because they are certainly an example for the Puerto Rican woman today.

I will just go over a couple of things that I think are important. You have my statement, and you can read it later on.

When we present that we only have 166 Puerto Rican children with AIDS, it does not seem to be impressive to anyone. It doesn't seem like a striking statistic. So I'd

like to try to compare it so you can see where we are right now.

We are fifth in the number of pediatric AIDS cases in the Nation. It is mind-boggling to me to see that we are an island of about 3.5 million citizens, and we have about 30-some cases less than the State of California, and we are about 100-some cases less than the State of New Jersey. So that is how big the problem is.

Not only that, but I'd like to point out a couple of other things. One is that 4 percent of our total AIDS cases are pediatric AIDS. If you compare that to the Nation, actually, right now you have 1.8 percent of the total AIDS cases.

The third thing that I want to try to convey to you is that the statistics that we have now of 166 patients are actually misdiagnoses and a lot of under-reporting that we have in the island. It is not until now that we have had newborn screening for the entire island, right now; we did not used to have that at all.

The second thing that I'd like to bring up is that even in tertiary centers, where Dr. Diaz and Dr. Zorilla are, where you do have the testing available, even in those centers

what we found was that the data collection system was not efficient; therefore, they were unable, even if they knew the child had AIDS, to have all the data available to qualify within the CDC definition of AIDS.

Thirdly, in Puerto Rico, none of the educational programs for AIDS included a detailed description of pediatric AIDS. It was not until the Pediatric AIDS Demonstration Project that came over to the island was created that we did have a complete program concerning pediatric AIDS.

What our program has done is enabled professionals both in churches, in community organizations, in schools, in government agencies, in health care settings to be informed and aware about AIDS, and then they can be sources of referrals.

More so, what we try to do is to enable the physician to be able to properly identify the pediatric AIDS cases and document them, so then they can become a statistic within the CDC definition.

We all know that the main cause of pediatric AIDS in children is perinatal transmission. I'd like to point out that it may not be very significant, but in the Nation as a whole, 80 percent is from perinatal transmission, and in

Puerto Rico by the CDC statistics, which I still insist are under-reported, it is 90 percent, and we feel very strongly that it is higher than this.

I just want to say a couple more things. Fifty percent of our women with AIDS are i.v. drug users. But the reality that we are seeing now is that most of these children with AIDS are actually products of women who have acquired the infection by heterosexual contact and not by i.v. drug use.

I bring this up to tell you that the increase that we have had in the Nation of AIDS caused by heterosexual transmission is also true in Puerto Rico.

In 1983, 19 percent of the women acquired the infection by heterosexual contact. Today in 1990, 38 percent. This is a 100 percent growth rate in seven years.

Furthermore, the majority of the women who do acquire AIDS by heterosexual contact are partners of i.v. drug users. And you have already heard how widespread i.v. drug use is in the island.

So obviously, as the amount of women acquiring AIDS by heterosexual contact increases, so will the children increase.

This is what I would like to leave with you today. The target of our educational efforts should therefore be directed toward the Puerto Rican woman. Although slowly changing, our culture traditionally has meant a passive posture for the Puerto Rican woman. This posture is dramatized by the thousands of women who are victims of domestic violence in this country. Implicit in all social events in Puerto Rico, clearly seen in the established double standard of acceptable sexual conduct, and resulting in a few number of women in leadership positions in our institutions and in our Government, the dilemma of the Puerto Rican woman is more complex. Even if well-educated and/or skillful, her success in life will always be linked to her success as a wife and as a mother.

Regarding the AIDS crisis, we have many women who accept their HIV-infected males' refusal to wear condoms, even being fully aware of the risk of infection and its lethal consequences. This upbringing is also seen in the woman's acceptance of repeated infidelity, even when aware that such behavior could result in HIV infection.

It is thus imperative that we direct our educational efforts toward empowering the Puerto Rican woman. Power can

be achieved by a case management approach which would enable her to survive in a highly-competitive and bureaucratic world, providing her with financial and legal assistance and accessibility to educational and employment opportunities.

The most important aspect of this approach would be to provide aid hand-in-hand with counseling in an attempt to effectively modify attitudes and behavior that will lead to risk reduction. Only with this approach will our educational efforts for HIV prevention in the Puerto Rican woman be productive. Only with this approach will we be able to significantly reduce heterosexually-transmitted AIDS and thus the number of Puerto Rican women and children with AIDS.

Thank you very much.

[Applause.]

VICE-CHAIRMAN ROGERS: Thank you very much, Dr. Santiago.

Ms. de los Angeles?

MS. CALDERON [Interpreted from Spanish]: Good morning.

I am Mrs. Maria Calderon, mother of four children ages 16, 12, 2 years and one year. The last one is a boy. I was living with a man who used drugs from 1987 to 1988, and

when I knew he was using drugs, I terminated my relationship with him.

This man died on April 16, and I learned of the risk that I was under. When I heard of this, I decided to find information in respect to AIDS for my family, my children and myself. I heard of the project, "Tu, Mujer", "You, Woman". It is a very special project, and they have helped me a lot.

I submitted myself to a test, and I am HIV-positive. Then they referred me to the CLET clinic in the Medical Center at Rio Piedras, and there, the doctors at CLET treated me with vitamins and medication for my hands. The "Tu, Mujer" project referred me to the WIC program, and I was also treated because of the same condition; my defenses were very low, so Dr. Zorilla told me that I was a very good candidate for AZT because the glands in my neck have grown, I have low defenses and very low hemoglobin. So they gave me a prescription for AZT, and sent me to CLET to get the medication there because they are the ones who are distributing it. There, a woman doctor--I don't remember her name--told me that she could not give me the AZT because I was not a resident of Rio Piedras. I asked her what was the reason she was doing this

to me, that I am a patient of the Medical Center, why would she do this to me, and she told me that she could not give me this prescription because when she helped Dr. Zorilla's patients, her patients would be deteriorating.

So I went back to Dr. Zorilla, and I explained the situation, and I had to go home without a prescription. The doctor at CLET who denied the prescription told me she was going to refer me to the Bayamon Regional Hospital in my area. I went there, and they wanted to do the test again and start all over again. I rejected that, because I had had the test done, and I rejected the fact that I had to submit myself to other tests because I had submitted myself to tests. If I qualified, I wanted it, and I had been told yes.

So they gave me an evaluation--the very good doctors that I have at the Regional Hospital--and at the present time, I am under the AZT program.

One of my children, the one year-old male, also tested positive. He is one full year of age, and he is being attended at the Regional Hospital in Bayamon. I told her that I noticed a gland on this child. She did not pay attention. She simply placed him under a certain treatment, and that is all, and on Mondays, Wednesdays and Fridays he is

getting antibiotic treatment. That is where I am. The tests have not been repeated. He is being seen every three months. I do not understand what type of health care is being given to my child, to my baby.

Let me see if I am leaving anything out. [Pause.] The problem that I bring before you is that I have not been given any orientation, counseling with respect to nourishment; I have not been given any orientation as to how to live with this. There is no orientation here as to services for nourishment, care, nutrition assistance--nothing. With respect to women, the project "Tu, Mujer", terminates this month, and we will not have that project. Aside from this project, we have nothing else that deals directly with women.

So I ask you, please, do something so that women who live with drug addicts can have better care and can learn how to protect themselves more. I think that is the person who is at a more high risk; that is my understanding.

So on my behalf I say to women that AIDS does not discriminate, not sex-wise nor age-wise, and while there is life, there is hope. So if you have it, let's learn how to deal with it and to ask God to help us not to bring children into this world to suffer. We need your help.

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[Applause.]

VICE-CHAIRMAN ROGERS: Thank you very much, Mrs. Calderon.

Thank you all for being so brief and so moving. I think we will now ask for questions from the panel.

Dr. Novello?

SURGEON GENERAL NOVELLO: I don't know if I'm going to do this in Spanish or English.

[Interpreted from Spanish]: It is very good to see all of you today, knowing that we work together in pediatrics, and Dr. Zorilla being the ob-gyn, together with Dr. [inaudible], who sees every patient with AIDS in this land.

[In English]: But I wonder, I wonder if the woman of Puerto Rico really knows that when she is not at risk by being an i.v. drug abuser or by being the partner of an i.v. drug abuser, if she, just by being a women and having normal sex with partners that she does not know, is at risk.

Does she?

DR. FELICIANO [Interpreted from Spanish]: I am going to answer in Spanish.

I think that in general terms, no, she is not aware of the great risk, and this is one of the tasks that we must

handle, that we must carry out. I mentioned that we had to improve our educational programs and that they must be more aggressive, and we must use the tools through women, and in addition to giving them the tools, to make them aware of the risks they have.

We are directing our services of primary care through [inaudible], and these centers are not directed to drug users exclusively. They are directed to the entire population at these centers. We go to the communities, to housing projects, universities, and we talk to everybody. We cannot talk about risk groups. This epidemic started with Haitians, bisexuals, drug addicts, but it has become part of the daily lives of any person who has sexual contact, with anyone.

I personally believe that our women in Puerto Rico are not aware of the severity of their problem, and one of the priorities that we must have in our educational programs should be directed to the female population in general terms.

SURGEON GENERAL NOVELLO: This is where I need your help, is AIDS with women. I can see that 21 percent of all cases of AIDS in Puerto Rico are females. Perhaps they are thinking that if they may be upper and middle class women, in

higher classes, who are not in consensual relationships, that this is not going to happen to them. This is one thing.

In the second place, we are in a country where our culture makes us aware of what happens in "social Fridays", they say. Let's not judge "social Fridays", but I think that prevention cannot be given only to women; I think there should be prevention for men, also, as well as women. Otherwise their families are going to disappear.

Second, I think if we are going to be ourselves protectors, we must engage the protection of our husbands, our boyfriends. If we do not engage their help, we are not going to have full prevention. It is going to be read but it is not going to be followed.

Prevention must be both for women and for men, because behind every infected woman there is an infected man, and there is a child who is going to be born infected. We must not just direct prevention to one place, but we must inform people that we must not keep using our instincts; we must use our intellect. That way, prevention, protection and education today, and not only for the high-risk groups but for the entire female population, and not ignoring men, not leaving them out, because we have many women who tell us

today that they have the same stigmatization that they had in prior populations, and if they were able to deal with the problem, we must do something for our new female generation. We must learn to protect ourselves. We must be aware, even if the man is very handsome and speaks very nicely--we must protect ourselves, we must protect ourselves. But if you love him, and he loves you, you must protect yourselves mutually--but do it always. What you do today, if you don't remember what you did last Monday, how can you remember what you did seven years ago?

So please, prevention at both levels, at two levels. What is happening today is happening to women who are not drug addicts.

VICE-CHAIRMAN ROGERS: It looks like several of you wish to answer.

Dr. Zorilla, and then Dr. Diaz.

DR. ZORILLA: The best example that our messages are not getting out is the one about cigarette smoking. There are lots of campaigns against cigarette smoking and against cigarette smoking during pregnancy. And I have seen in this population that the sero-negative controls quit smoking very easily during pregnancy and afterwards; but the

sero-positives do not quite smoking. And smoking does not have bias and does not have the impact of talking about condoms and sex.

The second example is the use of condoms by these women. Only 20 percent of them have ever used condoms in their lives.

VICE-CHAIRMAN ROGERS: Thank you.

Dr. Diaz.

DR. DIAZ: I would like to add a comment that I think makes a big difference in transmission rates and also in disease progression.

I think Puerto Rico has experienced a longer history than most other areas except perhaps certain regions in the Eastern seaboard of the United States. Longer history with exposure to HIV means that the viruses have been in latency stage long enough that now they activate and go into very active replicative cycle. And I think the risk of transmission, even in one encounter, in Puerto Rico may be much, much higher than that in other cities where the average viral load is not in as active a cycle as I think it is in Puerto Rico.

We have also seen in children that children born to

infected mothers here progress much more rapidly. I think that will cause a big impact in Puerto Rico.

VICE-CHAIRMAN ROGERS: Yes, Mrs. de los Angeles, did you wish to make a comment?

MRS. CALDERON [Interpreted from Spanish]: Yes. I had forgotten to add that many times I have gone to the Office of Family Planning to receive the contraception methods, the condoms, and I have had to wait two and three days in asking them for condoms because they don't have them available. When you go, you have to wait hours and hours to be told that they don't have them--"Come tomorrow," "Come day after tomorrow." A week passes, and we don't have any protection. I think this is a problem that is affecting the community, especially women. And myself, because I am infected, it is affecting me very much. So I think that you can do something about that.

VICE-CHAIRMAN ROGERS: Thank you.

Mr. Goldman and then Mr. Dalton, and then we're going to have to quit.

COMMISSIONER GOLDMAN: Thank you.

Any of you who can answer the question for me can. My understanding is that at the present time all children

born in Puerto Rico are tested for HIV, at the same time the PKU testing is done. That is correct, is it not?

DR. DIAZ: There are two separate programs. There is a seroprevalence study currently going on, conducted by CDC, which is an anonymous survey of newborn specimens, and that is the one you are referring to. That one was initiated by CDC primarily as a seroprevalence gathering data, just to quantify the magnitude of the problem.

But the program that we are talking about is a prenatal screening/testing offered during the first prenatal visit and offers, then, enrollment into the follow-up program both for mothers and infants in the health region that the university hospitals cover. That is a much more limited program.

The Central Office for AIDS Affairs is considering now the option of extending that to the rest of the island. I don't know at what stage they are in and if that is already in process.

COMMISSIONER GOLDMAN: Do any of you know the data on that surveillance study in terms of what the seroprevalence rates are, both in terms of public hospitals and private hospitals, in the City of San Juan and outside the City of

San Juan, and what that implies in terms of how many new children are being born each month who are HIV-positive?

DR. DIAZ: Yes. There is actually ample data that will be made available to you and all the members of the Commission on the seroprevalence of newborns in different regions. It again underlines what we had seen in the very limited prenatal screening that we had done, that the prevalence is high, an average of one percent, but with different variations according to the region in Puerto Rico as well as public versus private hospital setting.

The prevalence is higher in the public hospitals and reaching as high as 1.53 percent, but still, even in the private sector within the metropolitan region, it is much higher than you would see or has been documented in other centers outside of Puerto Rico, in the mainland, that are doing the same survey.

The actual figures will be made available to you and will be included in the information that you will have.

VICE-CHAIRMAN ROGERS: Dr. Feliciano?

DR. FELICIANO: We have conducted several seroprevalence. The unblinded unit in prenatal, it is one percent. But as I say, in the Sentinel Hospital in the last year, in

the ob cases, supposedly not at high risk, it came out to 3.8.

What we are seeing in our Diagnostic and Treatment Centers is a 3 percent general seropositivity and in the clinics in which we are dealing with STD, we are getting 10 percent of all the samples of our clients.

One thing I would mention is that we will be seeing, and we will have data very soon, the close relation between positive STD, syphilis, gonorrhea, chlamydia, and the higher percentage of positivity of HIV.

VICE-CHAIRMAN ROGERS: Mr. Dalton, you have the last question, and then we're going to have to quit.

COMMISSIONER DALTON: A brief comment and then a question for Dr. Zorilla.

I understand the emphasis today on this panel and by the Commission on the problem of heterosexual transmission of HIV to women. I am just concerned, though, that we not lose sight of the fact that at least until 1992, more than half the women with AIDS are infected because of intravenous drug use. My concern is that people who focus on intravenous drug use tend to focus on men i.v. drug users as the model, and there are any number of different ways in which one would look at that problem if one recognized that women, too, are

at risk. So I just want to make sure the balance doesn't get too far out of kilter.

My question is for Dr. Zorilla. I understand the ethical dilemma of being a researcher and documenting dramatically the need for treatment among people and then finding no treatment available--there is money for research by you and by Dr. Diaz, but we can't seem to keep "Tu, Mujer" afloat or provide help to people like Mrs. Calderon in how to live with this disease.

There is also the dilemma, exemplified in your testimony, of caring about women, but primarily because of the possibility that they may transmit to children. If I understand your testimony, the AZT, for example, is provided much more to symptomatic children than to their mothers. And I guess my question is what can we do, what can researchers like yourselves do, to make sure that the research is not way out ahead of treatment and that women don't get lost, given problems with their children.

DR. ZORILLA: I know that research funds have their limitations, but I do feel that if you consider some kind of basic treatment as an incentive for patients to be recruited into studies, then you could include such a treatment under

the umbrella of research. That would also benefit if we could, for example, in a research project where we give zidovudine to pregnant women just to try to prevent fetal transmission, but then after delivery there is no zidovudine for that woman if she needs it. So that is something that we should address.

DR. DIAZ: Can I add that it is fraught with danger and creates enormous dilemmas for us. We cannot do research if we do not provide primary care, if we do not give care. That is an absolute essential. If we are not able to give the adequate care, we will not do research. Those two have to be together, and access to therapy has to be in hand with what is available in other cities.

VICE-CHAIRMAN ROGERS: Thank you for a very powerful message.

[Applause.]

VICE-CHAIRMAN ROGERS: You have been a very eloquent panel, and we thank you all. The women and children of Puerto Rico are fortunate to have all of you as their advocates.

We are going to take a 15-minute break, and we're going to try and mean that it is a 15-minute break, which

would bring you back at 11:20.

Thank you all.

[Short recess.]

CHAIRMAN OSBORN: I want to welcome the final panel for the morning and thank you for your patience, since we are running quite late. We appreciate your willingness to wait for us.

I will ask you to introduce yourselves as you speak and ask you to make it as brief as you can because of the pressure of time. We have site visits this afternoon, which will mean that we are going to have to compress the remainder of the morning's program somewhat. So if you can focus our attention on your key points and be as brief as you can manage, we will surely appreciate that.

Thank you for your cooperation.

Mr. Morales?

MR. MORALES [Interpreted from Spanish]: Good morning, distinguished members of the Commission on AIDS. I am here to present for the National Commission on AIDS, and I coordinate the program of health education.

In the name of our office and myself, I appreciate your kindness in inviting us to speak this morning.

As you know, health education is a fundamental strategy for the achievement of better health because we can change behavior and attitudes that put the health of everyone at risk. We start from the premise that health is a personal value and it is the primary responsibility of the individual.

In the Central AIDS Office, one of the main areas of priority is the structure of the education area. We have three educators for each one of the immunology centers, which are located in each one of the education centers. We also have the aid of educators for the San Juan Education and Prevention Center.

The efforts in AIDS education go back to the 1980s when, once it was determined that it is a serious situation that affects the public health of Puerto Rico, we had a great initiative, especially in the health centers and the educational centers.

Also, in addition to the initiatives at the Latin American Center for Sexually-Transmitted Disease, it is necessary to recognize the cooperation we have received from the epidemiologists from the Epidemiology Program of the Health Department and the demonstration projects in pediatric AIDS and AIDS in adults.

During this period, we have a series of activities. We have organized and developed training for professional staff in coordination with the Latin American Center for Sexually-Transmitted Disease and the AIDS Education Center for Health Professionals of the Medical Campus of the University of Puerto Rico.

We had conferences for orientation for staff on HIV and AIDS and the development of training of staff for beauty shops, barber shops and beauty schools. We had activities at the community level, for health educators, and assistance in other professions. We have orientation in health education for community organizations which are interested in developing programs for AIDS patients, orientation for the community, distribution of educational materials, participation of health educators in counseling on HIV, publication of press articles and participation in health conferences to orient the public in general.

Specifically, the Latin American Center for Sexually-Transmitted Disease, which has been a group that has worked the most, has developed a series of training activities on AIDS and HIV, activities for patients and relatives, and conferences for high-risk groups. During the period between

1985 and 1990, close to 21,726 persons have benefitted from this type of education.

We also want to talk about the material that has been distributed--51,936 units of educational material have been distributed to students and professionals and health educators. We have answered 34,394 calls from the Help Line, where we give general information to persons who call regarding HIV and strategies for prevention.

We have also had participation of demonstration projects on pediatric AIDS and AIDS in adults. The year 1989-90 has been the year when we carried out these two programs, and 6,103 persons have been reached through education for patients and relatives, and in community activities. In the case of pediatric demonstration projects, 2,140 persons have been reached.

It is necessary to indicate the initiatives in the health education area; in spite of the fact that they were supported by the Health Department, in this period we didn't have a centralized program to facilitated its implementation and to assign resources for activities. With the creation of the Central Office for AIDS, we have a greater priority, and these responsibilities are shared by health educators and by

the other teams that participate in this. I am talking about the period from the time the Central Office was created.

After I was appointed Director of Health Education, we developed the following activities. We have recruited eight public health educators for both regional and central levels; we have had training 432 persons. We have participated in activities with 20,000 young people between 14 and 21 years of age. We have developed a working plan for the area of health education based on the Government Action Plan, and we have a series of activities that appear in the documents that you have.

In spite of the efforts that we have carried out to the moment, the demand for services is tremendous. The AIDS Central Office is willing to satisfy the most, and for that, we have placed emphasis in the following areas. We provide education to the community and through mass communication media. These groups include education to HIV-negative low-risk, HIV-negative high-risk, and HIV-positive. We also attempt to provide education to change behavior in the gay and drug addict population. We provide education for families and patients that come to the community centers. We carry out activities and education in relation to the AIDS

programs among those groups that are high-risk.

The techniques of risk reduction will include pre and post counseling individually and in groups and outreach programs, exchange programs for sharing of needles, showing the addict about use of condoms, and a seminar for values in the young groups.

We also want to exchange information, educational exchange, for prevention, such as the AIDS Institute, AIDS Foundation, in home care. We have coordinated services and different activities. To mention some, the AIDS Foundation, AIDS Institute, Department of Education, the [inaudible] home; all these activities have been coordinated with training, counseling, exchange of human resources, educational materials, just to give you some examples.

We also want to design, reproduce and distribute educational material for the population in general. We have started in that we want to use the agencies that provide public services to distribute this information, to establish an information center for information on HIV and AIDS, and to create a resource center that will include literature, investigative work, research, and anything that has to do with HIV and AIDS; development of training for the staff, and

coordinate with the Department of Education so that teaching on AIDS and HIV will reach all the school groups. With that, I think there will be some work, representation by the Department of Education, and also to establish the infrastructure to facilitate education and prevention among the population.

The importance of public health is recognized in the management of HIV and AIDS. We must assign whatever resources are available for this effort, but it cannot be the sole responsibility of OCAS. It must be a shared responsibility by the Government, private enterprise, and the community in general. That is what we are committed to.

Thank you very much.

[Applause.]

VICE-CHAIRMAN ROGERS: Thank you.

Dr. Gely?

DR. GELY: Good morning, distinguished guests, distinguished members of the National Commission on AIDS.

First of all, I want to thank you for the invitation to share with you some of the data and some of the activities and some of the concerns and recommendations that we are confronting here in Puerto Rico in the area of AIDS education

and training to health professionals.

As you mentioned before, you have a copy of my testimony, and I will try to just summarize the most important issues, and I prefer to speak in Spanish, so please use your earphones again.

[Interpreted from Spanish]: My name is Daisy Gely, Director of the AIDS Education and Training Center of the University of Puerto Rico. I have been working in the area of continuous education for health professionals during the past eight years.

Before I go ahead and share with you some of the findings of the tasks carried out and some of the recommendations that we wish to share with you, I hope that we do not lose sight of two important elements.

When we speak of education and training for health professionals--it is the same community, but my emphasis is on health professionals--we have to acknowledge and not forget that the changes through education are not achieved from one day to the next. Education is a process and as such, the final results that we are going to obtain from these interventions, we are going to look at them long range, even though we obtain short range data.

Second, when we are working in the education area, we should not forget that education has as its purpose to achieve changes in knowledge, changes in attitudes and skills of the health professionals so that they may effectively work with people affected with HIV or AIDS. And I emphasize these three phases--attitude, et cetera.

Precisely, the testimony that has preceded as well as experience do not show that we can achieve more immediate results in the area of knowledge, but in the areas of skills and attitudes, which especially require a bit more time. This is one of the problems that we are facing today with the health professionals, that is, changing attitudes to look at the person affected with HIV or AIDS as just any other human being on their own terms.

Since 1983, the Medical Sciences Campus has developed a series of training activities through the Division of Continuing Education. In 1986 and 1988, two symposia on AIDS were conducted, cosponsored by the National Institutes of Health and local organizations. Approximately 2,000 participants attended each activity. Between 1986 and 1987 funds were assigned for the publication in Spanish of a booklet entitled, "AIDS: Manual of Information and Resources

for Health Professionals".

The initiative taken by the Medical Sciences Campus in this area has been more evident in the establishment of the Puerto Rico AIDS Education and Training Center for Health Professionals, started in June 1988 through a subcontract with New York/Caribe AIDS Regional Education and Training Center. This project operates under Federal funds. During the past two years since this project has been established, from 1988 to the present, I will point out two of the most important achievements, some of the difficulties and some of the projections that we have in dealing with these difficulties, and recommendations we wish to share with you.

We know that in many communities the health professionals have access to the training programs. Generally, the trend is to centralize the training activities, and that is why the professionals in order to participate are limited because of only metropolitan areas.

So what we did was to establish six regional educational centers--and you have these in the written document--so that the health professional would have the opportunity to attend these activities on education and training on AIDS, to assist near their regions of work.

Another important thing contributing to lowering the barriers is that each one of the entities, the agencies, public and private, where health professionals are working, in some measure have populations that are affected by HIV and AIDS. We have appointed a liaison person who, together with ETC, sits down and prepare the training programs in such a way that they respond to the specific needs of those health professionals.

Another thing that I wish to share with you is that on many occasions we do not have on hand up-to-date medical information that erases doubts that we have in terms of transmission, of treatment, so we have established an information center located in the School of Medicine of the University of Puerto Rico that is not only accessible to the facilitators, but also as a resource for the teachers who are preparing the future health professionals, because we understand the process of education has to be part of the curriculum of the future health professionals.

Another thing that I wish to share with you and with the public here present is that in the time that we have been working, we have been able to reach 6,000 health professionals. Actually, we have 40,000 health professionals,

and we have touched about 6,000 to 7,000 of these professionals. The majority are nurses; second, social workers; third, professionals in health, and fourth, doctors and dentists.

We have been concerned, and we share this concern with others who receive these services from these professionals; we know that we have not reached a high number of doctors and dentists, not only in the public sector but also in the private sector. So we continue to have this concern.

To increase this number and to involve the doctors in these areas of training, we have adopted various strategies, but I wish to share only two of them with you. On many occasions, we are able to get better results when there is a peer who is making the outreach to the professional to involve him or her in these training activities. So we are now having a medical liaison who will reach the other doctors to make the training accessible to them.

Second, we are also conducting needs studies in meetings with nurses, doctors and dentists in order to see in fact what are the lacks, what are the areas, how much do they know, how much is knowledge, how much is attitude. This experience is giving us very good results, and we are finding

that the professionals are recognizing that there are definitely some lags, and therefore in the next years as we continue to work on the proposal that we are going to be submitting in the following three years, we will incorporate a great deal of clinical experience that has to do with administration, management and intervention.

However--and this is the last point I wish to share with you--we know that definitely, as I said at the beginning, the education process has to impact attitudes. Our educational experience makes us satisfied in terms of the knowledge that we are imparting, but we still have a lag in the part of attitudes and skills.

I wish to leave in your minds, definitely, to change attitudes and to increase skills of intervention require educational mechanisms that are different--we cannot look only at the number of persons reached, but what can we do with those we are reaching. This means that in the next few years when we evaluate the results of the educational interventions, that we should not only look at numbers but we should look at quality. If we work with attitudes, we have to work in smaller groups, with different strategies, with different resources, and therefore maybe we cannot reach that

large number; but if we are able to say that we have achieved change in fewer people, but those where we have achieved those changes will be role models in the work areas. So this is something that I wish to leave in your minds.

And second, which is a recommendation, is that definitely, changes are not achieved overnight. Educational intervention once, twice, will not change the attitudes, the beliefs, the customs of our Puerto Rican population, including ourselves as health professionals--we are subject to values, to beliefs, to prejudices, to discrimination--and we have to work with this because we are part of a culture. And definitely we need to continue to strengthen and continue to develop training activities in order that we be able to feel in the very near future satisfied with the results that we will achieve in our professionals.

Thank you very much.

[Applause.]

T3S1 CHAIRMAN OSBORN: Thank you very much.

Mr. Nieves?

MR. NIEVES: Good morning.

My name is Enrique Nieves, and I am with the Central Office for AIDS Affairs, OCAS, which is part of the

Department of Health of Puerto Rico.

I would like to thank the members of this distinguished Commission for giving me the opportunity to express my thoughts this morning.

I will start by saying that in 1985, when the Food and Drug Administration approved the ELISA antibody test to screen blood supplies for HIV, the Centers for Disease Control approved funds to be used in the establishment of alternate testing sites. These sites were to provide persons engaging in high-risk behavior for AIDS an alternative to going to a blood bank for an HIV antibody test.

Puerto Rico opened four of these sites--one each in Ponce, Rio Piedras, Mayaguez, and Caguas. In 1986, funds were also provided by CDC to initiate risk reduction activities in Puerto Rico. Thus the beginning of the HIV Prevention Program within the Department of Health.

Today the HIV Prevention Program as part of the newly-formed Central Office for AIDS Affairs, OCAS by its Spanish acronym, has expanded counseling and testing services on the island. There are now over 61 counseling and testing sites operating in Puerto Rico, providing services to the general public.

To the HIV-positive patient, these counseling and testing sites serve as the entrance into a large support infrastructure consisting of immunology clinics, psychosocial services, hospitals and hospices.

The Health Education/Risk Reduction and public information efforts have also improved. OCAS offers contracts to community-based organizations and other Government entities to expand Health Education/Risk Reduction activities. OCAS outreach teams are reaching more persons in the high-risk target areas of the island.

Public information is being disseminated through the Puerto Rican airwaves and press. Posters, bumper stickers and promotion materials have been distributed throughout the island.

Despite all the improvements, priorities are still being identified to continue our never-ending efforts against AIDS.

Heterosexual i.v. drug users continue to be the group with the highest incidence of AIDS and HIV infection. It is interesting to point out that the hierarchy of patient groups confirmed with AIDS is different from those of patients testing positive for HIV at the counseling and

testing sites. I refer you to Figure 1 in my handout.

This difference should be explored further, since a group such as heterosexual females may require different services than gay males. And if there is difficulty in attracting gay males to the counseling and testing sites, then we should explore avenues to attract this group or any other group that may be staying away from counseling and testing sites for any reason.

Needs assessments must take into consideration these differences in the hierarchy of patient groups if the HIV Prevention Program is to effectively plan ahead for future services.

Outreach activities among the i.v. drug users must remain priority within the program, but the focus of these outreach activities should be redirected to street intervention to promote drug treatment and referral, elimination of needle-sharing behavior, safer injection education through proper needle exchange programs, and demonstrations of proper condom use to persons in the streets engaging in risky behavior. We must take the classrooms to the streets.

Puerto Rico can no longer afford to be conservative in its policy toward HIV prevention. We must study and

consider creative alternatives such as needle exchange programs and drug maintenance programs for injectable drugs.

Public information must also be used to raise conscience among Puerto Ricans. In the recent past, lack of concern and understanding were the reasons why public information was not a priority. Situations like the one in Luquillo, where residents opposed the construction of a shelter for AIDS patients, must be defused before any erroneous information gets into the community. In the Luquillo case, the problem was compounded with a misinformation campaign.

Confidential testing and voluntary partner notification must be another priority within the HIV Prevention Program. Puerto Rico now has an infrastructure to care for any person testing positive for HIV. It is in the best interest of the patients to know and understand their condition, just as it is in the best interest of the program to maintain sero-negative those individuals testing negative and exhibiting high-risk behavior. We must continue to rely on voluntary partner notification until a better way of providing education and information to partners of those who test positive is found.

In 1989, CDC sent a special enjoy to explore the possibility of integrating AIDS services in Puerto Rico. In his report, the envoy recommended that an umbrella organization with fiscal responsibilities be created to coordinate all AIDS/HIV activities on the island.

The Central Office for AIDS Affairs, OCAS, was created to coordinate such activities. In July of 1990, OCAS made a major commitment to fund 32 new disease intervention specialist positions, marking the first time that Commonwealth funds will be used in Health Education/Risk Reduction activities within the HIV Prevention Program. Since the initial CDC grant awarded in 1985, no significant amount of commonwealth moneys have been assigned to the HIV Prevention Program.

The new plan to combat AIDS will address the actual needs of Puerto Rico if funded properly. OCAS may very well be the only institution with enough resources and expertise needed to integrate the five essential components for a comprehensive and much-needed AIDS strategy in Puerto Rico.

These five essential components are community-based organizations, prevention programs, treatment centers, hospitals and hospices, including shelters.

Community-based organizations that are currently running risk reduction programs can be immediately funded to continue and expand pertinent services, thereby reducing the delay in hiring staff and in program development that usually occurs in Government agencies.

Prevention programs must concentrate on implementing health education/risk reduction strategies proven effective with all patient groups. Treatment centers must offer persons with HIV infection a supermarket approach or rather, a one-stop-for-all clinical and psychosocial services needed.

More hospitals and shelters must be built for patients with acute and terminal conditions as well as hospices and home health services for patients with chronic conditions.

The proper integration of these services will help us reduce the incidence of HIV, increase knowledge of AIDS, improve patient care, and improve surveillance and reporting of cases.

In conclusion let me just say that funds are still desperately needed for AZT treatment and alternatives to AZT treatment, not only for all AIDS patients who need it, but

also for prophylactic treatment of HIV-infected patients who are asymptomatic. For this, we must start by helping with lobbying efforts in the U.S. Congress to eliminate funding ceilings on Medicaid and other Federal programs in Puerto Rico, in addition to identifying new sources of funds locally.

As an afterthought, upon reflecting on this problem, I have found that the situation is so overwhelming that it requires a radical change in the way we view problems.

The solutions may jolt the foundations of our traditional values and beliefs. Five thousand cases should not simply be a figure to justify funding. Five thousand cases are 5,000 fellow Puerto Ricans who must be cared for at all costs in the tradition of collectivism and survival that has been the bulwark of Puerto Rican society since Taino times.

We exhort all Puerto Ricans to work together to rid Puerto Rico of this terrible malady before we lose a generation of productive Puerto Ricans.

Thank you.

[Applause.]

CHAIRMAN OSBORN: Thank you very much.

Dr. Santiago?

DR. SANTIAGO: Good afternoon, honorable Commission on AIDS, and all of those present here this afternoon.

My name is Wilfredo Santiago, and I work in the AIDS Foundation in Puerto Rico. I started to work as a case manager, and actually, I am the director of operations of the Project Alto al SIDA, that is, "Stop AIDS". This project is directed exclusively to the bisexual and homosexual community in Puerto Rico. It is of extreme importance for us, the homosexual men and bisexual men who live in Puerto Rico, the objectives that bring you to this meeting.

The bisexual and homosexual community in our country is under a veil of persecution and attack that we know as "homophobia". The principal areas of the Government, sadly, manifest this prejudice, and as a consequence at the present time the programs on education and prevention of AIDS in Puerto Rico do not include in their work plan to reach our community.

It is curious and somehow paradoxical that this homosexual and bisexual sector of our population is impacted in accordance with the CLET, the Latin American Center for Sexually-Transmitted Disease, to make something of this.

The statistics as of November 5, 1990--statistics

that you as well as we have in our hands--show that one-third of the cases reported respond to homosexual and bisexual men in our country.

If we go ahead under the premise that the cases reported are only a fraction of the existing cases, and that for each case of AIDS there are ten asymptomatic cases, this will give us an idea of the magnitude of the problem within the homosexual and bisexual community.

Faced with this situation, the state has not assumed a positive attitude with respect to this problem, understanding that this is a reality and that the existing institutions do not have the criteria for objective intervention that has given birth to this project, "Stop AIDS" or "Alto al SIDA", which is an alternative for the bisexual and homosexual community in our country, with the understanding that the sexual option of an individual, the lifestyle of an individual, should not be an obstacle to their right to information and education on prevention of AIDS.

We have to emphasize the fact that many of you have not recognized us as a community. We have always existed. It is very sad that the AIDS situation should be the cause that many of you have to look back to see us as a community.

We have always been here.

In our society it is very difficult to be homosexual and bisexual openly. The double life, the hiding, constitutes one of the best strategies of survival. This reality has to be taken into consideration when you try to carry out work on intervention.

The Project "Alto al SIDA", "Stop AIDS", is in the homosexual and bisexual community seeing these characteristics not as personal deficiencies but as the result of a society that has continuously oppressed us. This movement, "Alto al SIDA", is based on the fact that the prevention and the awareness of AIDS is only possible if the gay, bisexual and homosexual communities take into their own hands the training and education on this subject.

We have been working very hard on the implementation of a model, understanding that a model of peers will facilitate intervention in the community with a higher reach within the members of the community. The process of awareness, the change of attitude, is better generated in an environment by those who are participants, peers. The project has as its primary objective the promotion of a professional and personal change, reducing high risk sexual conduct among gay

and bisexual men in Puerto Rico and to stimulate the participation of gay and bisexual men in organized groups.

It is important to point out that although the process of intervention has not been easy, the project has made its presence felt within the community, and at this time is getting support from the community. This is evidenced through the active participation of community members in the development of the model, and in individual efforts in the process of making pressure among individuals to establish new rules that will result in the diminution of high-risk sexual conduct.

Our commitment as a project is to stop AIDS within our community. My hope, here before you, is to bring to you awareness of the need and importance of projects directed to the homosexual and bisexual community in Puerto Rico.

We hope that the governmental institutions will support us economically so we may continue to carry out effectively the work that our project is carrying out.

I do not wish to conclude this paper without leaving with you and the public here present a few words, that we must understand that we have to respect the decisions of persons as well as their lifestyles.

Thank you.

[Applause.]

CHAIRMAN OSBORN: Thank you very much.

We have time only for a couple of quick questions because we have a very long list of public commentators, and we'll need to talk about that in a minute.

Don Goldman?

COMMISSIONER GOLDMAN: Thank you.

I have a series of quick questions, and I think most of them can be answered with a very short "yes" or "no".

Is the National AIDS Hotline "800" number available in Puerto Rico, for Puerto Rican citizens to call?

MR. NIEVES: Yes. The National AIDS Hotline is available, but in Puerto Rico we also have a local hotline.

COMMISSIONER GOLDMAN: Was the Spanish language version of Surgeon General Koop's report mailed to every resident of Puerto Rico as it was in the United States?

MR. NIEVES: Yes, it was.

COMMISSIONER GOLDMAN: How many anonymous test sites are there in Puerto Rico?

MR. NIEVES: We have over 61 counseling and testing sites. Of those, anyone wishing to have an anonymous test

can have the anonymous test. We stress confidential testing because we see the need for partner notification.

COMMISSIONER GOLDMAN: One of the witnesses earlier reported that it may take hours of waiting for a person to get a condom from a family planning center. What role does the Government play in the distribution of condoms, and what role ought it be playing?

MR. NIEVES: As far as public policy for distribution of condoms, I am not aware that any of the programs are distributing condoms except for the programs engaging in high-risk intervention as far as health education and risk reduction is concerned, and the family planning clinics and other clinics that cater mainly to female patients.

COMMISSIONER GOLDMAN: And are there professional education programs designed specifically for dentists, allied health professionals, judges and other people in the legal and correctional system, and teachers in the school system?

DR. GELY: Yes. For teachers, it depends, because teachers are not considered health care providers. But anyway, if a teacher asks us for some information, we provide information. But teachers are not included in our training now.

MR. MORALES: OCAS has developed different types of activities in the area of teacher education. This has been offered through the Central Office but also through regional instruction at the regional level. That includes training for supervisory personnel and also to teachers. On the other hand, the Public Education Department has taken initiatives in the training area, and there are a number of teachers--I don't know exactly the figure--but many teachers have been instructed in the HIV and AIDS area.

CHAIRMAN OSBORN: Eunice?

COMMISSIONER DIAZ: Daisy, I'd like to ask you a question. The AIDS ETCs primarily have been an interest of mine in terms of what they can do to increase manpower and people working in HIV, the many hands that we need to be able to tend to this epidemic.

Have you seen, in the brief time that you have directed these activities in conjunction with NYU, an increase in the number of primary care providers and physicians and nurses that really want to deal with AIDS as the direct result of your activities, or maybe jointly because of your activities and someone else's, and do you think that is going to impact what we are seeing here?

DR. GELY: The answer is yes, and the answer is yes because of the following. Before the ETCs were established, so many activities and entities have been trying to put together educational programs for health professionals--entities like CLET, for example, and professional associations. But they are not doing the education and training sessions in a systematic way.

Now, let me explain something. CLET has been doing the training sessions in a systematic way, but we know that CLET doesn't have enough spaces for all the health professionals. So as soon as the ETCs start functioning in Puerto Rico, we can expand the opportunity for different health professionals to attend the training sessions.

And we know, and we are very convinced, that through these activities health professionals start dealing with their attitudes and with their position as to dealing with persons with AIDS; we know that we have some type of input, but we know that we have to do a lot more work.

CHAIRMAN OSBORN: Let me thank all of you for your very useful testimony. We appreciate the input.

I would like to organize the next bit of time in a way that is a bit of a change from what I gather appeared in

the newspaper. We have only half an hour scheduled for public comment, and we have 20 people who have indicated their wish to speak to us.

Let me first invite anyone who finds that one and one-half minutes or thereabouts is too pressed a time to say what you want to submit your comments in writing, and we will assure you that we will read them and take them seriously, and perhaps even understand them better. That is my first suggestion.

What we are going to try and do is to establish two microphones so that people can take turns without any time for transition. The reason for the time pressure is that we have very important commitments at several places at some distance on the island where people have gone to extensive lengths to prepare for our visits. So I think we must honor those commitments, which have been planned for many weeks.

I therefore hope that each speaker will be as brief as you possibly can be--don't feel obliged to even take up your one and one-half minutes. If you can give us the sense of what you want us to hear, and if it has been said before, underscore it quite briefly, that will be very helpful.

We do want to hear from you, and we regret having

to compress the time so much, but I think it is important so that we can get the full benefit of our visit to Puerto Rico.

I am going to ask Eunice Diaz to help me by calling the names, because I know that I will not pronounce them correctly if I try, and I am very grateful to Eunice for so doing.

We will put the timer on, by the way, so we can keep track for ourselves, because we must be done before 1:00.

COMMISSIONER DIAZ: We will call first on Ineke Cunningham, Maria del Rosario Rodriguez, and Donald Babb.

MS. CUNNINGHAM: Distinguished members of the Commission and concerned colleagues, in two large surveys of 2,000 and 4,000 students at the University of Puerto Rico, we have found that although 95 percent of the students knew the use of condoms decreased the risk of transmission of AIDS, only 11 percent of those sexually active indicated they always use condoms, and over 40 percent never use them.

Over 30 percent of women and close to 40 percent of men who are sexually active indicate they have engaged in anal sex. The reasons given for this practice that the decision to engage in anal sex is usually made by men, and women accede to their partners' pleasure.

Alcohol use is high, and when students drink, there is a high correlation between risk behavior and alcohol consumption. If these findings hold true for a fairly conservative student population, what kinds of other populations are engaging in these risk behaviors?

Most students indicate they have little actual knowledge of how to protect themselves. Seventy percent wish to access to courses on sexuality and AIDS, and 90 percent would like to see an office of professional counselors.

COMMISSIONER DIAZ: Thank you.

To save time, I will introduce the speakers by their titles. Dr. Cunningham is a professor of sociology at the University of Puerto Rico.

Maria del Rosario is also a professor at the University of Puerto Rico in biostatistics.

MS. DEL ROSARIO RODRIGUEZ [Interpreted from Spanish]: Good afternoon.

My name is Maria del Rosario Rodriguez, and I have been a volunteer at the AIDS Foundation since 1987.

I believe that the contribution of volunteers is very important in the management of this disease. In 1989 we conducted a study in the AIDS Foundation to quantify the

financial contribution of volunteers. The services offered include a buddy program for emotional support, a support group facilitated by sociologist workers, and practical support by health educators. This type of study has not been carried out by community organizations frequently enough. Our study reflected a small annual budget of $340,000 during 1988-89; $130,000 additional were added, or 35 percent of the total budget, through contributions of volunteers.

Volunteers exist, we contribute, and our contribution has economic value for society and persons who are infected with AIDS.

Thank you.

[Applause.]

COMMISSIONER DIAZ: Thank you very much.

Mr. Donald Babb is former President, Board of Directors, Fundacion SIDA.

MR. BABB: Good morning. My name is Donald Babb. I am a journalist and an AIDS volunteer, but I am testifying today as a gay man.

Since the AIDS epidemic began in Puerto Rico in 1981, there have been 1,332 cases of AIDS reported among gay and bisexual men on the island. This is 26 percent of the

total number of cases reported as of October 29. In the past two years, the number of cases in this population increased by 394, a 42 percent increase.

The Health Department estimates that as many as 40 percent of the AIDS cases in Puerto Rico are not reported. It is my belief that many of these unreported cases are among gay men who can afford to get care from private physicians who are willing to protect their clients' privacy.

The 42 percent increase in cases among gay and bisexual men compares unfavorably with the rate of increase in this population in the United States, which is 36 percent. This should lead us to question why the health departments of Puerto Rico and San Juan have failed to carry out or fund preventive education for this population during the last nine years and, perhaps more important, why none of the millions of dollars in Federal funds provided to these agencies for AIDS prevention have been used or made available to educate gay and bisexual men.

The attempts by community-based organizations to get the Government to use a share of these funds to educate the gay community has met with two contradictory reactions--it is impossible to reach these people, and gay men are

educating themselves--both false statements.

The new Government plan to deal with AIDS in Puerto Rico contains no provision to provide education to gay and bisexual men, in spite of the fact that representatives of AIDS service organizations asked that this be included in the plan.

If the rate of increase of AIDS among gay and bisexual men does not move the Government to action, perhaps the findings of a survey financed by the CDC may. The study, done by the Northeast Hispanic AIDS Consortium, found that 65 percent of the self-identified gay men had unprotected sex with another man in the past year.

It seems clear to me that there is need for massive efforts of preventive education and that the gay community, which is not organized, does not have the clout to force the Government to carry it out.

My recommendation is that the Federal Government through the CDC insist and find ways of requiring that whenever funds are given to Government entities, those Government entities ensure that the gay population receives the funds it needs for education.

Thank you.

COMMISSIONER DIAZ: Thank you, Donald.

The next three people come forth: Frank Chardon, Hector Colon, and Dr. Victor Llado.

MR. CHARDON: Good afternoon to everybody. We are reaching meal time.

My experience in the AIDS field has been related to AIDS programs in San Juan as director. I direct an indigenous outreach to i.v. drug users on the streets. We were very successful for a year in terms of changing risk behaviors among i.v. drug users in the streets in terms of bleach. In terms of sexual condoms, we were not that successful with men, but we were very successful in terms of changed behavior with female i.v. drug users.

The success of Rosante [phonetic] both locally and nationally was due to the fact that in a year's time it achieved actual behavior modification of risky drug and sexual practices, and we were promoting the spread of the epidemic. It was a very complex process that I will try to convey to you in rather simple terms the most effective strategy that led to our success.

The best place in which to promote AIDS prevention among i.v. drug users is in their own neighborhoods, par-

ticularly where the action is--in the shooting galleries. Since the attention span of drug users is short, use of condom demonstrations and safe sexual practice must be given close to the place where they solicit their sexual transactions. This is not difficult in the case of most female i.v. drug users, since there are more or less regular hours and places for this type of activity. It is more difficult with the male counterparts.

Printed educational material about AIDS should be brief and very visual. I.V. drug users don't care much about reading pamphlets, newspapers, or watching television. Pocketbook-sized materials that can fit in their wallets may be the best of all.

The best outreach worker for an i.v. drug user is a recovered addict who knows the turf. The empathy that recovered addicts have with addicts on the streets enables them to do a more satisfactory job on health issues regarding AIDS than anybody else. This has been shown by [inaudible] and Hogar Crea las Americas.

It is rather risky to send health professionals with proper knowledge of i.v. drug user lifestyle to provide services to this population. Furthermore, it is far easier

to modify i.v. addiction practices, which are mostly public in Puerto Rico, than sexual practices, which are mostly private. Furthermore, it seems easier to prevent contamination by sharing dirty needles with bleach than to promote a new sexual practice of using condoms in intercourse. This implies that we have a more difficult task to promote safe sexual practice in Puerto Rico than in the United States, due to the "macho" lifestyle of our culture. We cannot copy sexual materials from the mainland if we do not incorporate specific strategies to deal with "machismo" and AIDS.

Since 1989, no free bleach or condoms or educational materials have been available to the i.v. drug users on the streets that I serve. Recently, a patient at the day care center for AIDS patients that I direct told me: "There were 14 guys before me who used the needle." We must face the reality that the majority of i.v. drug users are not in drug treatment and that we have not yet given the means to avoid AIDS.

My former staff and myself felt very proud to have rendered a valuable service--

VICE CHAIRMAN ROGERS: Mr. Chardon, you are going to have to conclude quite quickly.

MR. CHARDON: Okay. This is the last sentence. My former staff and myself were very proud to have rendered a valuable service by distributing in a militant way bleach and condoms in San Juan. We overcame the usual social and political tabus in dealing with condoms. Attached to my written statement will be an article on Orisante [phonetic].

Thank you very much.

COMMISSIONER DIAZ: Thank you so much, Frank.

[Applause.]

COMMISSIONER DIAZ: For the sake of time, could we withhold the applause until the last witness?

Dr. Llado?

DR. LLADO: My name is Victor Llado. I am a psychiatrist, and I am president of the Puerto Rico Chapter of the American Psychiatric Association.

I have submitted a position paper that I handed to your staffperson during the break, and I trust you have a copy of that paper.

I am a faculty member of the University of Puerto Rico, where I teach psychiatric epidemiology at the School of Public Health, and law and psychiatry at the Law School of the University of Puerto Rico.

I come here on behalf of our organization, which represents more than two-thirds of the practicing psychiatrists in Puerto Rico. We submit to you that the rampant propagation of AIDS in Puerto Rico is to a considerable extent the indirect result of the lack of adequate mental health and substance abuse services.

The Puerto Rico Department of Mental Hygiene, besieged by Federal court-imposed fines for its deficient, non-[inaudible]-accredited Psychiatric Hospital, although improved, still falls very short of meeting the most elementary needs of the affected population.

On the other hand, the Anti-Addiction Services Department is a mammoth bureaucracy, functioning in an isolated fashion, which renders fragmented services without sufficient coordination with the Health Department.

One of the most crucial concerns that we would like to present to you today is the lack of psychiatric services for the AIDS population--indeed, this is the one most serious deficiency in the current effort against AIDS in Puerto Rico.

In this day and age, when we are experiencing such an explosion of knowledge in the field of neurosciences, including the beginnings of pioneering areas such as psychoim-

munology and the development of innovative diagnostic and research techniques such as CD-scan, NMR, the availability of psychiatric consultation and treatment services is a must in any comprehensive strategy against AIDS.

We don't need to remind the honorable Commission of the fact that oftentimes it is precisely through the neuropsychiatric evaluation that we can detect early subtle signs and symptoms of the disease.

Our AIDS patients deserve the benefit of--

VICE CHAIRMAN ROGERS: Dr. Llado, you are running past your time. I am pleased that we have your written statement, so if you could conclude quickly.

DR. LLADO: Lastly, we would like to place our opposition on the record to the rather hysterical and desperate local government efforts to try to impose mandatory testing in Puerto Rico. We think this is absolutely wrong, and we substantiate our position in the position paper we have submitted.

Thank you.

[Applause.]

COMMISSIONER DIAZ: Thank you.

Evelyn Rosado, Director of Health Education for the

Puerto Rico Department of Education.

MS. ROSADO [Interpreted from Spanish]: An education project on AIDS was incorporated into the health program for the school year 1987-88. In the first stage of the project and in coordination with the Latin American Center for Sexually-Transmitted Disease, we trained supervisors of public health and school nurses. These two groups constitute the orientation staff for teachers in the 100 school centers for the education system.

The second phase of the project is adoption of a curriculum. Since 1988, we have started development of curriculum material, and we have prepared materials from kindergarten through the twelfth grade. To enrich this material, we have acquired films, videotapes, and books and pamphlets for teachers.

The impact of this project since 1988 to date is 710,864 students from kindergarten through the twelfth grade, and 15,400 teachers. During the school year 1989-90, we impacted at the elementary level 49 percent of the student population and 50 percent at the intermediate level, the high school level.

The public policy of the Education Department,

dated April 13, 1988, guarantees the right of any child who is infected with HIV or diagnosed with AIDS to receive educational services.

The projections of the Education Department for this year are: to offer special assistance to two educational regions which impact less than 50 percent; to prepare a manual and follow-up activities for eighth, ninth, tenth, and eleventh grades; to offer a workshop for teachers at the higher education levels, and to update public policy.

Thank you.

[Applause.]

MS. VALENTINE [phonetic] [Interpreted from Spanish]: I am Marie Valentine. I am supervisor of a health zone, and I am in charge of Rio Piedras Health Zone 5, in which we are implementing the public policy because we have two schools that have children with AIDS. This is confidential, and for that reason we cannot say how many children we have. But what we want to tell you is that we are dealing with the teachers; we are giving them orientation, especially in sexual education, so that although children at this age do not have sexual relations, they may be protected from touch--we tell them the acceptable touch and the unacceptable touch.

We have materials for all grades from kindergarten to grade 12.

COMMISSIONER DIAZ [Interpreted from Spanish]: Thank you very much. If you will give us that material, it will become part of the Commission's record. Thank you.

Dr. Jose Carrasquillo is next, from the Puerto Rico Corrections Administration, where he is the Medical Director; then Carlos Castro and Mr. Velez.

DR. CARRASQUILLO: Good morning. I am Dr. Jose Carrasquillo, Medical Advisor to the Administration of Corrections. Dr. Ramos [phonetic], Administrator of Corrections, has asked me to indicate to the distinguished members of the National Commission on AIDS to excuse her for not being here today. She had a prior invitation for a special activity with the Governor of Puerto Rico in a beautiful town in the western area of our island.

Also, she was not officially invited for these hearings. She indicated in writing her viewpoints regarding the Correction Administration, intervention, coordination, caring, understanding and love to inmate patients or convicts suffering from HIV or AIDS.

On her behalf and mine, we appreciate your attention

and collaboration with the Puerto Rican Society regarding the suffering of citizens with this condition in the States and Puerto Rico.

Thank you.

COMMISSIONER DIAZ: Thank you very much.

Danny Velez?

MR. VELEZ [Interpreted from Spanish]: Good afternoon. My name is Danny Velez, and I am a consultant in strategies of communication.

Yesterday and this morning, you have been witness to the problems existing in Puerto Rico in relation to AIDS. We are all aware that we have to do something soon for those who are infected and those who are at risk of being infected.

The most important thing that I wish to bring before you for consideration briefly is the need and importance of creating in Puerto Rico as quickly as possible a massive campaign of education. Under these circumstances, I request that this Commission request the Congress of the United States and the President of the United States to assign emergency funds for the people of Puerto Rico for a massive campaign to prevent this illness that is affecting us so much.

Thank you.

[Applause.]

COMMISSIONER DIAZ: Thank you.

Carlos Castro.

MR. CASTRO [Interpreted from Spanish]: Good afternoon. My name is Carlos Castro. I am a person with AIDS.

I wish this morning only briefly to tell you the experience that I have gone through, the rejection and the discrimination experienced by me in hospitals here in Puerto Rico. The year 1988 went by, and it still happens with a lot of persons here in Puerto Rico who are AIDS patients--in the offices of Government, also. When you present yourself as a person with AIDS, they put you aside, and you have to wait. When I went to ask for services, I had to look for my sister to go with me because they did not allow me to go into the social services office. This is happening here in Puerto Rico.

I am a volunteer in the AIDS Foundation, and I volunteer in other organizations here in Puerto Rico. I support everyone with AIDS and the families of those persons.

What has enraged me more is that not even after

death are we safe from discrimination against us; after you are dead, the discrimination continues, not only with us but with our relatives.

What I am asking is that I would like the Foundation on AIDS, as their client and as a volunteer--we have helped a lot of people, and we are continuing to do that--but the funds we have are not enough for so many patients here in Puerto Rico, and we really need your help, because here the Government of Puerto Rico is not doing anything.

Thank you.

[Applause.]

COMMISSIONER DIAZ: Thank you.

Delia Sanchez.

MS. SANCHEZ [Interpreted from Spanish]: Good morning. My name is Delia Sanchez. I am a businesswoman and mother of three children.

I lost only four months ago a child, and I have a message. Number one, to the patients: Have faith and hope. Do not give up when the doctor gives you a diagnosis. Look for alternatives. There are rights that all patients should explore. Governmental agencies, hospitals and insurance companies are exposed to a lot of risk of malpractice, but no

patient should be denied the right to be hospitalized and not be discriminated against. I have to mention the case of my son. The Presbyterian Hospital threw him on the floor of the emergency room, and his doctor when he was called did not come to resolve the problem that night.

To the medical clients, I say, like Dr. Siegel [phonetic]: Love, medicine and miracles. Never should you say there is nothing else to be done. The doctor should be the last one to lose hope. Don't be so logical; do not throw away alternatives. For the good of the patient, unite to search for solutions to this great ill.

And lastly, to the Government, especially the Department of Health: Remember that you have a commitment with the health professionals and with the population in general to [inaudible] the hospitals, the doctors, the emergency rooms for the rejection and maltreatment of patients, that this should not be tolerated. Listen to the complaints, and act upon these complaints. Do not allow that many profit from pain and suffering and the loss of hope of the people affected.

Health service is not a privilege; it is a right. It is a right, and I tell the Government we should not

tolerate these abuses. We hope that you act.

Thank you.

[Applause.]

COMMISSIONER DIAZ: Thank you.

Ms. Serrano.

MS. SERRANO: Good morning. I am a woman affected by AIDS. My husband is an AIDS patient. But after we cried after the initial news, we decided not to faint in the day of adversity, and we founded the Association of Relatives and Friends of AIDS Patients.

If AIDS is not a civil rights problem, then why was it necessary that we go to court in order to open our 10-bed hospice which we opened recently in Luquillo? It is. So we are happy that we finally opened our hospice, and we are operating, with only half of our budget. CBOs like ours need the funds to give the services patients need.

I also want to add that all of our members are also

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members of the ELISA [inaudible] Puerto Rico, and we emphasize that funds are desperately needed.

[Applause.]

COMMISSIONER DIAZ: Glorin?

MS. MARTIN [Interpreted from Spanish]: Good

afternoon. I am Glorin Martin, and I work in the [inaudible] Jesus, which is a place where we provide basic services to homeless people..

As you know, many of these people without homes are also AIDS patients. For them, the reality that we have heard here is complicated because they have no facilities where they can be treated.

We would like to present the reality of the people with AIDS. Once they have been infected, we have found many people who visit our facilities who don't have a place to go or to sleep until they are dying. In Puerto Rico, there are facilities where they can go, but they have to be dying in order to be admitted.

At the same time, there are other facilities, but they must be drug addicts and be willing to enter rehabilitation programs in order to be admitted to those centers.

However, there are people who are not drug addicts, and who have AIDS and who are not dying, and who are in the streets, without any type of attention. We are concerned. We need to have a place where they can come. We know that it is a health problem to have the hygienic facilities. We would like to suggest as an alternative to develop in the

community centers a place where they can take a bath, because it is so important for people with AIDS that they be able to wash their ulcers and their wounds, because they multiple when they are living on the streets. This would allow them to live with some dignity until they find a solution for them so they can treated.

Thank you.

[Applause.]

COMMISSIONER DIAZ: Thank you. I congratulate you.

Dr. Castano?

DR. CASTANO: Good afternoon, ladies and gentlemen. My name is Rafael Rivera Castano, and I am professor of epidemiology at the School of Public Health at the University of Puerto Rico Medical Sciences Campus.

In the brief moment I have, I just want to tell you that I am going to prepare a written position paper that will be sent to you in the next few days. I am very much concerned at the way this meeting has been organized, that you are not getting the whole picture of the AIDS problem in Puerto Rico.

Specifically, I am very much concerned because there has been no official position of the University of Puerto Rico during these two days, and I hope through my

presentation to express to you the role that I think the University of Puerto Rico should have in the training of professionals in the epidemiological and sociological research on HIV infection in Puerto Rico and in the establishing of public policy in the island. After ten years of the epidemic, we still lack a public policy that is really consistent with the real problem in Puerto Rico.

Thank you very much.

[Applause.]

COMMISSIONER DIAZ: Thank you.

Judith Rosy.

MS. ROSY [Interpreted from Spanish]: Good afternoon, everyone. I am Judith Rosy. I am the founder of the Mision Cristiane Hospice, which is a program for addicts and alcoholics. We are located on a farm, and we were founded in 1966.

Four years ago, when the young people started to get sick, we had to prepare a provisional hospice because they had no families. They were treated in the area hospital in [inaudible], but they were returned to our place, so we had to prepare this hospice.

We almost always have 35 or 40 cases which are

AIDS-positive. The social services program donated $40,000 for a building which is being constructed. We have annexed that to another building to expand our facilities and improve the services of physicians and nurses who treat these patients.

In regard to the issue of conditionality that I have indicated, as the director of a program, I have to deal with the wives, the sweethearts, the girlfriends and all the relatives of these patients, and because of the confidential aspect that we have, we have not been able to tell the truth to these people about the patients. This has brought trauma to me, knowing that there are many girls who have married these youngsters, and I have not been able to tell them the truth. We must bring this to the legislature to do something, because this disease is being propagated, and it has to do partially with the confidential aspect of the disease.

[Applause.]

COMMISSIONER DIAZ: Thank you.

Luzie de Muniz.

MRS. DE MUNIZ [Interpreted from Spanish]: Thank you, and good morning. Although I can give my statement in English, I think I am going to give it in Spanish because I

think I can put my heart out better in my own language.

My name is Luzie G. de Muniz, wife of 46 years and hoping for more. I am the mother of nine children, one of them adopted, and I am the grandmother of 18 grandchildren. I am a citizen who is concerned for my family and for the families of all Puerto Ricans.

I come here today to defend the life of a young mother who has honored me with her friendship. I hope that by defending her life I will be able to defend the lives of many girls under the same circumstances.

This young woman is 33 years of age. Three months after birth, she was found in a community of the island where they say that the Virgin Mary appeared. She had no identification. She was taken to a hospice for girls, and she lived there for 12 years. Some people who took affection for her adopted her, and she was dreaming of love, affection, a home, and a family, but awakened to the sad reality that what these people were in fact seeking was a maid.

When she was 13 years of age, a member of the family raped her, and she had to be hospitalized. Because she told the truth and they found the man guilty, she was thrown out of the house.

She worked wherever she could--family homes, businesses, et cetera--and at the same time, she studied and was able to graduate from high school. She is an intelligent and well-developed person who has the facility to express herself. She has three children. The oldest girl and the first child are healthy. The third child is five years old. His father was a drug addict who contaminated her, the mother, and she transmitted this to the child. To complicate things even more, the girl is RH-negative type of blood. Her husband mistreated her, abused her physically--

VICE CHAIRMAN ROGERS: Luzie, to my sorry, you will have to conclude fairly quickly.

MRS. DE MUNIZ: Oh, please, please--

VICE CHAIRMAN ROGERS: We must be fair to all those who wish to speak.

MRS. DE MUNIZ: I know, but I have been here two days, listening to everybody. And when I spoke with Mr. Carlton Lee in the office of Ms. Byrnes in Washington, he told me that I was the first person who called to speak as a citizen. And I am not going to leave this place until you listen to my statement. I am going to finish in a little while, just about three minutes more.

VICE CHAIRMAN ROGERS: Please go ahead. We just want to try and be fair to the whole group. We know how hard all of you have worked on this.

MRS. DE MUNIZ: Oh, yes, I will go ahead. Thank you very much.

CHAIRMAN OSBORN: As I mentioned, Luzie, we have many groups that have worked very hard as well--

MRS. DE MUNIZ: I know, I know, but when I spoke to Mr. Carlton Lee, he told me I was the first person, so I should have been the first person to talk here.

CHAIRMAN OSBORN: Finish your statement as quickly as you can, if you would, please.

MRS. DE MUNIZ [Interpreted from Spanish]: Her husband mistreated her physically, and she was desperate and fearing for her life, and had to leave the husband.

She now lives with a many who loves her in spite of everything. He takes care of the three children. I was able to see that he treats her well.

There is talk about AIDS in this family, and they speak of it as a reality of life, this mother of three children and her young partner who does not want to abandon her. The sick treatment is receiving treatment for his

condition. He appears to be healthy, but not the mother. She cannot receive preventive treatment because the policies in our country establish it that way. Only AIDS patients who have symptoms are included. If she were to live in the United States, she would be able to receive treatment with her Medicaid card. It is not that way in Puerto Rico, and this is discrimination. If somebody has a better word, please correct me. This is not a fair situation for this young mother and for many others.

That is why I am here. I ask--rather, I demand--that these regulations be reviewed and if necessary changed. If the amount of AZT available is not sufficient for all AIDS patients, it must be sufficient to take care of the thousands of young mothers who need it, even though they don't have the obvious symptoms. This should be done as a prevention measure.

For many centuries our society has discriminated against women, and I say it has been long enough.

I talk about my friend to show that this is the worst type of discrimination. She has not been given AZT, and in that way they are condemning her to a rapid death. It is our obligation to help her as my family has helped her; we

have adopted her.

I propose and I expect that the people of Puerto Rico who can listen to my testimony devote part of their time to support a family, to adopt a family. Many of us can do it.

Thank you very much.

[Applause.]

DR. DAVID: Good afternoon. My name is Dr. Emilio David, and I am the President of the Puerto Rico Public Health Association. I would just express my regret that this Commission did not deem it necessary or important enough to hear our opinions.

Thank you very much.

COMMISSIONER DIAZ: Thank you.

Carlos Hernandez and Joey Pons are the last persons to participate.

DR. HERNANDEZ-BADA: Good afternoon. My name is Carlos Hernandez-Bada. I am a doctor, and I have worked for the past two years with patients with AIDS.

There are many agencies here in San Juan that are working with AIDS patients, and this many times results in duplication of services; however, we are lacking others. Many times, the patients get tested and open their records,

and the same day they go to another institution, and they do the same thing at the other institution. So what happens--many things are duplicated.

However, first-line medications, 50 percent of the time are not available. Some patients have waited two or three weeks or two or three months for AZT, and as you have seen here, the mother very naively mentioned, "AZT--why?" because she felt very well. Maybe she had never had CD4.

To end, I will say the patients just wait too long. It is very painful. At the end of many weeks, I only have one bed and ten patients to be hospitalized. Many times, I have had to complete death certificates for many of them.

All the institutions are working, and I recommend that they group together, all of these institutions that are working well here in the metropolitan area, and join within one institution--not to close them, but that they integrate into one organization so that we have no duplicity of services and better treatment is given.

Thank you.

[Applause.]

COMMISSIONER DIAZ: Thank you.

Joey?

MR. PONS [phonetic]: Good afternoon. My name is Joey Pons. I am a Puerto Rican, a homosexual, and a person with ARC. I am here to express my anger at the fact that gay issues had no place in these hearings, although we make up a big part of the communities devastated by this pandemic.

It is shameful, disgraceful and outrageous that the facts regarding AIDS and gay men in Puerto Rico had to be brought up by an individual in the public comments section.

Gays with AIDS in Puerto Rico die secluded and marginated, not only because they have AIDS but because they are homosexuals. This has got to stop.

We are here, we are queer, and we will not under any circumstances die in silence. Get used to it, Puerto Rico.

[Applause.]

COMMISSIONER DIAZ: Thank you, all of you.

CHAIRMAN OSBORN: On behalf of the Commission, let me express our appreciation for your understanding of the kind of schedule that we need to compress such important feelings into and for your patience with us. We have had a very important pair of sessions here, and we look forward to getting a chance to see more of the problems and the efforts

at solutions this afternoon. It was because of that, as I mentioned, that we needed to compress the public comment time, and I am very grateful to you for having worked so hard to do so.

On behalf of the Commission, many thanks.

[Whereupon, at 12:55 p.m., the proceedings were concluded.]

Puerto Rico Community Foundation
Fundación de Puerto Rico

MEMORANDUM

TO : The National Commission on AIDS
ATTN : Maureen Byrnes
Dr. Helen Rodríguez Trías

Ethel Ríos de Betancourt

FROM : Ethel Ríos de Betancourt, Ph.D.
President

DATE : November 26, 1990

RE : The Puerto Rico Community Foundation
AIDS Projects

The Puerto Rico Community Foundation at present is sponsoring five AIDS projects as listed in the following page. Three of these projects are prevention and education oriented, particularly, directed toward adolescents. Another one supports a hospice for terminal patients with AIDS, and the fifth one is a Stop AIDS program operated in collaboration with the Fundación SIDA and backed with the grant of the Robert Wood Johnson Foundation.

We would appreciate it if this information would form part of your record of organizations in Puerto Rico which sponsor AIDS projects.

hma

Enclosure

(1)

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Ethel Ríos de Betancourt. PhD
(for the record) 11-28-90

AIDS Projects supported by the Puerto Rico Community Foundation

Puerto Rico Planned Parenthood Association
AIDS Education for Adolescents — **Years funded: 1** **Grant: $25,000**

A peer counseling model in which 45 teenagers trained in responsible parenthood, human sexuality, sexually transmitted diseases and AIDS serve as peer counselors in public schools, urban housing projects and colleges, reaching aproximately 1,600 persons. The project has been recommended to PRCF's Board of Directors for a second year grant of $15,000.

Asociación de Familiares y Amigos de Pacientes con Sida
Hospice for Terminal Patients with AIDS — **Years Funded: 1** **Grant: $37,700**

A shelter where terminal patients with AIDS receive medical, psychological, social and spiritual services until their death.

Nu Sigma Beta Fraternity
AIDS Prevention Project for Adolescents — **Years funded: 1** **Grant: $28,928**

An educational program addressed at preventing the incidence of AIDS among high-risk adolescents from twelve to sixteen years old in two high schools in San Juan, through the development of the skills needed to avoid the high-risk behavior associated with this disease.

AIDS Foundation
Stop AIDS Program — **Years funded: 3** **Grant: $353,707**

A restricted grant from the Robert Wood Johnson Foundation to develop a program aimed at preventing the spread of AIDS among homosexual and bisexual men in Puerto Rico, focusing on the education of safe sexual practices. It is expected that, during the three years of its donation, the program will impact between 4,000 and 5,000 individuals.

The American Red Cross, Puerto Rico Chapter
"AIDS: A talk with the people" — **Years funded: 1** **Grant: 49,000**

A community education project on AIDS prevention through the development and offering of a course in 1,109 communities island-wide.

(2)

Presentation to the National Commission on AIDS
by Eunice Diaz
San Juan, Puerto Rico
November 28, 1990

My fellow Commissioners, Dr. Mason and Dr. Novello. In order to hear from the people of Puerto Rico I would like to take this opportunity to share only thought with you and make a few brief recommendations.

As a matter of background, let me remind you that I too, as Dr. Ken Castro said yesterday, as a puertorican professional working and living on the mainland during the first ten years of the HIV epidemic, come before you with an intense feeling of emotion, passion, pain and devotion to the issues which have been discussed during this hearing.

Little did I realize 10 years ago that Hispanics would be so disproportionately impacted by the HIV epidemic, and that among the Hispanic subgroups puertoricans would become the group most severely impacted.

Approximately 3 years ago I began to work with others to identify and bring together interested and involved Latino professionals and expertise that could be brought together to discuss issues related to the rapid progression of HIV among Hispanics and alternative responses to the epidemic.

Toward this end we organized a first national conference on Latinos and AIDS in Los Angeles, California in early 1987 with over 100 participants discussing prevention and education, service organizations and delivery of care, legal & advocacy issues, and media communications.

Participants worked in multidisplay teams for two days and developed specific agendas and recommendations which needed local, regional and federal attention. Perhaps the greatest value of this meeting was the cross fertilization and sharing of ideas, programs, model interventions and evaluation strategies from professionals, ~~agencies~~ and peers.

At that time I convened a small group of people, primarily puertorican professionals from both the island and mainland to discuss the need to gage in a more meaningful discussion on issues related to AIDS in Puerto Rico and on the mainland.

With the help and support from Dr. Mason, Dr. Allen and Dr. ~~S.~~ Mathews we held a Think Tank I in Washington, DC in August 1989 with the following objectives.

1) To better understand two factors contributing to such a

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high incidence of AIDS in Puerto Rico.

2) To provide a forum for the sharing of knowledge, experience, and expertise about HIV.

3) To develop and strengthen ongoing networks.

4) To explore the need for collaboration in the development of a comprehensive and coordinated _____ of AIDS care.

I will summarize the salient points of this forum.

Read if time

This past August we held Think Tank II here in Puerto Rico to focus on care and Rx issues and the organization and delivery of AIDS care. Over 130 professionals participated and a core set of recommendations developed as a result of this second Think Tank.

From the experience of having been a driving force for these three meetings and having the privilege in 1987 of being a consultant to the Department of Health in the development of the HRSA AIDS service demonstration program, and working extensively with puertorican populations on the mainland heavily impacted by HIV, whether in New York, New Jersey, Connecticut, Florida and Illinois, I respectfully submit to you the following observation, "The tremendous challenge of AIDS in Puerto Rico can never be successfully dealt with until the corresponding attention is given to HIV within the puertorican populations on the mainland. It is not possible to fully address the AIDS epidemic among puertoricans unless the implications of the circular migration pattern - the case load usually occurs to & from the island & the numbers are underst[illegible].

Also the "coming home" phenomenon may be greater here in Puerto Rico than anywhere else in the United States due to many sociological factors and individual and family needs. The following represent in a nutshell six recommendations I offer to you my fellow Commissioners from my perspective and worked on many of these issue for the past 4 years.

1. I recommend strongly that this Commission urge that Congress direct a study to include a comprehensive view of the organization and delivery of health care in Puerto Rico, in _____ of the current and projected impact of the HIV epidemic as well as the health status of puertorican populations who migrate back and forth from the island and mainland. The uniqueness of the political status, the patterns of migration of our people, the rapid spread and modes of transmission of HIV and the ability and limitations of federal, state and local care systems to respond to the serious challenges facing our population, demand that this special attention be given at this time.

President - 1982 Senator Inouye from Hawaii request similar be done.

2. Development of a clear statement by the government of Puerto Rico of what is required or desired in terms of federal technical assistance. May mean up and down assistance.

3. Continue work toward broadening agenda of inclusion and involvement cooperation collaboration and true partnership with churches, private sector, pharmaceuticals and voluntary organizations and CBO's. It is urgent that CB response be an _____ and important voice throughout our play.

4. Support efforts for continued dialogue between island and mainland professionals, peers and organizations and funding agencies.

5. Prioritize the development of a pilot system of <u>case management</u> linking the island and the NE mainland emphasizing continuity of care and appropriate patient/family followup and referral.

6. Lastly, give upmost priority and attention to developing the infrastructure for preparing for receiving and being eligible to complete Ryan White monies. It is my sincere recommendation to the various _____ involved that a clear demonstration to ourselves and others of new, creative, truly collaborative maybe never tried before" negotiations in good faith can at this critical time be far more productive and do most benefit for those whom this legislation is to impact.

I am proud to be a partner with you in these efforts and with many in the audience who have served as an inspiration and support to my continued involvement in this epidemic.

Sra Eunice Diaz
Estoy en lista mañana para ofrecer mi testimonio -

Buenos días señoras y señores.

Soy Luzie García de la Noceda de Muñiz, esposa, madre de nueve hijos y abuela de dieciocho nietos. Soy una ciudadana preocupada por mi familia y por la familia de todos los puertorriqueños. Hoy vengo aquí a defender la vida de una joven madre que me honra con su amistad. Espero que defendiendo su vida, logre defender la vida de muchas en las mismas circunstancias.

Esta joven mujer tiene treinta y tres años. A los tres meses de nacida, fue encontrada abandonada en una comunidad de la isla donde decían que se apareció la Virgen. No tenía identificación alguna. Fue llevada al Hogar Insular de Niños, y allí vivió doce años. Unas personas dicen encariñarse con ella, y es adoptada. Sueña con amor, hogar, familia para despertar a la triste realidad de que estas personas lo que buscaban era servicio doméstico. A los trece años, un miembro de la familia la viola. Tiene que ser hospitalizada. Porque dice la verdad, y encuentran al hombre culpable, la echan de la casa. Trabaja donde puede: casas de familia, comercios, etc., y, a la vez, estudia y logra graduarse de la escuela superior. Por su tesón e inteligencia, se desarrolla en una joven de buenas maneras, voz pausada y una facilidad de palabra que envidiarían muchos políticos.

Tiene tres hijos. La niña mayor y el primer hijo son saludables. No tiene tanta suerte el tercero de cinco años. Su padre, un drogadicto, ha contaminado a su madre con el virus del SIDA, y ella se lo pasa al niño. Para complicar las cosas, la sangre de la madre es RH negativo AB. Su esposo la maltrataba físicamente por lo cual ella, desesperada y temiendo por su vida y la de sus hijos, lo abandona.

Hoy, vive con un compañero que a pesar de todo la quiere y le da apoyo. Cuida de los tres niños, y pude constatar que con mucho amor. En esta familia se habla del SIDA y de la muerte como se habla de otras realidades de la vida. Una madre de tres hijos y su joven compañero que no quiere abandonarlos, enfrentan el terror diario de perder sus seres queridos.

El niño enfermo está recibiendo tratamiento para su condición. El se ve saludable; no así su madre. No puede recibir tratamiento preventivo pues las políticas de nuestro país así lo establecen. Sólo los enfermos de SIDA que presentan síntomas, son incluídos en los programas. Si viviera en los Estados Unidos, podría recibir tratamiento con su tarjeta de Medicaid. No así en Puerto Rico. Esto es discriminación. Si alguien tiene una palabra mejor, que me corrija. Esta situación no es justa. No es justa para esta joven madre, ni para tantas otras.

Estoy aquí, hoy, por eso. Pido, o mejor dicho, exijo que estas regulaciones sean revisadas y, si necesario, cambiarlas. Si la cantidad de AZT disponible no es suficiente para atender todos los pacientes de SIDA, debe haber suficiente para atender los casos de miles de mujeres-madres que lo necesitan, aún cuando no presenten síntomas.

Nuestra sociedad, por muchos siglos, ha discriminado contra la mujer. Yo digo, basta. Considero esto que le pasa a mi amiga como una de las peores formas de discrimen. No administrarle la AZT preventiva, la está privando de un tiempo precioso para poder cuidar de sus hijos y disfrutar de una vida mejor. Estamos condenándola a una muerte segura y demasiado pronto. Es obligación de todos nosotros ayudarla. Muchas gracias.

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TOMMY MUÑIZ
Apartado 8302
Santurce, Puerto Rico 00910

20 de noviembre de 1990

Sr. Teodoro Vidal
Calle Encarnación 1573
Caparra Heights, PR 00920

Estimado señor Vidal:

Son las cinco de la mañana. Estoy desvelada. La noche anterior, leo el artículo publicado el 25 de octubre de 1990 en el "San Juan Star", escrito por Betsy López Abrahams, sobre sus sueños destrozados. (Acostumbro a guardar los periódicos cuando tengo que ausentarme de la Isla para repasarlos a mi llegada.) En esta ocasión, estuve fuera tres semanas acompañando a mi esposo Tommy a filmar una película en Hollywood. Nuestro pueblo es ingrato con muchos de los que lo quieren mucho. Me duele pensar que no los haya podido realizar.

La tarde del sábado, he almorzado con Myriam. Ella también, tiene sueños destrozados. A los tres meses de nacida, la encontraron envuelta en una sabanita cerca de donde, según dice, aparecía una Virgen en Arecibo, hace quizás treinta años. No conoció madre, padre ni hermanos. Vivió en el Hogar Insular de Niñas en Trujillo Alto por doce años. Allí, una señora dice que se encariñó con ella, y la "adoptó". Vive el sueño de ser amada para despertar a la realidad de la vida. La adopción es buscando una sirvienta. El cuñado de la señora la viola, tan brutalmente, a los trece años, que tiene que ser llevada al hospital. Porque dice la verdad, y el hombre es encontrado culpable, la madre adoptiva la rechaza y la echa a la calle.

Ahí, hace de todo. Trabaja donde puede, y trata de continuar sus estudios. Termina su escuela superior a duras penas. Es brillante. Aprovecha su tiempo en la escuela, y, por su inteligencia y tesón, desarrolla una facilidad de palabra, que ya quisieran muchos políticos. Tiene una hija de doce años que no ha conocido a su padre. Se casa luego, y tiene dos niños. El primero, tiene la suerte de nacer antes de que su padre, adicto a drogas, le pase el virus a su madre. El segundo, no tiene tanta suerte, igual que Myriam, tiene el HIV positivo.

Se establece un movimiento en Puerto Rico en el Departamento de Salud para ayudar a los enfermos de SIDA. Su nene cualifica, y está bajo tratamiento. Con él, no tiene "preocupaciones", aparte de que sabe que puede morir en cualquier momento. No así ella. No tiene recursos económicos, y al hacer el escogido de los enfermos sin recursos a tratarse, ella no tiene la suerte de ser incluída. La lista, da la casualidad, no incluye a ninguna mujer. El tratamiento por un doctor privado ascendería a unos cientos de dólares mensuales.

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En Puerto Rico no se le dá tratamiento con las drogas establecidas al enfermo de SIDA hasta que no presenta síntomas. ¡Que ley estúpida! ¡Si presenta síntomas, tiene una sentencia de muerte! Hasta ahora, no ha presentado ninguno, excepto que tiene cinco de hemoglobina. Tiene una muela dañada, hace tres semanas, que no la deja tranquila. Ningún dentista se expone a extraerla en su condición. Una amiga mía y yo, pensamos que vamos a hacer algo. Conseguir unas transfusiones de sangre o algo. Su sangre es de un tipo bien raro, RH negativo AB, bien difícil de conseguir.

Le cuento todo esto porque pienso que sus sueños y los de Myriam podrían unirse, y convertirse en una linda historia de amor. Su museo podría ser un museo viviente. Podríamos, usted, Jack Delano y Jaime Suárez, idear alguna solución. Esos santos, tallados con tanto amor por manos puertorriqueñas, podrían -con el mismo amor- tallar otra vida para muchas Myriams. No podemos curar a todos los enfermos de SIDA pero podemos tratar de curar a Myriam. Puede pensar que mi idea es descabèllada. No me estaría malo. Mi abuela decía que la peor gestión es la que no se hace.

Si quiere comunicarse conmigo, puede hacerlo para decirme lo que quiera, hasta que soy estúpida. Sólo me mueve el amor y la compasión. Mi familia y yo, hemos "adoptado" a la familia de Myriam. La ayudamos en lo que podemos. Le damos amor, cariño y ayuda económica pero necesitamos otros que también lo hagan. Por favor, comuníquese conmigo.

Con todo mi respeto,

Luzie G. de Muñiz

Luzie G. de Muñiz

PD: Myriam, no es su verdadero nombre.

cc: Jack Delano
Manny Suárez
Jaime Suárez
Dr. José Soler Zapata
Dra. Antonia C. de Novello
Dr. Pedro A. Borrás
Maureen Byrnes
Betsy López

(9)

HEMATOLOGY SERVICE
P.R. HEREDITARY DISEASE PROGRAM
UNIVERSITY PEDIATRIC HOSPITAL
G.P.O. BOX 5067, SAN JUAN, P.R. 00936

F A X

TO : Mrs. Patrician Randal, National Comm. on AIDS, Washington, D.C.
FAX # : (202) 254-3060

FROM : Dr. Pedro J. Santiago Borrero
Director, Pediatric Hemophilia Program
and P.R. Hereditary Disease Program
FAX :*809-751-5812

DATE : December 7, 1990

RE : Delivery of Health Care to Hemophilia Patients
and Relationship to HIV Disease in Puerto Rico
RE :

#OF PAGES: 6
(Including Transmittal sheet)

M E S S A G E

!HAPPY HOLIDAYS;

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PROGRAMA DE ENFERMEDADES HEREDITARIAS DE PUERTO RICO
DEPARTAMENTO PEDIATRIA, ESCUELA DE MEDICINA

HOSPITAL PEDIATRICO UNIVERSITARIO
RECINTO CIENCIAS MEDICAS U.P.R.
G.P.O. Box 5067 - San Juan, P.R. 00936

CENTRO MEDICO
DE PUERTO RICO
TEL 754-7410

December 7, 1990

Mrs. Patricia Randal
National Commission on AIDS
Washington, D.C.

Dear Mrs. Randal:

Enclosed please find fax of the presentation that I intended to submit to the National AIDS Commission in the hearings celebrated in San Juan, P.R. on November 27-28, 1990.

The subcriber is the director of the Puerto Rico Pediatric Hemophilia Program, which provides care to about 95% of all hemophiliacs below 18 years of age on the island. Unfortunately, I was out of Puerto Rico, and thus I was not able to address the Commission in that occasion.

Responding to the request made by the Commission, I hereby submit a Report on HIV Infection Among Hemophilia Patients in Puerto Rico.

I also direct a Project on Newborn HIV Seroprevalence in San Juan and nearby towns, sponsored by the Department of Health of Puerto Rico and CDC. A copy of the report of that survey is also included, which contains very recent (and disturbing) information.

I hope that this information is useful to the National AIDS Commission. Thank you for your attention.

Sincerely yours,

Pedro J. Santiago Borrero, M.D.
Director, Pediatric-Hemophilia Program
and P.R. Hereditary Disease Program

frs

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DELIVERY OF HEALTH CARE TO HEMOPHILIA PATIENTS AND RELATIONSHIP TO HIV DISEASE IN PUERTO RICO

- Presentation in Public Hearings of the National Commission on AIDS, San Juan, PR, November 27, 1990.

I. Introduction

I would like to express my appreciation for the opportunity to address the National Commission on AIDS in it's visit to Puerto Rico, by means of this report.

Due to existing time limits and to the fact that other presenters have discussed general aspects of AIDS and HIV infection in Puerto Rico, I will restrict my presentation to the description of the health care given to and needs of hemophilia patients, especially of those with HIV infection.

Assuming that the prevalence rate of hemophilia and related bleeding disorders (RD) in Puerto Rico is similar to that in other Western Countries, we would expect about 300 patients with these diseases on the Island. This estimate is similar to the number of 278 cases found recently by the local chapter of the Hemophilia Foundation.

Right now, 136 of those patients (49%) are registered in our P.R. Pediatric Hemophilia Program, presently operating at the Pediatric Hospital of the UPR Medical Sciences Campus, in Rio Piedras, P.R.

That group of patients includes the following: 78 patients with hemophilia A; 8 with hemophilia B; 40 cases with Von Willebrand's disease; and 10 with other genetic coagulation disorders. Thus, practically all the Pediatric patients with hemophilia, and about 50% of the total population of individuals with genetic bleeding disorders in P.R. are receiving comprehensive care at the presently existing Pediatric Hemophilia Treatment Center (HTC). This HTC has been operating during the last six (6) years, in a Program affiliated with the

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Comprehensive Hemophilia Center of Mount Sinai Medical Center in New York. Our HTC is partially funded by the MCH Bureau of the US Department of Health and Human Services.

Adult hemophilia patients receive health care in a less organized fashion in various health facilities on the Island. But the mayority of those with severe hemophilia and serious health problems receive health care at the Hematology Sections of the Departments of Medicine of the University Hospital (for adults) and of the San Juan City Hospital, in Rio Piedras, PR. Very few hemophilia patients receive health care in privates hospitals; and only a very small number of patients (7.7%) are covered by health insurance.

II. Services Available Regarding HIV Infection

A total of 87 out of 136 patients with hemophilia and related disorders (64%) were considered to be at risk of exposure to the human inmunodefificiency virus (HIV) in the period of 1978 to 1988. Out of those, 79 (91%) have been tested for HIV antibodies; and 31 of them (39%) have been found to be positive, or HIV (+). The group of HIV (+) patients included 29 with hemophilia A; one with Von Willebrands disease; and other with factor V deficiency. Their ages (at the time of testing) ranged from five to 19 years; but most of them were over 10 years of age. Due to the fact that many patients had reached the age of 18 years, during the last five years we have transferred 25 of these patients to the (adults) Hematology Service of the University Hospital, including 10 with HIV infection. Three of these patients have eventually died with AIDS. Thus, the Pediatric Hemophilia Program has kept and managed a total of 21

patients with HIV infection. Three of these patients (14%) have died with AIDS in the last 1 1/2 years. Thus, 18 HIV (+) patients in the pediatric age group are alive, and 2 now have the AIDS related complex or A R C.

All our pediatric patients and also some young adults have received initial evaluation and continuous comprehensive care by well trained physicians and a well organized psychosocial support and HIV risk reduction group. That group is composed of a hemophilia nurse, a social worker, a psychologist, a physical therapist, an oral hygienist, a general pediatrician, and a hematologist.

Psychosocial support and HIV risk reduction services have been provided to the patients, to their parents, and to the patients sexual partners in cases of sexually active young adults.

All patients have been observed closely for signs of progression of HIV infection, including serial testing for immunoglobulins, CD4 lymphocyte counts, and T_4/T_8 ratios. Those patients who qualify for AZT and TMP-SMZ therapy, according to recent national guidelines, are receiving that treatment.

All school age children and adolescents who attend our HTC are going to school or college; and most of the few young adults who attend our clinic are working.

I do not have first hand information on the health status of most adult hemophilia patients in Puerto Rico. However, information gathered by the social worker working for the Hemophilia Outreach Program of the Hemophilia Foundation Local Chapter suggests that many adult patients have not received counseling and testing services for HIV infection. It seems that work in this area is needed to avoid unnecessary exposure

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of the relatives and sexual partners of adult hemophilia patients to the HIV virus.

III. Interaction with other agencies:

The Pediatric Hemophilia Program interacts often with several agencies and programs in the community that offer services to other patients with HIV infection. Support by the Department of Health of Puerto Rico and the University Pediatric Hospital has been good to excellent. Collaboration with the Latin American Center for Sexually Transmitted Diseases has permitted us to obtain AZT regularly for the treatment of HIV (+) hemophilia patients who qualify for use of that medication. Communication with the San Juan Vocational Rehabilitation Center has facilitated arrangements to provide vocational training and support to several of our adolescent and young adult hemophilia patients. Although our patients do not receive services from the Gamma Project, located at the University Pediatric Hospital, staff from both programs meet often to discuss patient problems and to make therapy plans.

IV. Final Comments:

Despite the unfortunate occurrence of HIV infection in many of our hemophilia patients, due to the use of contaminated blood products in the period 1978-1988, we have been successful in organizing a well coordinated team of health professionals that is providing appropriate health care and phsychosocial support to our HIV infected pediatric patients and relatives.

We feel confident that our successful experience in the management of hemophiliacs can be useful in the management of other HIV infected patients, including both pediatric and adult cases.

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Thank you,

Pedro J. Santiago Borrero, M.D.
Director, Pediatric Hemophilia Program

HIV SEROPREVALENCE IN NEWBORNS IN SAN JUAN AND NEARBY TOWNS

P. J. Santiago-Borrero, J. Rullan, M. Garcia & M. Gwinn.

Department of Pediatrics, U. P. R.

P. R. Department of Health and

Centers for Disease Control (CDC), Atlanta, GA.

(Work presented at the UPR Medical Sciences Campus

Annual Research Forum, December 6, 1990)

A variable but very high percentage of HIV infected persons develop AIDS 8 to 10 years after exposure to that retrovirus.

As indicated in the CDC MMWR report of February 1990, a high prevalence rate of AIDS has been reported in some large cities of continental USA and Puerto Rico. The six (6) places with the highest prevalence rates are the following: Washington DC, Puerto Rico, New York, New Jersey, Florida and California; with rates per each 100,000 persons of: 80.6, 44.9, 33.5, 28.9, 27.9 and 22.7, respectively. Thus, Puerto Rico appeared as the second highest in that list, with an infection rate of one case per each 2,227 persons.

The Puerto Rico AIDS Surveillance System Report of

November 1990 indicated that by that month 5,122 AIDS cases had been reported in the island, of which 3,248 or 63% had died. Thus, 1,874 AIDS patients (37%) were alive in November, for a prevalence rate of 1:1,779 persons in PR.

The number of HIV infection associated with adult and adolescent recipients of blood products has decreased significantly in the past few years. However, there has been a significant increase in the rate of perinatal transmission of HIV in the past few years; although, it still represents less than 3% of all new AIDS cases reported in P.R.. Anyway, this figure is almost twice the percentage in the USA. And that number corresponds also to the higher rate of AIDS in women in P.R..

Responding to existing needs to identify present trends in the prevalence of HIV infection among pregnant women in Puerto Rico, the Centers for Disease Control (CDC) and the Department of Health of P.R. have been sponsoring a neonatal HIV seroprevalence survey during the last two years.

Newborn blood samples obtained from heel punctures, collected on the filter papers used for neonatal screening for hypothyroidism, PKU and hemoblobinopathies were utilized for anonymous testing for HIV antibodies. Filter paper discs containing dried blood samples were cut and placed in wells of appropriate trays, and the pertinent demographic

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data were recorded in a computer, preserving the anonymity of infants and mothers, and of individual hospitals. Tests for the presence of HIV antibodies were performed on the serum specimens eluted from the filter paper discs in a CDC sponsored laboratory, using a modified ELISA method. Doubful and positive cases were re-tested by the Western Blot technique. A rigorous quality control system designed by CDC was maintained throughout the survey.

Samples obtained from infants born at the University Hospital, the San Juan City and the Carolina Area Hospitals were placed together and identified as group code 01. Samples from the Dagues and the Bayamon Regional Hospitals were identified as group code 02. The blood samples obtained in private hospitals of San Juan and Bayamon were included in group code 03 (see Table I).

The results of the survey conducted between January 1989 and June 1990 are the subject of this presentation.

Participating hospitals entered the study in 3 phases at differents dates, as indicated in this table. By December 1989, about 90% of all neonates born monthly in hospital group 01 and 02 were being tested for HIV; and by June 1990 about 85% of infants born in private hospitals in San Juan and Bayamon were being tested. A total of 19,721 newborns blood samples were tested during the first 18 months of this

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survey.

The prevalence rate of HIV antibodies among 10,983 neonates born in hospital group 01 was 14.9 per 1,000 infants. The rate among 6,310 samples belonging to hospital group 02 was 9.7 per 1,000. And the corresponding figure among 2,428 blood samples taken from neonates born in private hospitals (code 03) was 0.8 per 1,000. The over all prevalence rate was 11.5 per 1,000; and that for infants born in the two groups of public hospitals was 12.3 per 1,000 (see table II).

TABLE III indicates that the largest number of positive cases occurred in the age group 20 to 29 years.

DISCUSSION

This report has significant importance for the study of HIV infection in Puerto Rico in 2 different ways. First, because of the methodology used; and secondly, due to the results obtained up to now.

The technology employeed for large scale neonatal testing for several genetic diseases has improved significantly in the last two decades, using small amounts of blood specimens collected onto filter papers. In

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1987-88, the then existing ELISA HIV antibody test was modified to test reliably very small amounts of serum eluted from dried blood samples collected on filter papers. Immediately it became apparent that large numbers of blood specimens collected regularly for neonatal screening for genetic diseases were available for HIV testing. Promptly, CDC became interested in using that technique in the surveillance for HIV infection among pregnant women. In a short time CDC developed programs for neonatal testing for HIV antibodies in cities with a high prevalence rates of HIV infection, such as the San Juan Metropolitan Area.

The methology used has proven to be reliable, reproducible, and cost effective, when performed in coordination with already existing neonatal genetic screening programs, like the one operating in Puerto Rico now.

The results obtained so far in Puerto Rico indicate that the presence of HIV antibodies in neonates born in two groups of public hospitals is extremely high; this is, 225 cases among 17,290 samples tested, or, 12.3 per 1,000. This means that there is one positive case per each 81.7 infants born in those public hospitals. Furthermore, the incidence in the 2 main public hospitals in San Juan is even higher; i.e., 1:41 newborns. As these infants are expected to have been exposed to HIV transplacentally, at least the

same prevalence rate of HIV infection must be occurring in their mothers.

On the basis of information published by several authors, 25 to 35% of infants born to mothers infected with HIV, develop HIV infection transplacentally. Thus, about 68 infected infants are expected to have been delivered among those 17,273 infants tested in the last 17 months. It is impossible to predict the prevalence rate of HIV infection in pregnant women in the rest of the island. Further studies are needed to determine the prevalence rate reliably in other cities and towns of Puerto Rico. However, if we assume that the prevalence rate detected in the samples already tested applies to the other public hospitals on the island, we could expect 516 infants exposed to HIV, and about 155 neonates actually infected by that retrovirus annually. If that is so, we do have a very serious problem in Puerto Rico now.

Thus, there is an urgent need to expand this seroprevalence study to the entire island of Puerto Rico, to clarify the present situation. And it seems that more aggresive and better planned education and preventive measures are urgently needed to control the present epidemics of HIV infection in the San Juan Area.

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UNIVERSITY OF PUERTO RICO
MEDICAL SCIENCES CAMPUS

ABSTRACT FORM

TYPE PERFECT ORIGINAL OF ABSTRACT HERE
(Do not type beyond outline of box)

1. Full name and address of PRESENTER

Dr. Pedro J. Santiago Borrero
Department of Pediatrics
UPR MSC School of Medicine
San Juan, PR 00936

2. Preferred mode of presentation:

- ☒ oral presentation
- ☐ poster presentation
- ☐ oral or poster mode acceptable

3. Scientific Classification
Please indicate a maximum of five representative Keywords:

a. HIV infection.
b. HIV seroprevalence.
c. HIV surveillance.
d. Newborn testing.
e.

HIV Seroprevalence in Newborns from San Juan and Nearby Towns. P. J. SANTIAGO-BORRERO*, J. RULLAN, M. GARCIA AND M. GWINN. Department of Pediatrics, U.P.R.; P.R. Department of Health, and Centers for Disease Control (CDC), Atlanta, GA.

Surveillance programs are a useful tool to monitor the effectiveness of education and preventive measures in places where there is a high prevalence rate of human immunodeficiency virus (HIV) infection. A newborn HIV Seroprevalence Study has been conducted in San Juan and nearby towns during the last two years, sponsored by CDC, the P.R. Department of Health, and the Latin-American Center for Sexually Transmitted Diseases. Dried blood samples collected onto filter paper cards for neonatal screening for hypothyroidism and phenylketonuria were used for anonymous testing for the presence of maternal HIV antibodies, by means of a modified ELISA test, followed by Western Blot confirmation. Nineteen thousand seven hundred twenty seven samples were tested between January 1989 and June 1990, including 10,983 in hospital group 01, 6,310 in group 02, and 2,428 in group 03. The HIV seroprevalence rate was 14.9, 9.7 and 0.8 per 1,000, respectively. The HIV Seroprevalence in hospitals 01 and 02 is extremely high and disturbing as it indicates that at least that rate of mothers is infected. It is estimated that approximately 240 newborns are being exposed annually and probably 25% to 35% of them are getting HIV infection. The HIV surveillance is being expanded slowly to the rest of the island. It seems that more aggresive and better planned education and preventive measures are needed to control the present HIV infection rate in San Juan and nearby towns.

4. Reviewer's Ratings:					5. Disposition:		
☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ O	☐ P	☐ R

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TABLE I

DATE OF ENTRY AND HOSPITAL GROUP CODE IN NEONATAL HIV SEROPREVALENCE STUDY

PHASE	HOSPITALS	CODE NUM.	ENTRY DATE	NUM. CASES	PERCENT
I	UNIVERSITY HOSP. SAN JUAN CITY HOSP. CAROLINA AREA HOSP.	01	Jan-Feb. 1989	10,983	55.7%
II	BAYAMON REG. HOSP. CAGUAS RES. HOSP.	02	Aug-Oct. 1989	6,310	32.0%
III	PRIVATE SAN JUAN HOSP'S. PRIVATE BAYAMON HOSP'S.	03	Feb-April 1990	2,428	12.3%
	TOTAL			19,721	100%

TABLE II

NEWBORNS HIV SEROPREVALENCE RATE IN SAMPLES FROM VARIOUS HOSPITAL GROUPS IN 1989 AND 1990

HOSPITALS GP	NUM. CASES TESTED	CASES POSITIVE	RATE PER THOUSAND
01	10,983	164	14.9
02	6,310	61	9.7
03	2,428	2	0.8
TOTAL	19,721	227	11.5

12.3

TABLE III

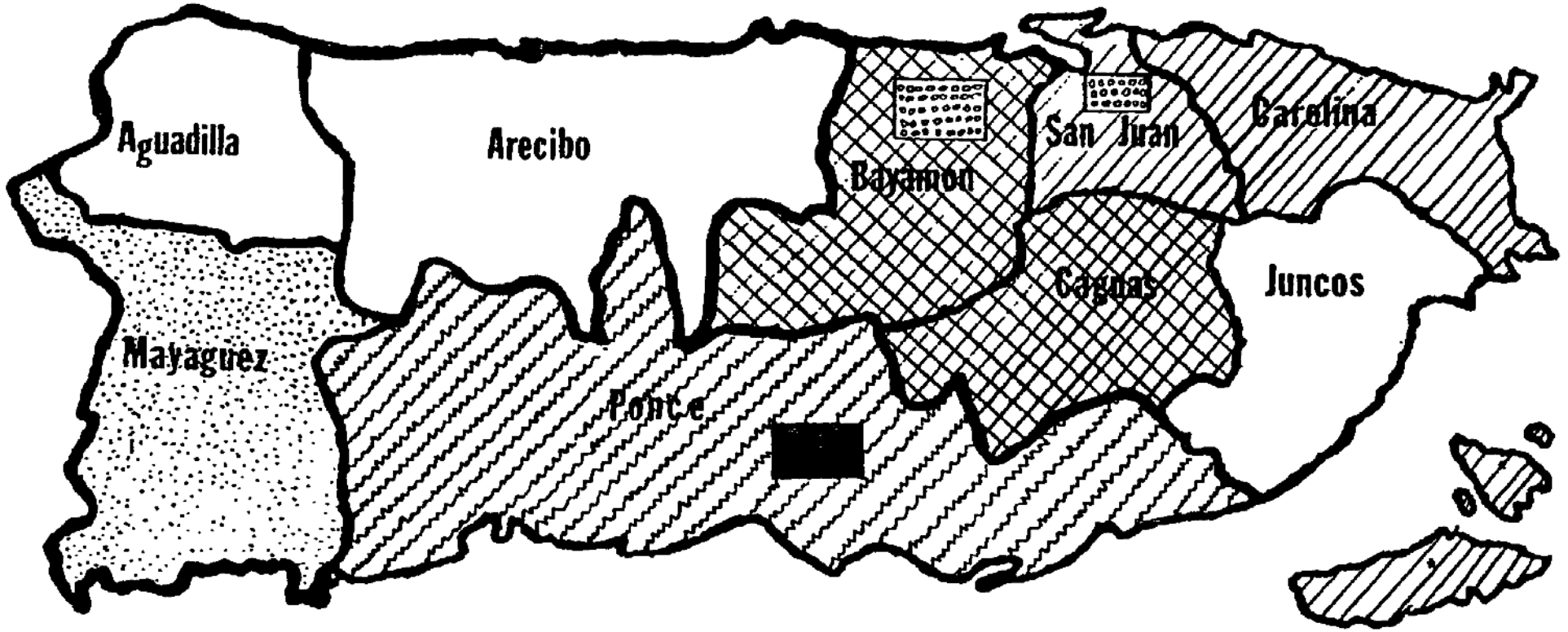
NEWBORNS HIV SEROPREVALENCE RATE BY MATERNAL AGE GROUP AND HOSPITAL GROUPS; 1989 & 1990

AGE GROUP (YRS.)	HOSPITAL GROUPS (PHASES) 01		02		03	
UNDET'd	(20)	1.8	(18)	2.9	0	
< 15	(1)	0.1	(0)	0	0	
15-19	(19)	1.7	(7)	1.1	0	
20-24	(54)	4.9	(20)	3.2	(1)	0.4
25-29	(45)	4.1	(9)	1.4	0	
30-34	(16)	1.5	(6)	1.0	(1)	0.4
35-39	(8)	0.7	(1)	0.2	0	
40-44	(1)	0.1	(0)	0	0	
<45	(0)	0	(0)	0	0	
TOTAL	(164)	14.9	(61)	9.7	(2)	0.8

HIV SEROPREVALENCE SURVEY

HOSPITALS PARTICIPATING IN VARIOUS PHASES OF THE STUDY
IDENTIFIED BY CODE NUMBERS

(26)



* Pertenece al área de Carolina

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FAX COVER SHEET

DATE : December 5, 1990

TO : Ms. Maureen Byrnes
(Executive Director)

FAX NUMBER: (202) 254-3060

FROM : Ineke Cunningham
Dept. of Biology

FAX NUMBER: 758-9306

TOPIC : Testimony about Immune Deficiency Syndrome -- National Commission

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Number Pages (including the cover) 7

Observations:

N/A

Note: If you have any problem with the document, please call Phone: (809) 764-2258.

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(27)

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DEPARTAMENTO DE SOCIOLOGIA Y ANTROPOLOGIA

December 5, 1990

Ms. Maureen Byrnes
Executive Director
NATIONAL COMIMISSION ON
ACQUIRED IMMUNE DEFICIENCY SYNDROME
1730 K Street, N.W., Suite 815
Washington, D.C. 20006

Dear Ms. Byrnes:

Attached please find the testimony which I had prepared to give to the National Commission on Acquired Immune Deficiency Syndrome last week. I appreciate that you allow me to send it to you at this date, since I would like for this to be part of the testimony from Puerto Rico. I would be thankful if a copy of the testimony could be provided to each member of the Commission.

It was a pleasure to work with the Commission. I trust that the materials sent to you at the request of members of your staff were of help to the Commission. The local quilts added a special atmosphere to the hearings.

Cordially,

Ineke Cunningham

Ineke Cunningham
Professor of Sociology

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REMARKS TO THE MEMBERS OF THE NATIONAL AIDS COMMISSION AT THE HEARINGS IN SAN JUAN, PUERTO RICO, NOVEMBER 28, 1990

Ineke Cunningham
Professor of Sociology, University of Puerto Rico
President of MOSAICO de NOMBRES

Introduction

For the past three years I have worked as an investigator in two distinct projects, about which I would like to comment. This last year I have also presided over MOSAICO de NOMBRES, a non-profit organization which unites some twenty organizations, and which brought the QUILT of the NAMES PROJECT to Puerto Rico.

Results of Surveys on AIDS Knowledge and Risk Behavior

In two large surveys of 2,000 and 4,000 students at the University of Puerto Rico, we have found that although over 95% of the students know that the use of condoms decreases the risk of transmission of HIV, only 11 per cent of those sexually active indicate they always use condoms, and over 40% never use them. Over 30% of women and close to 40% of men who are sexually active indicate they have engaged in anal sex. The reasons given for this practice suggest that the decision to engage in anal sex is usually made by men, and women accede for their partners' pleasure.

Whereas most students do not consume alcohol every day, they frequently take three or more drinks when they do so. We found highly significant relationships between alcohol use and risk behavior, and feel that it is important to further study this

link.

If these findings hold true for a middle and working class university population, what percentage of other sectors engage in these types of risk behavior? Most students indicate they have little actual knowledge as to how to protect themselves, yet 70% wish to have access to courses on sexuality and AIDS, and 90% of the students would like to see an office with a professional counselor on campus.

I believe we cannot neglect to answer their needs. We need to provide education to prevent the transmission of HIV. If the University should decide not to support such a project, those who comprise the university--students and professors--should shoulder the task. This education should include specific skills as to how to use condoms as well as how to communicate with sexual partners. In addition we need to work with both attitudes and fears.

I applaud the money dedicated to biomedical research, but for prevention we need to know what risk behavior persons of different sectors are engaging in. The virus is the same in the Netherlands, China and Puerto Rico, but the social and economic conditions and the cultural practices between and within these societies vary greatly. The relationship between these factors and risk behavior have not been studied sufficiently in many societies. The cost of such research need not be great. We did our two studies with student help for less than $30,000. However, if we are to establish priorities and better prevention

programs, we need to know more about the reasons for engaging in risk behavior. Therefore, in addition to sorely needed funds for treatment, we need more funds for research in the social sciences.

The Positions of the Political Parties and the Church

As a people, we have been manipulated. AIDS has for too long been too much of a political issue here. We have analyzed AIDS reporting in the local press since 1981. From 1984 to 1987 there were public controversies between both health care professionals and other officials of different political parties over such issues as incidence figures and the promotion of condom use. In September, 1987, we almost lost our federal funding because San Juan and the Commonwealth Government could not work together on AIDS priorioties and planning. From these hearings so far it is clear that serious differences still exist.

While some sectors of the churches have accepted the responsibility of loving and caring, we should not forget that others continue to mention the wrath of God, and the Cardenal has been quoted in the press as saying that using a condom is worse than having AIDS. Our present governor opposed the use of condoms for AIDS prevention until March, 1989.

You have become aware in these hearings that we are sitting on a powder keg. The needs are great, the funds are limited and there are serious problems between both the public and the private sectors as to how to work together. We agree with Eunice

Diaz, who eloquently expressed that we need to fight the HIV virus and not each other.

We must learn to work together with respect and determination. For it is only with a united front, organizing at the grassroots, if you will, and including persons with HIV, organizations that provide services to PWAs and their family members, other community organizations, agencies, universities and churches that we stand a chance in the fight against AIDS. Only then we will be able to plan more rationally, educate better, and provide more humane services at lower costs. All these activities should be directed to enpower people to have a greater voice in the destinies of their own lives with respect to AIDS.

MOSAICO de NOMBRES

Last August 27-29 the QUILT of the NAMES PROJECT of San Francisco was exhibited here in San Juan. Over twenty organizations worked together in making this possible. We gave workshops, more than 200 individual quilts were made here on the island, hundreds of volunteers gave their time, and thousands of people came to see the QUILT.

At present the Puerto Rican Quilt is traveling through the Island, giving other communities a chance to experience it. No individual organization can request a display, for the prerequisite for its exhibition is that local organizations form

a committee which makes the request. We hope that thus people will learn to know one another, and work shoulder to shoulder on a concrete event. On March 1, 1991 the Puerto Rican QUILT will join the other quilts in San Francisco, yet I believe MOSAICO de NOMBRES will continue to exist. The next few months we will conjointly work on an agenda of tasks that can be realized and done together.

Although many said it could not be done.....it was done! In a society that has a colonial heritage, where dependence has been created both through the Welfare State and through a government that frequently is patriarchal and slow in planning, we as a people need to learn to work together and we should be made to do so, for it is our only salvation in the struggle against AIDS.

The Comission requested some local quilts from the NAMES PROJECT, who referred you to MOSAICO de NOMBRES. On these walls, therefore, we see some of the memories of pain and love that families and friends of those who died have left for history. MOSAICO de NOMBRES.....Let us keep love alive, plan and work together for the day when we need not make any more quilts.