FOIA Number: 2018-0758-F

FOIA MARKER

This is not a textual record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Todd Summers

Subseries:

OA/ID Number: 21088

FolderID:

Folder Title:
Issues - Groups - Latinos [1]

Stack:	Row:	Section:	Shelf:	Position:
S	66	6	2	2

A Multi-Media Partnership: Reaching Latinos With Health Information

The Project

A recent Kaiser Family Foundation survey found that more Latinos name television than doctors as their most important health information resource with other forms of media also figuring significantly. Collectively, the media – newspapers, television, and radio – play a powerful role in getting out health information to Latinos. Yet, many Latinos say they want to know more about health policy issues like coverage for the uninsured, Medicare and Medicaid, and HIV/AIDS, and look to the media to do more to provide that information.

The Foundation, a national health care philanthropy not affiliated with Kaiser Permanente or Kaiser Industries, and Latino Issues Forum (LIF), a leading health policy institute, have created a unique partnership. To enhance coverage of health policy issues affecting Latinos, the partnership brings together the leading Spanish-language newspapers, *el diario/La Prensa* and *La Opinion,* Univision television stations in various markets (New York City, Los Angeles, Miami, Houston, San Antonio, and Chicago), and the Hispanic Radio Network. *El Nuevo Herald* was also invited to participate.

Focusing on a series of three health topics identified as priorities by many Latinos, this project consists of three inter-related components:

- Tailored briefing sessions and background materials for the media partners;
- Special supplements produced by *el diario/La Prensa* to appear in *Vista Magazine*; and
- Town meetings, co-hosted by the media partners, and broadcast by the television and radio partners.

The three topics for this project include:

- Medicare
- Children's Health Insurance Program
- HIV/AIDS

Three Briefings

On each of the three topics, the Foundation and LIF will convene a full day briefing for the editors, reporters, and producers from the partner media organizations. Each briefing includes leading national experts on the topic as well as written fact sheets and policy summaries prepared especially for the briefings and media partners. The materials prepared for the briefings will also include general information useful for future coverage of health policy issues.

- Latinos & Medicare, Miami, FL, April 21, 1999
  Speakers included:
  Marta Sotomayor, President, National Hispanic Council on Aging;
  Moya Thompson, Director of Congressional and Public Affairs, Administration on Aging;
  Andrew R. Perez, Associate Regional Administrator (Dallas), Health Care Financing Administration;
  Josefina Carbonell, President, Little Havana Activities and Nutrition Centers of Dade County

Latino Issues Forum
785 Market Street Third Floor
San Francisco CA 94103

Kaiser Family Foundation
2400 Sand Hill Road
Menlo Park CA 94025

Background on the Issues: Medicare, Children's Health Insurance, and HIV/AIDS

Medicare and the new Medicare+Choice program, children's health insurance, and HIV/AIDS have been selected because they are issues that have a disproportionate impact on Latino communities and are issues identified in our research as top priorities for many Latinos.

- *Medicare:* A number of studies indicate that a large share of elderly Latinos lack basic knowledge about the Medicare program. A recent Foundation survey found that a majority of Latinos say they are not getting the information they need to understand Medicare. Moreover, our recent review of Medicare HMO advertising in areas with high concentration of Latino beneficiaries found that plans do not appear to be marketing to Latino beneficiaries. As the new Medicare+Choice program is implemented, and new private plans begin enrolling elderly beneficiaries, the two million Latinos covered by Medicare could be at a comparative disadvantage if they do not get the information they need to understand how to choose among the new Medicare health plan options that may be offered in their communities.

- *Health insurance for children:* Latino children are significantly more likely to both lack a regular source of care and be uninsured than are African American or white children. In fact, almost one in four of the nearly 10 million uninsured children living in the U.S. is Latino. There are longstanding problems with Medicaid participation and enrollment for Latino children. Of Latino children eligible for Medicaid, about 40 percent are not enrolled. Expanding health care and health insurance access for Latino children will be a crucial issue in the coming years as the Latino population continues to grow and the New Children's Health Insurance Program and Medicaid broaden their efforts to enroll more uninsured children.

- *HIV/AIDS:* HIV has disproportionately impacted Latinos since the onset of the epidemic. Today, 20 percent of new AIDS cases are among Latinos despite the fact that Latinos account for just 11 percent of the total US population (13 percent including Puerto Rico). Approximately 110,000 to 170,000 Latinos are currently infected with HIV of whom over 52,000 are estimated to be living with AIDS. A survey recently conducted by the Foundation found two thirds of Latinos saying that AIDS is a very serious problem for people they know, and nearly half being personally very concerned about becoming infected with HIV.

Tomando Medidas: Latinos y el VIH/SIDA

A Briefing for Journalists
October 7, 1999
New York, New York

SPEAKER BIOS

Moisés Agosto is a Senior Associate and Managing Director of Community Access, a health communications company based in New York City. Prior to his work at Community Access, he was the Director of Research and Treatment Advocacy for the National Minority AIDS Council (NMAC) in Washington DC and the editor of SIDAAhora, the Spanish publication of the People with AIDS Coalition of New York. Mr. Agosto has served on numerous advisory boards and community groups and is the founder of the National AIDS Treatment Advocates Forum. He has played a crucial role in making sure that communities of color have equal access to care, treatment, and life saving information. Mr. Agosto has been living with HIV for the past 13 years.

Ana Maria Arumi is currently a Research Associate in Public Opinion & Media Research at the Kaiser Family Foundation, a non-profit health care philanthropy based in Menlo Park, California. Her work at the Foundation focuses on understanding public opinion and knowledge on a variety of healthcare and social policy issues. Prior to her position at the Foundation, Ms. Arumi worked as the Deputy Director of News Surveys CBS News/*New York Times*, a Public Opinion Consultant for the Public Policy Institute of California, and Research Manager for the Office of Survey Research at the University of Texas at Austin. She has also worked as a Policy Analyst on Latino election behavior for *Telenoticias* and as a research consultant for the National Institutes of Health *En Accion Contra el Cancer* program. In addition, she has worked in the Latino community promoting awareness on diabetes, cancer, and HIV screening. Ms. Arumi has completed graduate course work in psychology and anthropology at the University of Costa Rica and received her BA in Linguistics and Economics from the University of Texas at Austin.

Dennis deLeon is President of the Latino Commission on AIDS, a service and advocacy program addressing HIV/AIDS in the Latino community. Under his leadership the Commission has developed a national clearinghouse for AIDS treatment information in Spanish, a network of religious leaders offering HIV prevention programs to Spanish-speaking congregations, and a technical services program that address the needs of Latino community based organizations. Mr. deLeon served as Chair of the New York City Commission on Human Rights successfully developing legislation to reform the City Human Rights Law. Under his direction, the Commission assumed a new level of public advocacy for the rights of Latinos, Gays and Lesbians, women, immigrants, and all other groups protected by the City Human Rights Law. While working as the Senior Assistant Corporation Counsel in the New York City Law Department he also served as Executive Director for the Mayor's Commission on Hispanic Concerns. Mr. deLeon was born in Los Angeles and has degrees from Occidental College and Stanford Law School.

Kenneth L. Dominguez, MD, MPH is a Medical Epidemiologist with the Centers for Disease Control and Prevention, National Center for HIV, STD, and TB Prevention in the Epidemiology Branch. His current focus is in the area of maternal/child transmission. Specifically Dr. Dominguez is a Project Officer for the Pediatric Spectrum of HIV Disease and Medical Consultant to Perinatal Guidelines Evaluation Project. Dr. Dominguez also serves as a consultant to the Hispanic People of Color Initiative and is a member of the National Hispanic Medical Association. Dr. Dominguez has a Masters Degree in Public Health from Columbia. He attended medical school at Columbia's College of Physicians & Surgeons and completed his undergraduate studies at Harvard.

Latino Issues Forum
785 Market Street Third Floor
San Francisco CA 94103

Kaiser Family Foundation
2400 Sand Hill Road

Maria G. Perez is the incoming Director for Planning and Program Development for the County of Los Angeles Department of Health Services' Office of AIDS Programs and Policy (OAPP). Prior to joining OAPP she was the Director of Bailey Holt-House, a residential facility for 44 persons living with AIDS. Before joining Bailey House, Ms. Perez was responsible for the start-up of a case management program targeting Latinas in East Harlem in New York City and was the Bronx Site Director for Hispanic AIDS Forum, where she oversaw all aspects of service provided to Latinos in that location. In addition to her numerous years of work in the field of AIDS, Ms. Perez has held positions as a Director of New York City's Board of Education's Latino Commission on Educational Reform and as Director of Early Childhood Programs for Committee for Hispanic Children and Families. Ms. Perez received her undergraduate degree from Princeton University and her graduate education from Rutgers University.

Heriberto Sanchez Soto, MSW is currently the Executive Director of the Hispanic AIDS Forum, Inc., a health and human services organization serving the Latino Community in New York City. Mr. Sanchez Soto has been involved in AIDS outreach since early 1984 and has since worked diligently in advancing public policy and programming that is responsive to Latinos infected/affected by HIV/AIDS. He has served in numerous HIV/AIDS planning bodies and has improved extensive training and technical assistance to other service providers in a developing capacity to meet the challenges posed by HIV to the Latino community both locally and nationally. Mr. Sanchez Soto is a graduate of Rutgers University, where he completed both undergraduate and graduate studies in Urban Planning and Social Work.

Tomando Medidas: Latinos y el VIH/SIDA

A Briefing for Journalists
October 7, 1999
New York, New York

AGENDA

9:00 - 9:30	**Registration/Breakfast**
9:30 - 9:45	**Welcome & Introductions** • Viola Gonzales, Executive Director, Latino Issues Forum
9:45 - 11:00	**Status of the HIV Epidemic** • Dr. Ken Dominguez, Epidemiologist, HIV/AIDS Prevention Centers for Disease Control and Prevention • Ana Maria Arumi, Research Associate, Public Opinion & Media Research, Kaiser Family Foundation
11:00 - 12:30	**The Role of the Cultural Issues in the Epidemic** • Cynthia A. Gómez, Ph.D, Assistant Professor, Department of Medicine, Center for AIDS Prevention Studies University of California, San Francisco • Dr. Freddy Molano, Associate Executive Director for Women's Health and AIDS Prevention, Community Healthcare Network
12:30 - 1:30	**Lunch**
1:30 - 3:30	**Getting the Message Out: What Latinos Need to Know** • Dennis de Leon, President, Latino Commission on AIDS • Maria G. Perez, Director of Planning & Development Los Angeles Office of AIDS Programs and Policy • Dr. Sam Martinez, Team Leader, HIV Prevention Team Centers for Disease Control and Prevention • Moisés Agosto, Senior Associate Director, HIV Field Force Community Access
3:30 - 3:45	**Closing Remarks & World AIDS Day Event "Dialogo Por Vida"** • Heriberto Sanchez-Soto, Executive Director Hispanic AIDS Forum

A Partnership with the Media

Latino Issues Forum
785 Market Street Third Floor
San Francisco, CA 94103

Kaiser Family Foundation
2400 Sand Hill Road
Menlo Park, CA 94025

Clinton Presidential Records
Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

CHART PACK

National Survey of Latinos on HIV/AIDS

THE HENRY J. KAISER FAMILY FOUNDATION

May 1998

CALIFORNIA OFFICE: 2400 Sand Hill Road, Menlo Park, California 94025 (650) 854-9400 FAX (650) 854-4800
WASHINGTON OFFICE: 1450 G Street, NW, Suite 250, Washington, DC 20005 (202) 347-5270 FAX (202) 347-5274

Clinton Presidential Records
Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

Kaiser Family Foundation

National Survey of Latinos on HIV/AIDS

One in two Latinos rate AIDS the nation's most urgent health problem • Half of Latinos say AIDS is more urgent problem for their local community • Two in three Latinos say AIDS is a very serious roblem for people they know • Nearly half of Latinos are worried about becoming infected with HIV • Seven in ten Latinos are very worried about their children becoming infected with HIV • One in two Latinos would like to know more about discussing sex and AIDS with artners • Seven in ten Latinos would like more information about discussing AIDS prevention with ids • One in five Latinos say they received information about HIV/AIDS from their church or local eligious organization • One in two Latinos say their local church cares "a lot" about the fight against IDS • One in two Latinos rate AIDS the nation's most urgent health problem • Half of Latinos say IDS is a more urgent problem for their local community • Two in three Latinos say AIDS is a very erious problem for people they know • Nearly half of Latinos are worried about becoming nfected with HIV • Seven in ten Latinos are very worried about their children becoming infected vith HIV • One in two Latinos would like to know more about discussing sex and AIDS with artners • Seven in ten Latinos would like more information about liscussing AIDS prevention with kids • One in five Latinos say they eceived information about HIV/AIDS from their church or local religious rganization • One in two Latinos say their local church cares "a lot" about the fight against AIDS

THE HENRY J. KAISER FAMILY FOUNDATION

Harvard AIDS Institute

FOR IMMEDIATE RELEASE

CONTACT: Michael S. Broder
617-432-4121

LATINO LEADERS GATHER AT HARVARD TO CATALYZE NATIONAL RESPONSE TO AIDS CRISIS AMONG LATINOS

Rosie Perez Joins Latino Community Leaders in Call for Action

May 4, 1998 —New statistics released by the Centers for Disease Control show that the AIDS epidemic continues to have a disproportionate impact on Latino Americans. In response, the Harvard AIDS Institute hosted a one-day summit today to galvanize the nation's Latino leaders to address the epidemic in a coordinated campaign. In five years, the annual number of Latino AIDS cases will surpass the annual number of non-Latino white AIDS cases, according to a recent Harvard AIDS Institute projection. The *Leading for Life / Unidos Para la Vida* summit was held to catalyze leaders in academia, business, entertainment, law, the media, medicine, politics, religion, and sports to raise awareness nationally and to develop a national follow-up campaign. Leaders at the summit adopted a call for action outlining concrete action steps to address the epidemic among Latinos.

Among those attending the summit were actress Rosie Perez; Norma Lopez, vice president of the National Council of La Raza; Ingrid Duran, assistant director of policy development for the National Association of Latino Elected and Appointed Officials (NALEO); and Rosanna Rosado, editor-in-chief of *El Diario-La Prensa*. Dr. Helene D. Gayle, director of the Center for Disease Control and Prevention's National Center for HIV, STD, and TB Prevention, presented the latest epidemiologic findings.

The leaders confronted an epidemic that is already severe. During the first decade of the epidemic, Latino Americans had the fastest growing rate of AIDS cases compared to other racial/ethnic groups. While Latinos represent 11 percent of the U.S. resident population, they account for nearly one-fifth of all AIDS cases reported to the U.S. Centers for Disease Control and Prevention in 1997. Nearly a quarter of all children diagnosed with AIDS were Latino as of last

-more-

year. In 1996, the rate of HIV case diagnoses for Latino Americans was more than three times higher than that for non-Latino whites.

"The *Unidos Para la Vida* summit is an important step in addressing the AIDS crisis among Latinos," said Dr. Rafael Campo, a physician at Beth Israel Deaconess Medical Center. "We must stop this disease from ravaging Latino communities."

"I know that the tens of thousands of Latinos who have died because of AIDS would be proud of what we are doing here today," said Dennis deLeon, president of the Latino Commission on AIDS. "For the first time we have the beginnings of a national response to AIDS in the Latino community."

The Latino Commission on AIDS announced the formation of the National Coalition of Latinos Responding to HIV/AIDS. The National Coalition will speak out on issues affecting Latinos throughout the United States and educate leaders and governmental agencies on the needs of the Latino community. The National Coalition will be reaching out to all segments of the Latino community to create a national voice on one of the most critical health issues in our community. The Coalition will work to ensure that the needs of the Latino community are addressed by every level of government and by private and public funders.

The Harvard AIDS Institute cosponsored the summit along with the Latino Commission on AIDS, the American Red Cross Hispanic HIV/AIDS Education Program, the U.S.-Mexico Border Health Association, and the Mauricio Gastón Institute. The Henry J. Kaiser Family Foundation—a non-profit, independent national health care philanthropy based in Menlo Park, California—provided primary funding for the campaign, as well as support and guidance. Epidemiologic assistance was provided by the Centers for Disease Control and Prevention.

The Harvard AIDS Institute is a university-wide organization that conducts and catalyzes research to end the worldwide AIDS epidemic.

—end—

Clinton Presidential Records
Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

CHART PACK

National Survey of Latinos on HIV/AIDS

THE HENRY J. KAISER FAMILY FOUNDATION

May 1998

CALIFORNIA OFFICE: 2400 Sand Hill Road, Menlo Park, California 94025 (650) 854-9400 FAX (650) 854-4800
WASHINGTON OFFICE: 1450 G Street, NW, Suite 250, Washington, DC 20005 (202) 347-5270 FAX (202) 347-5274

COSSMHO

25 Years of Connecting Communities & Creating Change

National Coalition of Hispanic Health and Human Services Organizations

THE HENRY J. KAISER FAMILY FOUNDATION

EMBARGOED FOR RELEASE UNTIL:
9:30 am, ET, Friday, May 1, 1998

For Further Information Contact:
Tina Hoff or Matt James/KFF
(650) 854-9400
Xiomara Sosa/COSSMHO
(202) 797-4335

TWO NEW STUDIES ON LATINOS AND AIDS IN AMERICA:

- **SURVEY OF LATINOS FINDS WIDESPREAD CONCERN ABOUT HIV/AIDS; IMPACT OF DISEASE FELT "CLOSE TO HOME"**
- **REPORT DOCUMENTS IMPACT OF HIV/AIDS ON HISPANICS AND OFFERS GUIDANCE FOR COMMUNITY HEALTH PROVIDERS**

WASHINGTON, DC – Next week Latino leaders will gather at Harvard University for the first ever Latino "Leading for Life/*Unidos Para la Vida"* conference to discuss how to address the growing problem of HIV/AIDS among Latinos. As Latino leaders mobilize to address the problem of HIV/AIDS, most Latinos living in the U.S. today say they are extremely concerned about the impact of this deadly disease on their communities, families and themselves, according to a new national survey released today by the Kaiser Family Foundation, along with the National Coalition of Hispanic Health and Human Services Organizations (COSSMHO).

Highlights from the *Kaiser Family Foundation National Survey of Latinos on HIV/AIDS*:

- One in two Latinos (50%) rate AIDS as the nation's most urgent health problem, and nine in ten (91%) say it is a major threat to public health in this country;
- Half of all Latinos (52%) say AIDS is a more urgent problem *today* for their local community than it was a few years ago and one in five (20%) say their community is losing ground on AIDS;
- Two thirds of Latinos (67%) say AIDS is a very serious problem for people they know and a third (35%) say they personally know someone who has HIV or AIDS or who died from AIDS;
- 46% of Latinos say they are very worried about becoming infected with HIV, a level of worry which far exceeds that among a national sample of all Americans (24%), and 41 percent say their personal worry has grown in recent years.

Responding to the concerns and information needs of Hispanics about HIV/AIDS at the community level, COSSMHO also released today *HIV/AIDS: The Impact on Hispanics*. This report, which contains the most current data on the AIDS epidemic among Hispanics, including national trends as well as variations by region, supports the need to intensify community-based prevention and education efforts. Produced for community-based organizations, health and human services professionals, and others, it offers information for accessing Hispanics' response to HIV/AIDS and suggestions for a course of action.

"At a time when public perception moves in the direction of viewing HIV/AIDS as a manageable disease, Hispanic communities continue to be devastated by this epidemic," said Jane L. Delgado, Ph.D., President and Chief Executive Officer of the National Coalition of Hispanic Health and Human Services Organizations (COSSMHO).

-- more --

COSSMHO recommends that every comprehensive community-based HIV/AIDS program should have the following:

- Access to culturally and linguistically appropriate, voluntary and anonymous testing, and appropriate medical care for early diagnosis and treatment of HIV infection;

- AIDS education curricula (that include information about HIV/AIDS, skill building on condom use, the interpersonal challenges of negotiating safer sex, and avoiding drug use) to be used in junior- and senior-high school settings, and targeted settings for out-of-school youth;

- Outreach, education, and prevention -- including the provision of prevention tools such as sterile injection equipment -- to persons who are injecting drugs.

THE FACTS from *HIV/AIDS: The Impact on Hispanics*: As of June 1997, a total of 109,252 Hispanic AIDS cases had been reported in the U.S. While Hispanics make up 12 percent of the U.S. population (including Puerto Rico), they account for 18 percent of all AIDS cases in this country. This represents a continued upward trend: in 1995, Hispanics accounted for 15 percent of all AIDS cases. While AIDS mortality declined by 32 percent in 1996 for non-Hispanic whites, Hispanics experienced a 20 percent decline and non-Hispanic blacks a 13 percent decline.

There is significant variation in the regional distribution of Hispanic AIDS cases by exposure category. In the Eastern part of the U.S. and Puerto Rico, injection drug use (IDU) constitutes the most significant exposure category for Hispanic AIDS cases (MA, NJ, NY). For the other states studied in this report (AZ, CA, CO, FL, IL, NM, TX), men who have sex with men represent the most significant exposure category.

The Role of Information in Fighting HIV/AIDS

According to the Kaiser Family Foundation survey, almost all Latinos know that HIV is sexually transmitted (98%) and that a pregnant woman with HIV can pass it to her baby (92%). Slightly fewer, though still the majority, know there is no cure for AIDS (77%) and that no vaccine against HIV is available (68%).

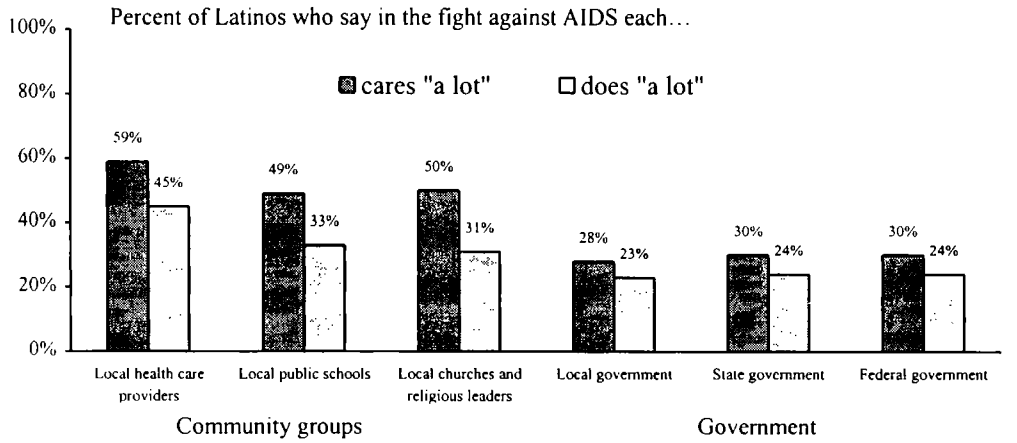
"Even those who are most knowledgeable about AIDS say there is more information they want, especially about the most practical aspects of HIV prevention: how to talk with children and partners, and where to go for testing and treatment," said Sophia Chang, MD, Director of HIV Programs, Kaiser Family Foundation.

While Latinos know the basic facts about HIV/AIDS, most say there are areas they want to know more about, such as how to talk with children (70%) and partners (51%) about this disease and where to go if exposed to HIV for testing (58%) and treatment (63%). Many (41%) also say that to help guard against the spread of HIV they want more information about how to properly use condoms. Importantly, respondents interviewed in Spanish (50% of the sample) cited an even greater desire for information in all areas, highlighting the importance of making education and prevention materials available in both English and Spanish.

The media, especially television and radio, is a leading source of information about HIV/AIDS for Latinos. Seven in ten Latinos (70%) say they heard something about HIV/AIDS in the past month on a television news program, and two in five (44%) got information from an entertainment show on television. Radio talk or call-in shows (42%) and other radio programming (34%) also figure as information sources. Beyond the media, health care providers (32%), family and friends (28%), and the church (20%) are the next most commonly named resources on HIV/AIDS. There is also some variation in information resources used by Latinos depending on the language of their interview: Latinos who were surveyed in Spanish were most likely to have gotten information about HIV/AIDS from broadcast outlets, including television news (73%) and entertainment (49%) programming and radio call-in or talk shows (48%); those who were interviewed in English also most frequently named television news programs (67%), but were more likely to turn to print media such as magazines (56%) and newspapers (50%).

Taking the Lead: Whose Responsibility?

Latinos see a variety of players in the fight against AIDS, giving slightly higher marks to community level efforts than to government. Latinos see community groups, such as local health care providers, churches, and schools, as among the most concerned and most active in reducing the impact of the epidemic. Fewer Latinos say government at any level *cares* or *does* as much in the fight against AIDS. Among all groups -- community and government -- Latinos leave room for more action.



In terms of what is needed to fight against the disease, Latinos strongly support more government efforts. Two in five (44%) say the government spends too little money on HIV/AIDS and the majority supports increased spending across a range of areas including education and other prevention activities (94%), expanding access to new drug therapies (94%), and research to find more effective treatments (95%) as well as a vaccine (94%).

A majority (56%) of Latinos also favor needle exchange – programs that offer clean needles to IV drug users in exchange for used ones. Opinions on this issue, however, appear to be influenced by how it is presented. When given an argument made by opponents of needle exchange – that it gives tacit approval of illegal drug use – support is lower among Latinos: 41% favor, 56% oppose.

Survey Methodology

The *Kaiser Family Foundation National Survey of Latinos on HIV/AIDS* is a random-sample national survey of 802 Latino adults, 18 years and older. The survey was designed by staff at the Foundation and conducted by telephone in both English and Spanish by Princeton Survey Research Associates (PSRA) between September 19 and October 26, 1997. The margin of sampling error is plus or minus 4 percent. The margin of sampling error may be higher for some of the sub-sets in this analysis.

The Kaiser Family Foundation, based in Menlo Park, California, is an independent national health care philanthropy and is not associated with Kaiser Permanente or Kaiser Industries.

The National Coalition of Hispanic Health and Human Services Organizations (COSSMHO) for 25 years has been connecting communities and creating change to improve the health and well-being of Hispanics in the United States. Headquartered in Washington, DC, COSSMHO is the sole national organization focusing on the health and human services needs of the diverse Hispanic communities. COSSMHO's membership consists of thousands of front-line health and human services providers and organizations serving Hispanic communities in the United States and Puerto Rico.

A more detailed report on the survey findings, including analysis by age, gender, region of the country, religion, income and education, is available by calling the Kaiser Family Foundation's publication request line at 1-800-656-4533 (Ask for 1392 in English or 1393 in Spanish).

LEADING FOR LIFE

UNIDOS PARA LA VIDA

Secretariat
Harvard AIDS Institute
651 Huntington Avenue
Boston, MA 02115
phone: 617-432-4400
fax: 617-432-4545

UNIDOS PARA LA VIDA UPDATE

August 5, 1998

Dear *Unidos Para la Vida* supporter:

On May 4 1998, more than 60 national Latino leaders convened at the first *Leading for Life/Unidos Para la Vida* meeting to help respond to the AIDS epidemic among Latino communities. The meeting was held at Harvard University and sponsored by the Harvard AIDS Institute, the American Red Cross Hispanic HIV/AIDS Education Program, the Henry J. Kaiser Family Foundation, the Latino Commission on AIDS, the Mauricio Gastón Institute, and the U.S.-Mexico Border Health Association.

The following information serves as an informal update of some of the events, accomplishments, and news associated with the participants of *Unidos Para la Vida.*

Latino Commission on AIDS
Dennis deLeon

As a result of discussions at the *Unidos Para la Vida* meeting, the Latino Commission on AIDS has proposed the creation of a Latinos Responding to AIDS Network ("LRAN") as one step in meeting the challenges of uniting Latino leaders. LRAN will help to mobilize our diverse Latino communities into a unified voice of compassion and action.

The following are goals laid out by LRAN:

- LRAN will support the work of the National Minority AIDS Coalition, National Council of La Raza, Coalition of Hispanic Health and Human Services, National Latino Lesbian and Gay Organization and other national organizations in leveraging additional resources to address AIDS in the Latino community;

- LRAN will advocate on critical issues involving the Latino community and HIV;

- LRAN will build support from within the Latino community to meet the challenge of HIV/AIDS; and

- LRAN will offer its voice in support of programs serving Latinos through advocacy and assistance.

Dennis deLeon states, "We have all been part of coalitions in the past and know how difficult it is to maintain communication and to have an impact. The Latino Commission on AIDS has agreed to coordinate LRAN's efforts as we get started." They will be facilitating communication and taking a leadership role. Because this is an "outside of Washington" strategy, it is important to set up local efforts and networks.

If you wish to be part of this effort, please contact the Latino Commission on AIDS at 212-675-3466.

HoMoVisiones Inc.
Gamalier de Jesús
HoMoVisiones is a 30 minute non-commercial TV program that has reached New York City's cable viewers since 1994. Every week there are interviews with popular artists, film & theater reviews, music videos, AIDS information, and community events.

On May 25th and May 28th, *Unidos Para la Vida* was the feature of the program. Using footage from the meeting, the show focused on the AIDS epidemic in the Latino community and the need for leaders of the community to take the lead in fighting the epidemic.

Young Adults Against Drugs and Alcohol (YAADA)
Edwin Ortiz
YAADA Executive Director Edwin Ortiz was invited to be a guest on the *Cristina Show*. Known as the most watched talk show in the world, the *Cristina Show* reaches an estimated audience of 100 million people. Host Cristina Saralegui is very concerned about the AIDS epidemic in the Latino community and has recently contacted the Harvard AIDS Institute to receive information and utilize the *Unidos Para la Vida* network of leaders. On July 29th, Edwin was in Miami to tape the show that will be a two-part series on "Teens and Sex." One of the issues of focus is HIV/AIDS and Latino youth. At the time of this mailing, the airing date of the two-part series was not known.

National Hispanic Religious Partnership for Community Health
Reverend Luis Cortes
The results of the *Unidos Para la Vida* meeting were discussed at the recent Philadelphia Clergy meeting. The discussion raised a positive response. Clergy at the meeting proposed the provision of increased support for existing local AIDS groups.

National Council of La Raza (NCLR)
Norma Lopez
The NCLR held their annual conference in Philadelphia during the week of July 19th. The conference offered workshops that provided attendees the opportunity to receive up-to-date information on the key issues facing the Latino community. This year there were two workshops focused on HIV/AIDS, "Critical Issues in HIV Prevention Case Management" and "Latino Small Business Survival in the HIV/AIDS Era." These workshops were very popular, and as a result, the NCLR plans to have even more people develop and conduct HIV/AIDS related workshops for the next annual conference.

National Latina/o Lesbian, Gay Bisexual and Transgender Organization (LLEGO)
Martín Ornelas-Quintero
LLEGO, an organization committed to addressing issues of homophobia and AIDS care and prevention for Latinos, hosted a successful reception in Philadelphia during the NCLR meeting. Among the attendees at this popular event were the executive staff of the NCLR. This was an encouraging step for the HIV agenda among Latino community leaders. It appears that the reception will be an annual tradition with the support of the NCLR.

American Red Cross, Hispanic HIV/AIDS Education Program
Ledia Martinez
Information and materials introduced at the *Unidos Para la Vida* meeting, such as CDC materials and the Kaiser Family Foundation Survey, are now being distributed to Red Cross instructors nation-wide.

Arcos Communications
Roy Cosme
Michael DeLorenzo, star of the Fox Network Television show *New York Undercover* , has agreed to join the efforts of *Unidos Para la Vida.* He has agreed to endorse a future event (still to be determined) that furthers the goals outlined by leaders at the meeting.

El Diario la Prensa
Rosanna Rosado
El Diario was a sponsor for the annual POZ Life Expo in New York City held in May. This marks the first time a major spanish medium has sponsored the event which is in its fifth year. The POZ Life Expo is held in several cities and offers anyone an opportunity to learn more about life with HIV and AIDS. The Expo is sponsored by POZ Magazine and AIDS, Medicine & Miracles. El Diario also provided an AIDS supplement for the Expo program.

National Association of Latino Elected and Appointed Officials (NALEO)
Ingrid Duran
NALEO is working hard to get an appointment with the National Congressional Hispanic Caucus before they adjourn in September. Ingrid Duran is coordinating with Dr. Helene Gayle, Director of the CDC National Center for HIV, STD, and TB Prevention to tailor a presentation with statistics for the members of the Hispanic Caucus and their districts. They will ask that the Caucus declare AIDS a health emergency among the Latino community.

Harvard AIDS Institute
The *Unidos Para la Vida* report is in the final stages of production. The *Unidos Para la Vida* website has a posting of the press release of the May 4th meeting and the "Call for Mobilizing the Latino Community" document that was adopted by leaders at the meeting.

As part of the joint African American and Latino Leading for Life efforts, eight minority medical students will take part in the second year of the Arthur Ashe Program in AIDS Care. This medical training program, cosponsored by the Kaiser Family Foundation and National Medical Fellowships Inc., aims to train African American, Latino, and Native American medical students in clinical AIDS care.

If you have information for future updates please contact Helen Kao at the Harvard AIDS Institute by phone (617) 432-4119 or by e-mail hkao@hsph.harvard.edu.

Sincerely,

Dennis deLeon, Esq.
Latino Commission on AIDS

Rafael Campo, MD
Beth Israel Deaconess Medical Center

Office of HIV/AIDS Policy

Office of Public Health & Science
Offfice of the Secretary
200 Independence Avenue, S.W., Room 736-E
Washington, D.C. 20201

Deliver To: Todd

Fax: (___) 456-2438

Phone: (___)____-____

From: **Deborah von Zinkernagel**
Senior Policy Analyst
Phone: (202) 690-5560
Fax: (202) 690-7560
E-mail: DvonZinkernagel@osophs.dhhs.gov

Date: __/__/__

This fax contains 34 **page(s) + cover**

If transmission problems occur, please call: Shellie Abramson @ (202) 690-5560

Comments:_____

Latino Commission on AIDS

Compartiendo Estrategias Para Salvar Vidas (Sharing Strategies to Save Lives)

April 2, 1998

Keynote - 25 minutes

Good morning.

I would like to start today by talking a little about the epidemiology of Latinos and HIV/AIDS, and comparing the epidemic in Latinos to other racial and ethnic groups in the U.S.

Before I begin I would like to say that I would not have this information to present to you – at least, not in its current form – if not for the reporting work of healthcare providers and health departments across the country. I know some of you represent such organizations, and I want you to know that CDC appreciates the collaborative relationships we have with you. If not for the information you provide CDC, we would not be able to monitor the HIV/AIDS epidemic appropriately. Furthermore, it would not be possible for me to stand here today and talk about in specifics about the status of the epidemic in Latinos.

So let's look at the epidemic. Then I would like to talk about subepidemics in the Latino community, some related sociocultural issues, CDC programs targeting the Hispanic population, and changes in approaches to prevention. Finally, I would like to leave you with some food for thought.

[Slide 1: Percentage of Hispanics in the U.S. Population and in the Population of Persons with AIDS]

- Hispanic Americans are disproportionately represented in the AIDS epidemic.
- This graph shows the percentage of the U.S. population that are adult Hispanic men, women and children (in blue), as well as the percentage of Hispanic men, women, and children among persons with AIDS reported last year.
- Of all persons reported with AIDS, Hispanics were
  - 21% of adult men
  - 20% of adult women
  - 23% of children under the age of 13
- In each of these three groups, the percentage of Hispanic persons with AIDS exceeds the percentage in the U.S. population.

[Slide 2: Annual Rates of AIDS per 100,000 Population, Hispanic and White Non-Hispanic, by Age Group and Sex, Reported in 1997, United States]

- This table shows the rate of AIDS in Hispanics and white nonHispanics in 1997.
- For example, about 79 out of every 100,000 adult Hispanic men were reported with AIDS for the year 1997.
- The rate for women was about 22, and for children it was about 1.
- When you divide this value by the rate for white nonHispanics, you find that, for adult men, the rate of AIDS is three-and-a-half time greater among Hispanics. Among women and children, the rate is about seven times greater among Hispanics.

[Slide 3: Proportion of Adult AIDS Cases by Race/Ethnicity and Year of Report]

This slide describes the proportion of the total U.S. AIDS epidemic found among whites, African Americans, and Hispanics, from 1985 to 1997. The percentage of Hispanics with AIDS appears here in blue. That percentage has increased from 15% of the total epidemic in 1985 to over 20% in 1997.

[Slide 4: AIDS in Hispanics by Gender /Age]

[HELENE: NOTE END OF YEAR 97 NUMBERS WERE 78% MEN, 21% WOMEN AND >1 CHILDREN – BUT SLIDE 4 SHOWS MID-YEAR 97 NUMBERS]

At mid-year 1997, among Hispanics in the United States,

- 81% of reported AIDS cases were in adult/adolescent men
- 17% of reported cases were among adult/adolescent women and
- 2% of reported cases were in children under the age of 13

[Slide 5 Cumulative AIDS cases by cause of infection in U.S. men through June 1997]

Looking at all Hispanic men compared to all U.S. men with AIDS tells us that:

- The greatest AIDS exposure category for Hispanic men is unprotected sex in men who have sex with men, followed by injecting drug use.
- A larger proportion of Hispanic men report exposure to HIV through injecting drug use as a cause of infection than in all other AIDS cases among men.

[Slide 6 : Cumulative AIDS cases by cause of infection in U.S. women through June 1997]

Looking at all Hispanic women compared to all women with AIDS tells us that:

- For Hispanic women, the major mode of exposure to HIV is unprotected sexual intercourse with an HIV-infected partner -- 47%.
- Often, this sexual contact is with an injecting drug user – underscoring the link between substance abuse and HIV/AIDS in Hispanic women.

[Slide 7: AIDS Deaths among Hispanic Persons]

- For the U.S. population as a whole, deaths among people with AIDS declined 25% between 1995 and 1996.
- Deaths among adult Hispanic Americans with AIDS dropped slightly less: these fell 20% between 1995 and 1996, from 9,000 deaths to 6,900 deaths.
- The decline in deaths is attributed to some combination of three factors:

1. The number of new infections
2. The number of people who are HIV positive and who develop AIDS

(this may have slowed due to the impact of new combination therapies)

and

3. The number of people with AIDS who go from AIDS to death (again, this also may have slowed due to the impact of new combination therapies)

So the decline in deaths among Hispanics is less than the decline for the U.S. population with AIDS. However, we cannot say exactly what combination of the factors I just mentioned is responsible for either of these declines. All we know is that the decline is due to some combination of the three.

In sum, there has been some progress in the fight against HIV/AIDS. However, the Hispanic community has not fully shared the fruits of this progress. This may be related to issues such as economic inequality, homophobia, access to care, and gender inequality. I'll talk more about these issues in a few minutes.

Next, I would like to present a brief overview of subepidemics within the Hispanic community.

- Hispanics in the United States include a diverse mixture of ethnic groups and cultures.
  - With more than 25 million Hispanics, the United States has the fifth-largest Hispanic population in the world.
  - U.S. Hispanics represent more than 30 regions of origin. Approximately 62% of Hispanics are Mexican, 13% are Puerto Rican, 12% are Central and South American, 5% are Cuban, and 8% are from other Hispanic populations.

Both modes and rates of infections among Hispanics vary by place of birth.

[Slide 9: Adult/Adolescent AIDS Cases Among Non-Hispanic White and Hispanic Men by Ancestry and Exposure Mode, 1997]

[Please note here that this slide title is incorrect – there are no "non-Hispanic white" men shown on the slide].

These next two slides came from a multi-site interview study that supplements

CDC surveillance data.

- Among AIDS cases in Hispanic men by birthplace, Central Americans and Mexicans have the greatest proportion of unprotected male-to-male sex as a reported exposure mode. However, there is some question as to whether unprotected male-to-male sex as an exposure mode goes under-reported in Hispanic communities due to stigma against homosexuality.
- Also among AIDS cases in Hispanic men by birthplace, Puerto Ricans have the greatest proportion of injecting drug use as a reported exposure mode.

[Slide 10: Adult/Adolescent AIDS Cases Among Non-Hispanic White and Hispanic Women by Ancestry and Exposure Mode, 1997]

[Please note here that this slide title is incorrect – there are no "non-Hispanic white" women shown on the slide].

Among AIDS cases in Hispanic women by birthplace, women born in the United States have the greatest proportion of injecting drug use as a reported exposure mode.

- Also among AIDS cases in Hispanic women by birthplace, women born in the Dominican Republic, Puerto Rico, Mexico, and Central America

have the greatest proportion of heterosexual contact as a reported exposure mode.

[Slide 11: AIDS Rate per 100,000 Hispanic Population Reported in 1997]

- The number of Hispanics with AIDS varies widely in different regions of the United States. This is partly because of different regional concentrations of Hispanics by origin.
  - The majority of Hispanic AIDS cases in the continental United States is concentrated in the Northeast. A large part of the Hispanic population in the Northeastern U.S. is from Puerto Rico.
  - Puerto Rico has one of the highest AIDS rates among U.S. states and territories and was the region of origin for 27% of new AIDS cases among U.S. Hispanics in 1997.
  - Rates of AIDS among Hispanics are also high in Florida and Puerto Rico.
  - The rates in other regions of the U.S., including the West and Southwest, are much lower. (One reason for lower rates in the Southwest is that its Hispanic inhabitants are largely of Mexican descent. Rates of AIDS in Mexicans are lower than in other Hispanic populations.)

[Slide 12: Adult/Adolescent Hispanics with AIDS by Place of Birth, Reported in 1992 and 1997, United States]

- Country of birth is also a factor in AIDS rates among Hispanics.
  - In 1997, among Hispanics in the U.S. with AIDS, the largest percentage was born in the U.S. Hispanic individuals born in Puerto Rico make up a close second-largest percentage. This is followed by individuals born in Mexico, and then by individuals born in Central and South America.
  - Comparing this to the breakdown of the AIDS epidemic in Hispanics by place of birth in 1992, there has been little change. This suggests that new AIDS cases have occurred in all sub-groups.
- The fact that an HIV-negative test result is a requirement for immigration supports the conclusion that foreign-born Hispanics with AIDS are acquiring their infection in the U.S.

(Note, though, that visits to these individuals' countries of origin after initial immigration might affect where they acquired HIV infection. However, AIDS incidence is lower in Latin America than in the U.S.)

Next, I would like to talk briefly about related sociocultural issues.

Looking at the sociocultural context of Hispanic Americans, we may be able to obtain a better understanding of why AIDS rates are higher among Hispanics than among whites, and why the epidemic is on the rise in the Hispanic community. I also want to touch on how HIV/AIDS fits with some of the other challenges facing various Hispanic subcommunities.

[Slide 13: Issues in HIV Prevention Among Hispanics]

To design prevention interventions for the Hispanic community, we need to look at underlying reasons for the disproportionate number of AIDS cases among Hispanics.

- The higher proportion of AIDS cases may be due to any of a number of factors, including ancestry and place of birth as well as underlying cultural and economic conditions, such as language or other cultural barriers, acculturation, higher rates of poverty, or limited access to health care.

    - National studies have shown that foreign-born Hispanics, especially those residing in the U.S. less than 15 years, are more

likely to lack health insurance than U.S.-born Hispanics or non-Hispanics.

- In addition, less acculturated Hispanic adults, for example, those who prefer to speak Spanish over English, are more likely to lack a routine source of medical care, to be in poor health, and to live in poverty.

  - In one study conducted among less-acculturated Hispanic individuals in San Francisco, 35% of men reported having multiple sex partners, but 79% of women reported never using condoms.

  - In another study, conducted among foreign-born Hispanic women in New York City, it was found that women were less likely to use condoms, but believed or knew that their sex partner(s) had other partners.

Economic conditions associated with lessened access to health care play a role in the AIDS epidemic in the Hispanic community. Here are some economic

indicators for Hispanic men and women with AIDS.

[Slide 14: Socioeconomic Status by Ancestry of Hispanic Men with AIDS]

[Note that this actually shows annual income, not household income and that these are Hispanic men with AIDS, not all Hispanic men]

[Slide 15: Socioeconomic Status by Ancestry of Hispanic Women With AIDS]

[Note that this actually shows annual income, not household income, and that these are women with AIDS, not all Hispanic women]

- Cultural issues may also play a part in elevated rates of AIDS in the Hispanic community.
  - For example, many Hispanics are extremely reluctant to acknowledge the existence of homosexuality among Hispanic males, especially those who portray the ideal "macho" male.
  - Bisexuality is also deeply suppressed among Hispanics. Those who engage in bisexual encounters often do not realize or admit to themselves or others that they are bisexual.

- Widespread cultural stigma against discussing sex is also a factor. Ambiguous terminology and glossing over sensitive concerns may not provide the information that individuals need to avoid risky behavior.

What I have just presented here is only a very brief look at sociocultural issues in Hispanic subcommunities. There is a good deal more information on these issues that can help us better grasp underlying reasons for the spread of HIV. However, there remains a gap in research on effective interventions among Hispanics. We know, from the data, that one-size-fits-all interventions are inappropriate. There is, however, still a need for more studies that look at interventions targeting specific subgroups.

Now I would like to talk about CDC programs that target Latinos. Specifically, I want to mention the 704 and Community Planning funding mechanisms.

- In 1997, CDC funded 94 community-based organizations through Announcement 704. The total budget for 704 was $18.3 million.

- Out of those 94 organizations,
- 64 target Latinos and Latinas either as their primary or secondary population
- 61 target youth in general

- Of the 64 organizations targeting Latinos,
  - 36 targeted Latinos as a primary population
  - 28 targeted Latinos as a secondary population
  - 40 targeted men who have sex with men
  - 48 targeted injecting drug users
  - 45 target the heterosexual population.

Then there is the Community Planning process. The Community Planning process calls on state health departments to work with representatives of the

epidemic in their jurisdiction as well as scientists and prevention service providers to determine funding priorities that respond directly to the epidemic in that jurisdiction.

I will describe the process in more detail in the next section of this talk. For now, I just want to give you an idea of the make-up of Community Planning groups, the distribution of Community Planning funds, and where the Health Departments say they are going to allocate funds – particularly as it relates to the Hispanic community.

[Slide 16: Racial / Ethnic Representation, 1998]

This slide comes from a recent in-depth analysis of the Community Planning process. It shows the racial / ethnic make-up of members of Community Planning groups which submitted applications for funding for 1998.

We can also see, in this slide, the proportion of each racial / ethnic group in the HIV / AIDS epidemic from July 1996 to June 1997 as well as the proportion of cumulative AIDS cases in each group.

[Slide 17: CTRPN by Race / Ethnicity and Service Delivery Statistics]

The following two slides tell us where the Health Departments allocated Community Planning funds reported these funds were going in 1997.

This slide shows that, of the approximately $92 million allocated by Community Planning groups towards counseling, testing, referral, and partner notification (CTRPN) activities, an average of 13% of budgets were going to programs targeting Hispanics. Again, you can see a comparison here of the cumulative AIDS cases among Hispanics (18%). Of the total budget allocated to CTRPN activities targeting Hispanics, 16% went to counseling and testing services.

[Slide 18: HE/RR by Race / Ethnicity]

This slide shows that, of the approximately $98 million allocated to health education and risk reduction (HE/RR) activities, 20% went to programs targeting Hispanics. That follows very closely the cumulative proportion of the AIDS epidemic in Hispanics (18%) and the proportion of the AIDS epidemic in Hispanics for July 1996 to June 1997 (20%).

I would like to shift now and talk about how changes in treatment are bringing about changes in prevention programming.

Prevention is changing just like treatment is changing. Here are some examples of how those changes are manifest in CDC prevention programs:

- As prevention changes, we are working to implement a scientific basis for HIV prevention programs. We are identifying good theoretical frameworks relevant to priority populations. We are no longer applying "cookie cutter" strategies just because they work well elsewhere or with another population. For example, we are looking at developmental stages and the types of interventions that might apply to various stages. We are trying to build programs around a better understanding of these stages. As another example, we recognize, through the IOM report, the relevance of STD treatment as an HIV prevention strategy.

- Prevention is being challenged by new treatments and their successes. The fact that some treatments may reduce infectiousness has important implications for prevention programming.
    - First, there is the danger of individuals letting down their guard and participating in risky behaviors because they have

undetectable viral loads. For example, the recent increase we saw in rectal gonorrhea among men who have sex with men (in STD clinics in several large U.S. cities) may be an indicator that individuals no longer perceive themselves to be at risk. Prevention programming needs to be able to address this.

- And second, some are questioning whether we should be putting more money into treatment or prevention. With treatment advances, support for prevention spending may be impacted. It is important that providers of prevention programming account for use of money as well as its benefits and outcomes. In addition, prevention may have to contend with a certain amount of apathy born out of a false sense of hope that there is a "cure".

- Prevention is also being impacted by the fact that the public is not, in general, as alarmed about HIV/AIDS today as they once were. The public has shifted its focus, and the impact of this will be fewer prevention dollars in the future. Did you know, for example, that in our $1 trillion dollar national budget, we spend less than one percent on population-based prevention? . . . And that is prevention for all diseases, not just HIV.

We need to ensure that the public has more information on the importance of prevention. We need to see that there is better understanding that prevention is our first, best defense against HIV.

- New technologies are impacting prevention. For example, the greater emphasis on rapid HIV testing. We now have the potential to tell someone very quickly whether or not they are infected. This increases access, but it also creates challenges for prevention. Prevention providers must be able provide clear and relevant messages about risk reduction.

  They also must be able to give good referrals in a timely fashion. Individuals who find out they are positive need to be directed immediately to care. Prevention providers also need to get feedback on these individuals – to find out if they are successful in accessing care.

  And with more people finding out their test status, there is the possibility of taxing available care resources. Rapid testing, unfortunately, does not necessarily equal rapid access to care.

- Community Planning represents an important shift in prevention. Community Planning, begun in 1993, requires that health departments receiving CDC HIV prevention funds complete a community planning process. As I mentioned earlier, the process calls for health departments, representatives of affected communities, and epidemiologists and behavioral scientists to work together to identify high-priority prevention needs. These identified needs serve as the basis for health departments' HIV prevention allocation decisions.

The Community Planning process presents a significant challenge to all prevention providers at the local level. It asks them to address prevention efforts to high priority groups in their localities and to partner with the local health department and other communities. It asks individuals with often divergent opinions and interests to cooperate in order to establish funding priorities in their locality. It calls for a dialog rather than two or more monologues.

The Community Planning requirement to engage in dialog is often very challenging. In order to create real dialog, we have to not just bring people to the table - but bring them in a way that ensures they will be comfortable advocating their positions. We have to be cognizant of the

fact that sometimes we hear what want to, not what has actually been said. We have to be willing to really listen – actively – and participate in conversations. That is what makes a true dialog.

- We are looking to new ways to get prevention messages to those who need them most. For example, we are targeting prevention messages very closely to specific groups and sub-groups of at-risk individuals. We have worked -- and will continue to work -- with experts to develop messages relevant to specific communities.

For example, I understand that in some Hispanic cultures, death is a more integral part of life than in some other cultures. Thus, the message of "AIDS = Death" may not resonate in some parts of the Hispanic community, where individuals may fear death less than the U.S. population in general.

- Prevention in injecting drug users presents another challenge for prevention in the future. The spread of infectious diseases, including HIV, is one of the most devastating and long-lasting effects of substance abuse in this country. Injection drug use particularly fuels the HIV epidemic among women, and as a result it impacts children. To address

the prevention needs raised by injecting drug use, we need to (1) keep people from starting to use drugs, (2) advocate for effective and widespread treatment, and (3) expand the options for individuals who continue to use drugs – including increased access to publically funded drug treatment.

- And finally, with new directions in prevention, it is vital that prevention providers stay up to date. It is very important that providers read and talk with others in the field. Prevention is more than just instincts -- there is a science involved. For example, just being Hispanic is not enough to guarantee successful prevention programming in the Hispanic community. You may not understand all the sub-communities within each community (for example, Latino gay men, Latino gay women). Gatherings like this one help us update each other on the changing needs of prevention.

Next, I would like to offer some future challenges for you to consider.

The growth of the AIDS epidemic in the Hispanic community makes it clear that there are unmet needs in prevention and treatment in the community. Following are a number of issues that need further consideration if we are to address these gaps.

Today I would like to throw out some questions in the areas of

- Immigration
- Public policy
- Health services and
- Media

I hope that the questions I raise might help us all think about HIV prevention and treatment in some different ways.

First, I'd like to address immigration issues:

- The number of immigrants from Latin America to the U.S. has stayed more or less steady over the past 10 years. By the year 2005, Latinos will outnumber African Americans as the largest minority group in the U.S.
- Latin Americans tend to immigrate back and forth between their home

countries and the U.S. (as opposed to other nationalities who immigrate to stay).

Here are some points to consider:

- Immigrants entering this country legally or illegally face concerns about being deported if they are infected with HIV. We need to think about linking information on this issue to HIV prevention programs.

- Recent arrivals in the U.S. tend not to be acculturated. We need to inform newly arrived immigrants about the health system, how it works, and how to be "health-wise" to avert diseases – particularly HIV.

- We need to work with AIDS programs in Latin America to link HIV prevention goals for people who are considering immigrating to the U.S. or individuals who have visited home and are returning to the U.S.

- Many recent immigrants have competing priorities in their new lives in the U.S. – and those priorities are not health maintenance and services. We need to get messages to immigrant communities that maintaining ones health is a priority.

- Many Latin American immigrants leave behind spouses to care for children or elderly parents. The spouse who comes to the U.S. may begin risky sexual behavior when confronted with the loneliness of a foreign country. We need to develop programs for recent immigrants to inform them of the high HIV infection risks of promiscuous behavior.

- Many recently arrived immigrants – and some individuals whose families have lived in this country for generations – work as migrant farm workers. Rates of HIV infection in these communities are some of the highest in the U.S. and health care is lacking. We need programs that will teach prevention and ensure continuity of care among migrant farm workers.

There are also public policy issues:

Looking at public funding issues, it is important that individuals from every community impacted by HIV take part in the public dialog and work with public officials.

Here are some points to consider:

- Are you working with Latino officials or "Latino-friendly" officials in

your area to develop and support public policies that affect your program and service providers?

- For those of you who are public health officials, are you working to educate Latino leaders on local and state AIDS-related funding, policies, and laws?

- Do you understand existing or proposed policies and have a stand on them? (e.g. mandatory HIV reporting, needle exchange deregulation, etc.)

- Would you be willing to network your resources and expertise with those of another organization toward public policy advocacy?

Looking at health services issues:

- It is estimated that around 30% of Latinos do not have insurance coverage.
- In part because of this, Latinos with AIDS tend to present later for diagnosis and therefore, have more delayed treatment and less access to newer therapies than white-non-Hispanics. Recently immigrated Latino children

tend to present later for diagnosis than other children.

Here are some points to consider:

- We need to identify barriers for Latinos to get initially HIV tested.
- We need to determine the cultural competency of health services for Hispanics with AIDS.
- We need to think about infrastructure capabilities available to impact on this problem (e.g., radio stations, advertising capabilities, large audiences, money, etc.).

Finally, looking at media issues:

- Hispanics are underserved by the general market media – if not in language, then in relevance, content, and broadcast talent.
- English-language companies tend to ignore Hispanics that speak English. Meanwhile, studies have shown that Hispanics are generally bilingual.
- Communications directed toward Hispanics will be ineffective if they

are simply translations of English to Spanish. They should be written in Spanish and feature subjects which appeal to Hispanic cultural values and country-of-origin distinctions.

Here are some points to consider:

- We need to be familiar with current Latino-directed efforts coming out of various media -- print, TV, radio.

- We need to understand the obstacles to getting information out.

- And, beyond the news, we need to develop other media strategies to get prevention messages heard.

In sum, today I have tried to give you a brief overview of the AIDS epidemic in the Hispanic community, some of the underlying sociocultural issues, some background on the numbers of CDC programs targeting Hispanics, and some questions for further consideration.

I wanted, also, to mention two initiatives which I think represent a step forward in the effort to focus attention on the issue of HIV/AIDS in the

Hispanic community.

One is the Department of Health and Human Services Hispanic Agenda for Action. This initiative has grown out of an HHS workgroup charged with developing recommendations to ensure that HHS workforce composition and programs are reflective of and sensitive to the Hispanic customers it will be serving in the future. It has presented recommendations, including a Hispanic health agenda. It is an important step in preparing to more effectively serve the growing Hispanic community.

The second is the President's Race Initiative. President Clinton has called for a year-long focus on racial issues, with town meetings and special events throughout the year. The President has also appointed a seven-member commission to study the issue.

A portion of the Race Initiative is an effort aimed at "Reducing Disparities in Health" that exist among certain racial groups. HHS is committed to developing a comprehensive strategy to reduce health disparities in infant mortality, cancer, cardiovascular disease, diabetes, adult and child immunizations, and HIV infection. $80 million has been set aside to address these public health issues through research. The goal of the research is to

identify new knowledge about causes of health disparities and effective means of delivering preventative and clinical services.

Initiatives such as these should create new opportunities for dedicated, effective people like yourselves. Whether you take part at the local or national level, your leadership in the fight against AIDS in the Hispanic community is vital to our future success. I commend you for your commitment to this vital public health issue.

Thank you.

Harvard AIDS Institute

FOR IMMEDIATE RELEASE

CONTACT: Michael S. Broder
617-432-4121

LATINO LEADERS GATHER AT HARVARD TO CATALYZE NATIONAL RESPONSE TO AIDS CRISIS AMONG LATINOS

Rosie Perez Joins Latino Community Leaders in Call for Action

May 4, 1998 —New statistics released by the Centers for Disease Control show that the AIDS epidemic continues to have a disproportionate impact on Latino Americans. In response, the Harvard AIDS Institute hosted a one-day summit today to galvanize the nation's Latino leaders to address the epidemic in a coordinated campaign. In five years, the annual number of Latino AIDS cases will surpass the annual number of non-Latino white AIDS cases, according to a recent Harvard AIDS Institute projection. The *Leading for Life / Unidos Para la Vida* summit was held to catalyze leaders in academia, business, entertainment, law, the media, medicine, politics, religion, and sports to raise awareness nationally and to develop a national follow-up campaign. Leaders at the summit adopted a call for action outlining concrete action steps to address the epidemic among Latinos.

Among those attending the summit were actress Rosie Perez; Norma Lopez, vice president of the National Council of La Raza; Ingrid Duran, assistant director of policy development for the National Association of Latino Elected and Appointed Officials (NALEO); and Rosanna Rosado, editor-in-chief of *El Diario-La Prensa*. Dr. Helene D. Gayle, director of the Center for Disease Control and Prevention's National Center for HIV, STD, and TB Prevention, presented the latest epidemiologic findings.

The leaders confronted an epidemic that is already severe. During the first decade of the epidemic, Latino Americans had the fastest growing rate of AIDS cases compared to other racial/ethnic groups. While Latinos represent 11 percent of the U.S. resident population, they account for nearly one-fifth of all AIDS cases reported to the U.S. Centers for Disease Control and Prevention in 1997. Nearly a quarter of all children diagnosed with AIDS were Latino as of last

-more-

year. In 1996, the rate of HIV case diagnoses for Latino Americans was more than three times higher than that for non-Latino whites.

"The *Unidos Para la Vida* summit is an important step in addressing the AIDS crisis among Latinos," said Dr. Rafael Campo, a physician at Beth Israel Deaconess Medical Center. "We must stop this disease from ravaging Latino communities."

"I know that the tens of thousands of Latinos who have died because of AIDS would be proud of what we are doing here today," said Dennis deLeon, president of the Latino Commission on AIDS. "For the first time we have the beginnings of a national response to AIDS in the Latino community."

The Latino Commission on AIDS announced the formation of the National Coalition of Latinos Responding to HIV/AIDS. The National Coalition will speak out on issues affecting Latinos throughout the United States and educate leaders and governmental agencies on the needs of the Latino community. The National Coalition will be reaching out to all segments of the Latino community to create a national voice on one of the most critical health issues in our community. The Coalition will work to ensure that the needs of the Latino community are addressed by every level of government and by private and public funders.

The Harvard AIDS Institute cosponsored the summit along with the Latino Commission on AIDS, the American Red Cross Hispanic HIV/AIDS Education Program, the U.S.-Mexico Border Health Association, and the Mauricio Gastón Institute. The Henry J. Kaiser Family Foundation—a non-profit, independent national health care philanthropy based in Menlo Park, California—provided primary funding for the campaign, as well as support and guidance. Epidemiologic assistance was provided by the Centers for Disease Control and Prevention.

The Harvard AIDS Institute is a university-wide organization that conducts and catalyzes research to end the worldwide AIDS epidemic.

—end—

Clinton Presidential Records
Digital Records Marker

This is not a presidential record. This is used as an administrative marker by the William J. Clinton Presidential Library Staff.

This marker identifies the place of a publication.

Publications have not been scanned in their entirety for the purpose of digitization. To see the full publication please search online or visit the Clinton Presidential Library's Research Room.

CHART PACK

National Survey of Latinos on HIV/AIDS

THE HENRY J. KAISER FAMILY FOUNDATION

May 1998

CALIFORNIA OFFICE: 2400 Sand Hill Road, Menlo Park, California 94025 (650) 854-9400 FAX (650) 854-4800
WASHINGTON OFFICE: 1450 G Street, NW, Suite 250, Washington, DC 20005 (202) 347-5270 FAX (202) 347-5274

COSSMHO

25 Years of Connecting Communities & Creating Change

National Coalition of Hispanic Health and Human Services Organizations

THE HENRY J. KAISER FAMILY FOUNDATION

EMBARGOED FOR RELEASE UNTIL:
9:30 am, ET, Friday, May 1, 1998

For Further Information Contact:
Tina Hoff or Matt James/KFF
(650) 854-9400
Xiomara Sosa/COSSMHO
(202) 797-4335

TWO NEW STUDIES ON LATINOS AND AIDS IN AMERICA:

- **SURVEY OF LATINOS FINDS WIDESPREAD CONCERN ABOUT HIV/AIDS; IMPACT OF DISEASE FELT "CLOSE TO HOME"**
- **REPORT DOCUMENTS IMPACT OF HIV/AIDS ON HISPANICS AND OFFERS GUIDANCE FOR COMMUNITY HEALTH PROVIDERS**

WASHINGTON, DC – Next week Latino leaders will gather at Harvard University for the first ever Latino "Leading for Life/*Unidos Para la Vida"* conference to discuss how to address the growing problem of HIV/AIDS among Latinos. As Latino leaders mobilize to address the problem of HIV/AIDS, most Latinos living in the U.S. today say they are extremely concerned about the impact of this deadly disease on their communities, families and themselves, according to a new national survey released today by the Kaiser Family Foundation, along with the National Coalition of Hispanic Health and Human Services Organizations (COSSMHO).

Highlights from the *Kaiser Family Foundation National Survey of Latinos on HIV/AIDS*:

- One in two Latinos (50%) rate AIDS as the nation's most urgent health problem, and nine in ten (91%) say it is a major threat to public health in this country;
- Half of all Latinos (52%) say AIDS is a more urgent problem *today* for their local community than it was a few years ago and one in five (20%) say their community is losing ground on AIDS;
- Two thirds of Latinos (67%) say AIDS is a very serious problem for people they know and a third (35%) say they personally know someone who has HIV or AIDS or who died from AIDS;
- 46% of Latinos say they are very worried about becoming infected with HIV, a level of worry which far exceeds that among a national sample of all Americans (24%), and 41 percent say their personal worry has grown in recent years.

Responding to the concerns and information needs of Hispanics about HIV/AIDS at the community level, COSSMHO also released today *HIV/AIDS: The Impact on Hispanics*. This report, which contains the most current data on the AIDS epidemic among Hispanics, including national trends as well as variations by region, supports the need to intensify community-based prevention and education efforts. Produced for community-based organizations, health and human services professionals, and others, it offers information for accessing Hispanics' response to HIV/AIDS and suggestions for a course of action.

"At a time when public perception moves in the direction of viewing HIV/AIDS as a manageable disease, Hispanic communities continue to be devastated by this epidemic," said Jane L. Delgado, Ph.D., President and Chief Executive Officer of the National Coalition of Hispanic Health and Human Services Organizations (COSSMHO).

-- more --

COSSMHO recommends that every comprehensive community-based HIV/AIDS program should have the following:

- Access to culturally and linguistically appropriate, voluntary and anonymous testing, and appropriate medical care for early diagnosis and treatment of HIV infection;
- AIDS education curricula (that include information about HIV/AIDS, skill building on condom use, the interpersonal challenges of negotiating safer sex, and avoiding drug use) to be used in junior- and senior-high school settings, and targeted settings for out-of-school youth;
- Outreach, education, and prevention -- including the provision of prevention tools such as sterile injection equipment -- to persons who are injecting drugs.

THE FACTS from *HIV/AIDS: The Impact on Hispanics*: As of June 1997, a total of 109,252 Hispanic AIDS cases had been reported in the U.S. While Hispanics make up 12 percent of the U.S. population (including Puerto Rico), they account for 18 percent of all AIDS cases in this country. This represents a continued upward trend: in 1995, Hispanics accounted for 15 percent of all AIDS cases. While AIDS mortality declined by 32 percent in 1996 for non-Hispanic whites, Hispanics experienced a 20 percent decline and non-Hispanic blacks a 13 percent decline.

There is significant variation in the regional distribution of Hispanic AIDS cases by exposure category. In the Eastern part of the U.S. and Puerto Rico, injection drug use (IDU) constitutes the most significant exposure category for Hispanic AIDS cases (MA, NJ, NY). For the other states studied in this report (AZ, CA, CO, FL, IL, NM, TX), men who have sex with men represent the most significant exposure category.

The Role of Information in Fighting HIV/AIDS

According to the Kaiser Family Foundation survey, almost all Latinos know that HIV is sexually transmitted (98%) and that a pregnant woman with HIV can pass it to her baby (92%). Slightly fewer, though still the majority, know there is no cure for AIDS (77%) and that no vaccine against HIV is available (68%).

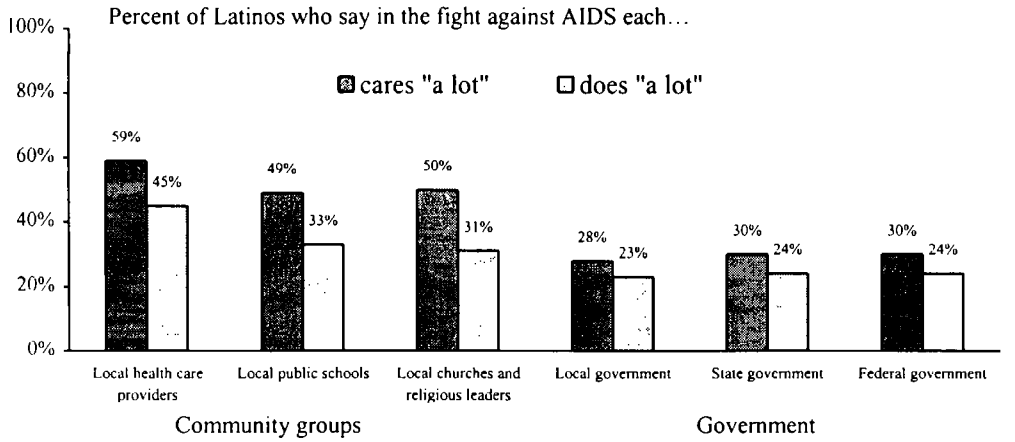
"Even those who are most knowledgeable about AIDS say there is more information they want, especially about the most practical aspects of HIV prevention: how to talk with children and partners, and where to go for testing and treatment," said Sophia Chang, MD, Director of HIV Programs, Kaiser Family Foundation.

While Latinos know the basic facts about HIV/AIDS, most say there are areas they want to know more about, such as how to talk with children (70%) and partners (51%) about this disease and where to go if exposed to HIV for testing (58%) and treatment (63%). Many (41%) also say that to help guard against the spread of HIV they want more information about how to properly use condoms. Importantly, respondents interviewed in Spanish (50% of the sample) cited an even greater desire for information in all areas, highlighting the importance of making education and prevention materials available in both English and Spanish.

The media, especially television and radio, is a leading source of information about HIV/AIDS for Latinos. Seven in ten Latinos (70%) say they heard something about HIV/AIDS in the past month on a television news program, and two in five (44%) got information from an entertainment show on television. Radio talk or call-in shows (42%) and other radio programming (34%) also figure as information sources. Beyond the media, health care providers (32%), family and friends (28%), and the church (20%) are the next most commonly named resources on HIV/AIDS. There is also some variation in information resources used by Latinos depending on the language of their interview: Latinos who were surveyed in Spanish were most likely to have gotten information about HIV/AIDS from broadcast outlets, including television news (73%) and entertainment (49%) programming and radio call-in or talk shows (48%); those who were interviewed in English also most frequently named television news programs (67%), but were more likely to turn to print media such as magazines (56%) and newspapers (50%).

Taking the Lead: Whose Responsibility?

Latinos see a variety of players in the fight against AIDS, giving slightly higher marks to community level efforts than to government. Latinos see community groups, such as local health care providers, churches, and schools, as among the most concerned and most active in reducing the impact of the epidemic. Fewer Latinos say government at any level *cares* or *does* as much in the fight against AIDS. Among all groups -- community and government -- Latinos leave room for more action.



In terms of what is needed to fight against the disease, Latinos strongly support more government efforts. Two in five (44%) say the government spends too little money on HIV/AIDS and the majority supports increased spending across a range of areas including education and other prevention activities (94%), expanding access to new drug therapies (94%), and research to find more effective treatments (95%) as well as a vaccine (94%).

A majority (56%) of Latinos also favor needle exchange – programs that offer clean needles to IV drug users in exchange for used ones. Opinions on this issue, however, appear to be influenced by how it is presented. When given an argument made by opponents of needle exchange – that it gives tacit approval of illegal drug use – support is lower among Latinos: 41% favor, 56% oppose.

Survey Methodology

The *Kaiser Family Foundation National Survey of Latinos on HIV/AIDS* is a random-sample national survey of 802 Latino adults, 18 years and older. The survey was designed by staff at the Foundation and conducted by telephone in both English and Spanish by Princeton Survey Research Associates (PSRA) between September 19 and October 26, 1997. The margin of sampling error is plus or minus 4 percent. The margin of sampling error may be higher for some of the sub-sets in this analysis.

The Kaiser Family Foundation, based in Menlo Park, California, is an independent national health care philanthropy and is not associated with Kaiser Permanente or Kaiser Industries.

The National Coalition of Hispanic Health and Human Services Organizations (COSSMHO) for 25 years has been connecting communities and creating change to improve the health and well-being of Hispanics in the United States. Headquartered in Washington, DC, COSSMHO is the sole national organization focusing on the health and human services needs of the diverse Hispanic communities. COSSMHO's membership consists of thousands of front-line health and human services providers and organizations serving Hispanic communities in the United States and Puerto Rico.

A more detailed report on the survey findings, including analysis by age, gender, region of the country, religion, income and education, is available by calling the Kaiser Family Foundation's publication request line at 1-800-656-4533 (Ask for 1392 in English or 1393 in Spanish).

LEADING FOR LIFE

UNIDOS PARA LA VIDA

Secretariat
Harvard AIDS Institute
651 Huntington Avenue
Boston, MA 02115
phone: 617-432-4400
fax: 617-432-4545

May 27, 1998

Greetings everyone!
We wanted to provide an informal update as to where we are in our campaign, *Leading for Life/Unidos Para la Vida.* It's been over three weeks since the meeting at Harvard University and suffice to say that the work has just begun.

The final version of the Call for Action and Proposed Specific Action Steps, which were discussed at the meeting, are completed. You will find both enclosed in this mailing. In addition we have included four press clippings from media coverage on the meeting and an updated Participant's list.

Press Coverage
1. Front page of the May 5 edition of the Miami Herald--coverage of meeting.
2. Living Section of the May 6 edition of the Miami Herald--featuring Rosie Perez.
3. May 8 edition of the Washington Blade--coverage of the meeting.
4. May 7 edition of the Harvard Gazette--coverage of the meeting.

Also:
- HoMo VISIONES in New York is planning to air a 30 minute program featuring the meeting.
- We will keep you updated on continuing press coverage of the meeting and issues.

Network Lists
Who else do we need to involve in our campaign? If you know someone who may want more information about *Leading for Life/Unidos Para la Vida*, you can use the last page in the meeting binder to enter the information. The Network List Form can be mailed or faxed to us.

Continuing updates
We are committed to keeping you updated on what is happening in this campaign, including all of your efforts. These updates may be in the form of mailings or faxes. If you have any specific news that directly relates to *Leading for Life/Unidos Para la Vida* and our Call for Action and Specific Action Steps, please contact us.

Here's how to contact us:

Mailing Address	Harvard AIDS Institute *Leading for Life/Unidos Para la Vida* 651 Huntington Avenue, 6th Floor Boston, MA 02115
Phone	(617) 432-4137
FAX	(617) 432-4545
E-mail	gmadriga@hsph.harvard.edu

Again, our sincerest gratitude for your concern, efforts and commitment to taking action against this epidemic that has a grip on our community.

Sincerely,

Dennis deLeon, Esq.
Latino Commission on AIDS

Rafael Campo, MD
Beth Israel Deaconess Medical Center

A CALL FOR MOBILIZING THE LATINO COMMUNITY: LEADING FOR LIFE/UNIDOS PARA LA VIDA

WHEREAS, Latinos constitute 11 percent of the U.S. population but 20 percent of U.S. AIDS cases in 1997 were among Latinos;

WHEREAS, in many states the rate of HIV/AIDS among Latinos is several times higher than for other groups and epidemiologists predict that with current trends Latino AIDS cases will surpass the number for non-Hispanic White cases shortly after the year 2000;

WHEREAS, while other racial/ethnic groups report declines in the number of new HIV infections, the numbers continue to climb in the Latino community;

WHEREAS, every Latino family has been touched by this disease and in some Latino communities in the United States, a whole generation of family members and future leaders have been lost to AIDS; and

WHEREAS, HIV/AIDS has a direct and devastating economic, social, and emotional impact on our communities and families and is inextricably linked to other socioeconomic maladies.

The leaders of *Unidos Para la Vida* declare we will not abandon our family members with HIV/AIDS. Hundreds of thousands of Latinos live with a legacy that cannot be healed. Our shame will kill them. Mobilize!

We call upon all sectors of our Latino community to rise to the challenge and address the health crisis created by AIDS.

We call upon all Latinos to educate themselves on AIDS and to support, develop, and enhance community-based AIDS programs developed by Latinos for their communities at the local level;

We call for renewed initiatives that address the HIV prevention and health care needs of all individuals in the Latino community regardless of sexual orientation, gender and drug use history;

We call upon Latino community leaders to develop strategies to address the health and social needs of the hundreds of thousands of Latinos already infected with HIV and to advocate for increased clinical and behavioral research on prevention programs within Latino communities; and

We call upon the Congressional Hispanic Caucus, in addition to the President and his cabinet, to meet the health, housing, and social service needs of all Latinos with HIV/AIDS, regardless of their immigration status;

We call upon Secretary of Health and Human Services Donna Shalala to declare a national health emergency in the Latino community regarding HIV/AIDS; and

Furthermore, we affirm the need for federal, state, and local governments, and all branches thereof, to address HIV/AIDS in a fair and equitable manner, and to allocate HIV funding to serve the needs of Latinos proportional to their need and level of risk.

We acknowledge the challenge of these difficult issues and we urge all to join us in prayer, education, advocacy, and political action.

Finally, we call upon all Latinos to reach out, hand-in-hand, to others locally and globally, to advocate for, care for, and affirm our commitment to the health of our communities.

Adopted by Latino leaders at the *Unidos Para la Vida* meeting on May 4, 1998, in Cambridge, Massachusetts.

PROPOSED SPECIFIC ACTION STEPS

ARTS / ENTERTAINMENT / ATHLETIC LEADERS

Volunteer your name and time to host philanthropic events for organizations targeting HIV/AIDS prevention, education, treatment, and social services for Latinos. Join together in a national philanthropic effort (perhaps simultaneously in Houston, Los Angeles, Miami, and New York) to raise money for specified Latino community-based AIDS organizations.

Use your unique, broad, and powerful influence in the Latino community, particularly with Latino youth, by adopting the AIDS crisis as your battle. Join with local organizations and campaigns to make HIV/AIDS awareness and education a visible and high profile issue. Encourage organizations such as the Screen Actors Guild or Major League Baseball to support AIDS prevention messages and AIDS philanthropies.

Work with the Centers for Disease Control, the National Minority AIDS Council, the Latino Commission on AIDS, and/or other such organizations/agencies to develop (bilingual) PSAs for print, TV, and radio to reach Latino youths in the United States. Ensure that the information being delivered is consistent between English and Spanish language versions.

BUSINESS LEADERS

Develop comprehensive HIV/AIDS workplace programs and sponsor HIV/AIDS prevention/ education sessions at your business. Programs should be bilingual and bicultural if the composition of your workforce is largely Latino.

Invest in the well-being of your employees and insure that they have adequate health care and prevention/education opportunities for themselves and their families. Develop comprehensive and equitable "return to work" policies and offer insurance programs that provide for treatment and do not discriminate against HIV disability.

Encourage your business to make HIV/AIDS one of the focuses of your corporate giving/ community relations philosophy. Post local organizations that can receive tax-deductible contributions in your company rooms, and offer matching gifts for your employees' donations to AIDS service organizations.

Encourage community volunteerism among your employees. Work in partnership with local AIDS service organizations to set up volunteer teams of employees from your business.

EDUCATION LEADERS

School education: Review your school's HIV education curriculum with local school officials. Where appropriate, provide bilingual resources or teaching materials for children to take back to their homes. Offer HIV education that takes a broad approach to looking at sexual health. Emphasize skill-building, decision-making, self-esteem, and negotiating safer sex. Incorporate needle exchange, substance use, violence, and condom use issues in a relevant way into the curriculum. Enlist Latino professors and students to hold discussion groups on their university campuses (especially for incoming students) about AIDS in the Latino community. Hold career forums to inform students about career options in medicine, public health, and social services.

Health professions education: Provide continuing education to all health care providers. Enlist the help of Latino health providers in speaking to their communities about HIV/AIDS prevention.

Community education: Develop and support prevention education programs, particularly those programs which are peer-to-peer and are culturally relevant to the target population. Develop resources for parents on how to effectively communicate with their adolescents and with each other.

FOUNDATION LEADERS

Hold workshops to assist community-based organizations in developing and submitting successful fundraising proposals.

Join the Council on Foundations, Funders Concerned About AIDS, and other philanthropic interests in creating a special committee to address prevention, care, AIDS research, and treatment within communities of color. Hispanic oriented foundations should network with other foundations—such as the Kaiser Family Foundation, the Ford Foundation, and the MacArthur Foundation—to earmark funds for Latino HIV/AIDS prevention and direct care efforts.

Provide financial resources to Latino community based organizations so as to create coalitions and collaborations that would provide the support to develop a national agenda for HIV/AIDS advocacy and public policy development to assure access to care.

GOVERNMENT LEADERS

Join together with advocates and persons with HIV/AIDS to create specific strategies for protecting the health of those impacted by HIV/AIDS, and other chronic diseases, as they implement Medicaid, social security, and welfare reform.

Become actively engaged in HIV/AIDS prevention and public policy issues. Hold town hall and regional meetings to inform the Latino community about your policies and actions in support of HIV/AIDS prevention, care, and research that directly supports or affects Latinos. Take a leadership role on the impact of HIV/AIDS on Latino communities.

Ensure that Latino communities benefit from government funding initiatives. Latinos must exert their influence upon the public health policy development process. The involvement of Latinos becomes critical in Medicaid and welfare reform since many Latinos—and many people living with HIV—receive basic health care through these programs.

Elected and appointed officials should require information from existing government agencies on: 1) the extent to which public health resources and specifically HIV treatment dollars are directed to Latino communities; 2) the extent to which Latino community based organizations receive funding support in order to provide treatment; and 3) the extent to which AIDS Drug Assistance Programs (ADAP) provides availability of the pharmacology that is needed for treatment.

HEALTH SERVICE / CARE / SOCIAL SERVICE LEADERS

Develop culturally relevant programs to educate the community about prevention. Ensure that managed care systems make care affordable and accessible for people with HIV and educate Latinos on their health rights and how to access health and social services. Ensure that the necessary medications and clinical trials are available to those with HIV.

Advocate for partnerships between AIDS Service Organizations and more traditional community organizations.

Advocate for further clinical and behavioral research on HIV/AIDS issues related to Latinos. Increase the number of studies conducted by and for Latinos.

Develop and maintain networks of health providers (especially those who work with HIV and/or who work with Latino communities).

MEDIA LEADERS

Utilize multiple communication strategies. Media attention that is both national and local, English and Spanish, should address the epidemic among Latinos.

Encourage responsible, accurate, and empathetic reporting on HIV/AIDS issues. Ensure that more articles include personal accounts of people living with HIV. The media must help to remove the stigma of AIDS. Too often, people living with HIV/AIDS and those who care for them bear burdens of isolation, misunderstanding, and intolerance.

Write articles for local media outlets. Highlight the successes of local organizations responding to the HIV/AIDS epidemic.

Encourage all television networks to broadcast responsible condom advertising, especially during prime time programming targeted to young people. Encourage both radio and television to broadcast PSAs with HIV prevention messages (in both English and Spanish).

NATIONAL ORGANIZATION LEADERS

Place HIV/AIDS at the top of your public health policy agendas, and become actively engaged in public policy and community efforts to ensure fair access to all treatment and care services for Latinos affected by HIV/AIDS.

Provide opportunities for organizations that work with Washington lobbyists—such as COSSMHO and the National Council of La Raza—to learn more about AIDS public health policy.

Provide organizations with a direct link to COSSMHO, CDC, etc. to get updated and accurate HIV/AIDS information.

Demand that other Latino organizations are responding to the epidemic in their communities with appropriate HIV/AIDS related programs and policies.

RELIGIOUS LEADERS

Respond to HIV/AIDS with messages of compassion, solidarity, love, unity and hope.

Encourage efforts to reach church congregations about acceptance of those infected or affected by HIV/AIDS. Motivate church communities to help families affected by the epidemic.

Encourage church leaders to engage their congregation in discourse on HIV prevention, particularly during the National Week of Prayer for the Healing of AIDS (the first week of March), National AIDS Awareness Month (October), and World AIDS Day (December 1).

Mr. Gonzalo Aburto Iniesta
Editor in Chief
POZ en Español
349 West 12th Street, 2nd Floor
New York, NY 10014
Phone: (212) 242-1900 x245
Fax: (212) 675-8505

Mr. David Acosta
Executive Director
The GALAEI Project
1233 Locust Street, 3rd Floor
Philadelphia, PA 19107
Phone: (215) 985-3382
Fax: (215) 985-3388

Mr. Moíses Agosto
Director of Research and Treatment Advocacy
National Minority AIDS Council
1931 13th St., NW
Washington, D.C. 20009-4432
Phone: (202) 483-6622
Fax: (202) 483-1135

Ms. Elena Alvarado
Executive Director
National Latinas Health Network
4818 Montgomery Lane
Bethesda, MD 20814
Phone: (301) 951-9633
Fax: (301) 951-9637

Ms. Marina Alvarez
702 Taylor Avenue, Apt. 2
Bronx, NY 10473
Phone: (718) 589-7664
Fax: (718) 328-4152

Dr. Joe Betancourt
Commonwealth Fellowship for Minority Health Policy
164 Longwood Ave.
Boston, MA 02115
Phone: (617) 432-2669
Fax: (617) 432-3834

Mr. Tonio Burgos
Tonio Burgos and Associates, Inc.
909 3rd Avenue, 17th floor
New York, NY 10022
Phone: (212) 453-3722
Fax: (212) 644-7485

Dr. Rafael Campo
General Medicine
Beth Israel Deaconess Medical Center
330 Brookline Ave.
Boston, MA 02215
Phone: (617) 667-4476
Fax: (617) 667-9620

Mr. Guillermo Chacón
Director of Community Development
Latino Commission on AIDS
80 Fifth Avenue, Suite 1501
New York, NY 10011
Phone: (212) 675-3288 x205
Fax: (212) 675-3466

Dr. Pablo R. Colon
Director of Treatment Education and Advocacy
Gay Men's Health Crisis
119 West 24th Street
New York, NY 10011
Phone: (212) 367-1450
Fax: (212) 367-1528

Mr. Mario Cooper
Founder
Leading for Life
#P-10A
One Irving Place
New York, NY 10003
Phone: (212) 979-7720
Fax: (212) 533-5849

The Reverend Luis Cortes
President
National Hispanic Religious Partnership for Community Health
Nueva Esperanza
4261 N. 5th Street
Philadelphia, PA 19140
Phone: (215) 324-0746
Fax: (215) 426-2542

Mr. Roy Cosme
Arcos Communications
114 West 26th Street, Suite 1003
New York, NY 10001
Phone: (212) 807-1337
Fax: (212) 807-8857

Dr. Elaine M. Daniels
Office of HIV/AIDS Policy
200 Independence Ave. SW
Washington, DC 20201
Phone: (202) 690-5560
Fax: (202) 690-7560

Mr. Gamalier de Jesús
Executive Director
HoMoVISIONES, Inc.
24 W. 25th St., 12th Floor
New York, NY 10010
Phone: (212) 807-4655
Fax: (212) 807-6644

Mr. Dennis deLeon
President
Latino Commission on AIDS
80 Fifth Avenue, Suite 1501
New York, NY 10011
Phone: (212) 675-3288 x202
Fax: (212) 675-3466

Ms. Lillian Diaz-Imbelli
Founder
Mothers on Media (MOM)
2848 East 194th Street
Bronx, NY 10461
Phone: (718) 892-0692
Fax: (718) 931-0717

Dr. Ken Dominguez
HIV/AIDS Prevention & Surveillance / Epidemiology
Centers for Disease Control and Prevention
1600 Clifton Road (E-45)
Atlanta, GA 30333
Phone: (404) 639-6129
Fax: (404) 639-6118

Mr. Andres Duque
Associate Director of Community Development
Latino Commission on AIDS
80 Fifth Avenue, Suite 1501
New York, NY 10011
Phone: (212) 675-3288 x212
Fax: (212) 675-3466

Ms. Ingrid Duran
Assistant Director of Policy Development
Washington Office
National Association of Latino Elected and Appointed Officials (NALEO)
514 C Street NE
Washington, D.C. 20002
Phone: (202) 546-2536
Fax: (202) 546-4121

Ms. Nely Galán
Galan Entertainment
915 Electric Avenue
Building C
Venice, CA 90291
Phone: (310) 452-8400
Fax: (310) 452-5154

Dr. Helene Gayle
Director
National Center for HIV, STD, and TB Prevention
Centers for Disease Control and Prevention
1600 Clifton Road, MS-E07
Atlanta, GA 30306
Phone: (404) 639-8000
Fax: (404) 639-8600

Mr. Heriberto Gonzalez
Producer
HoMoVISIONES, Inc.
24 W. 25th St., 12th Floor
New York, NY 10010
Phone: (212) 271-2464
Fax: (212) 807-6644

Ms. Miryam Granthon
Office of Disease Prevention & Health Promotion
Department of Health and Human Services
c/o Mana National Latina Organization
1725 K Street NW, Suite 501
Washington, D.C. 20006
Phone: (202) 690-6245
Fax:

Dr. Richard Jimenez
University of Texas School of Public Health
Room E-345
1200 Herman Pressler Drive
Houston, TX 77030
Phone: (713) 500-9197
Fax: (713) 500-9198

Ms. Maria Lemus
HIV/AIDS Specialist
National Latina Health Organization
PO Box 7567
Oakland, CA 94601
Phone: (510) 534-1362
Fax: (510) 534-1364

Ms. Norma Lopez
Vice President
National Council of La Raza
1111 19th Street NW
Suite 1000
Washington, D.C. 20036
Phone: (202) 785-1670
Fax: (202) 776-1792

Dr. Orlando Lopez
Executive Director of AIDS
Puerto Rico Health Department
PO Box 70184
San Juan, PR 00936
Phone: (787) 274-3339
Fax: (787) 274-5503

Mr. Dominic Maldonado
Health Educator
AIDS Division
New Haven Health Department
540 Ella Grasso Blvd.
New Haven, CT 06519
Phone: (203) 946-8980
Fax: (203) 946-8708

Ms. Miguelina Maldonado
Director of Government Relations and Policy
National Minority AIDS Council
1931 13th St., NW
Washington, D.C. 20009-4432
Phone: (202) 483-6622
Fax: (202) 483-1135

Dr. Richard Marlink
Executive Director
Harvard AIDS Institute
651 Huntington Avenue
Boston, MA 02115
Phone: (617) 432-4400
Fax: (617) 432-4545

Mr. Victor Marquez
Executive Director
La Raza Centro Legal, Inc.
474 Valencia Street, Suite 295
San Francisco, CA 94103
Phone: (415) 575-3519
Fax: (415) 225-7593

Dr. Ledia Martinez
National Program Coordinator
Hispanic HIV/AIDS Education Program
American Red Cross
National Headquarters
8111 Gatehouse Road, 6th Floor
Falls Church, VA 22042
Phone: (703) 206-7408
Fax: (703) 206-7754

Dr. Adolfo Mata
AIDS Coordinator
Center for Substance Abuse Treatment
Rockwall II, Suite 740
5600 Fishers Lane
Rockville, MD 20857
Phone: (301) 443-8435
Fax: (301) 443-3543

Mr. Michael Melendez
Policy Analyst
Office of the Bronx Borough President
851 Grand Concourse
Bronx, NY 10451
Phone: (718) 590-2509
Fax: (718) 537-3583

Dr. Edgar Monterroso
HIV/AIDS Prevention & Surveillance / Epidemiology
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30333
Phone: (404) 639-6146
Fax: (404) 639-6118

Mr. Daniel Montoya
Executive Director
Presidential Advisory Council on HIV/AIDS
736 Jackson Place
Washington, DC 20503
Phone: (202) 456-2437
Fax: (202) 456-2438

Mr. Xavier Morales
Associate Editor
POZ en Español
349 West 12th Street
New York, NY 10014
Phone: (212) 242-1900
Fax: (212) 675-8505

Dr. Doris Mosley
HIV/AIDS Bureau
Health Resources and Services Administration (HRSA)
5600 Fishers Lane
Parklawn Building, Room 9A-39
Rockville, MD 20857
Phone: (301) 443-6685
Fax: (301) 443-9887/9880

Mr. Martin Ornelas-Quintero
Executive Director
National Latina/o Lesbian, Gay, Bisexual & Transgender Organization
1612 K Street NW, Suite 500
Washington, D.C. 20006
Phone: (202) 466-8240 x232
Fax: (202) 466-8530

Mr. Edwin Ortiz
Executive Director
Young Adults Against Drugs & Alcohol
2390 Grand Concourse, 2nd Floor
Bronx, NY 10458
Phone: (718) 364-9529
Fax: (718) 364-0667

Reverend Altagracia Perez
Church of St. Philip the Evangelist
2800 Stanford Ave.
Los Angeles, CA 90011
Phone: (213) 232-3494
Fax:

Mr. Moises Perez
Executive Director
Allianza Dominicana
2410 Amsterdam Ave., 4th Floor
New York, NY 10033
Phone: (212) 740-1960
Fax: (212) 740-1967

Ms. Rosie Perez
Baker, Winokur, and Ryder
c/o David Pollick
405 South Beverly Drive, 5th Floor
Beverly Hills, CA 90211
Phone: (310) 247-8709
Fax: (310) 550-1701

Ms. Rebeca Ramos
Director
Training & Technical Assistance Program
U.S.–Mexico Border Health Association
6006 North Mesa
El Paso, TX 79912
Phone: (915) 581-6645 x26
Fax: (915) 833-4768

Mr. Joel L. Rhea
National President
Sigma Lambda Beta International Fraternity, Inc.
2219 S. Elmwood St.
Berwyn, IL 60402
Phone: (888) 486-2382
Fax: (708) 524-3035

Ms. Joyce Rivera
Executive Director
St. Ann's Corner of Harm Reduction
312-316 Cypress Avenue, 2nd Floor
Bronx, NY 10454
Phone: (718) 585-5544
Fax: (718) 585-8314

Dr. Christopher Rodriguez
Associate Executive Director for Public Policy
Hetrick Martin Institute
2 Astor Place
New York, NY 10003-6998
Phone: (212) 674-2600 x276
Fax: (212) 674-8650

Ms. Rosanna Rosado
Editor in Chief
El Diario la Prensa
143 Varick Street
New York, NY 10013
Phone: (212) 807-4691
Fax: (212) 807-4766

Ms. Jackie Rosenthal
Communications
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30333
Phone: (404) 639-8890
Fax: (404) 639-8910

Ms. Sandra Ruiz Butter
Executive Director
VIP Community Services
1910 Arthur Avenue, 4th Floor
Bronx, NY 10457
Phone: (718) 583-5150 x401
Fax: (718) 299-4899

Dr. Joao Soares
AIDS Program Director
Massachusetts Alliance of Portuguese Speakers (MAPS)
92 Union Square
Somerville, MA 02143
Phone: (617) 628-6065
Fax: (617) 628-2943

Mr. Todd Summers
Presidential Advisory Council on HIV/AIDS
736 Jackson Place
Washington, DC 20503
Phone: (202) 456-2437
Fax: (202) 456-2438

Mr. Sam Taveras
Community Assistance Planning
Centers for Disease Control and Prevention
1600 Clifton Road
Atlanta, GA 30333
Phone: (404) 639-5241
Fax: (404) 639-8607

Dr. Andres Torres
Co-Director
Mauricio Gastón Institute
University of Massachusetts, Boston
100 Morrissey Blvd.
Boston, MA 02125-3393
Phone: (617) 287-5790
Fax: (617) 287-5788

Dr. Nancy Torres
Commonwealth Fellowship for Minority Health Policy
164 Longwood Ave.
Boston, MA 02115
Phone: (617) 432-2669
Fax: (617) 432-3834

Ms. Lara Vaz
Health Education Manager
La Clinica de La Raza
1515 Fruitvale Ave.
Oakland, CA 94601
Phone: 510-535-4155
Fax: 510-535-4221

Ms. Toni Villarruell
President
National Association of Hispanic Nurses
1501 16th Street NW
Washington, D.C. 20006
Phone: (202) 387-2477
Fax: (202) 483-7183

Mr. Jose Zuniga
Deputy Director
International Association of Physicians in AIDS Care
225 W. Washington St., Suite 2200
Chicago, IL 60606-3418
Phone: (312) 419-7512
Fax: (312) 419-7160

Leading for Life/Unidos Para la Vida

OBSERVERS

Ms. Ivette Achong
LCG Latino

Ms. Martha Blandon
Kaiser Family Foundation

Ms. Mollyann Brodie
Kaiser Family Foundation

Ms. Doris Campbell
Glaxo Wellcome

Ms. Carol Carrozza
Ansell-Americas

Ms. Adisa Douglas
Public Welfare Foundation

Mr. Aaron Foster
Harvard School of Public Health

Ms. Jennifer Kates
Kaiser Family Foundation

Ms. Nina Kjellson
Kaiser Family Foundation

Ms. Jeannine Lynch
Agouron Pharmaceuticals

Ms. Jennifer Meyer
Ogilvie Public Relations Worldwide

Ms. Angela Saffo Daniel
Bristol-Myers Squibb Immunology

Mr. Luis Stuart
Agouron Pharmaceuticals

The Miami Herald

TUESDAY, MAY 5, 1998

Hispanic leaders call for war on AIDS

By STEPHEN SMITH
Herald Health Writer

BOSTON — An unprecedented summit of Hispanic leaders from across the country produced a call Monday for the formation of a national coalition dedicated to stopping AIDS and a promise to convene the 20 Hispanic members of Congress to help draft a war plan.

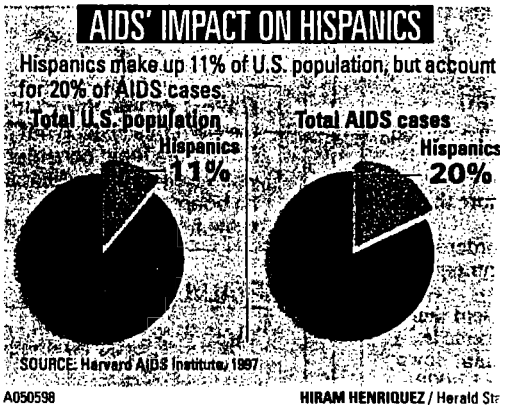
Their labors were framed by a new forecast showing that, within five years, the number of new AIDS cases among Hispanics will eclipse the figure for non-Hispanic whites.

Congress members will be asked for help.

"It's 1998, and we're still acting as though we're a tail on the dog that's the response to AIDS," said Dennis deLeon, a prominent AIDS warrior and one of the forces behind Monday's summit at Harvard University. "Enough is enough. We cannot lose more people to this epidemic. It is quickly becoming a disease of color now."

That's why, two years ago, black leaders from across America journeyed to Harvard for a historic gathering to search for ways to halt the virus in their communities. At a pace even more devastat-

PLEASE SEE AIDS, 19A



Hispanic leaders call for AIDS war

AIDS, FROM 1A

ing than among Hispanics, AIDS has disproportionately infected and killed blacks.

The success of that summit — it has led, for instance, to the nation's premier organization of black doctors committing to a $3 million trial of AIDS drugs — persuaded the Harvard AIDS Institute to call together 70 Hispanic leaders from the worlds of business, religion, medicine and entertainment.

Statistics released Monday show that Hispanics in the United States are 3.3 times more likely to develop AIDS than non-Hispanic whites. Unless dramatic measures are embraced, Harvard researchers estimate that risk will double by 2005. Already, Hispanics, who make up 11 percent of the nation's population overall, account for 20 percent of all AIDS cases. A study by the Kaiser Family Foundation reports that Hispanic Americans rank AIDS as the nation's most pressing health issue.

"These numbers are terrifying," said Dr. Rafael Campo, a Harvard medical school professor and Boston doctor whose practice specializes in treating people with AIDS. "It's an emergency, and we need to absolutely recognize what a crisis this is."

That urgency is worn on the face of Marina Alvarez, a strong face that melts into tears when she recounts the lives stolen by AIDS in her family. A brother and sister-in-law. Cousins. Most recently: news that her 70-year-old uncle is infected. Nine lives, in all, mourned from one family in the South Bronx. And, yes, Marina Alvarez is saying, she, too, is infected with the virus.

Hispanics account for 20 percent of the nation's AIDS cases.

"That's just my family — we have this silent weapon killing our community," Alvarez told the gathering. "Please, please do something so that later on, when my granddaughter is growing up, there can be a freedom from this devastation for all of our children."

Daunting proposition

That, the 70 people gathered at Harvard agreed is a daunting proposition. It's a task made more complex by the diversity of America's Hispanic communities. Hispanics on the West Coast, for instance, use a different Spanish word for condom than Hispanics on the East Coast. Those are the easy issues to deal with.

More challenging is this: The epidemic has strikingly different profiles in different Hispanic communities. For Cubans living in America, injecting-drug use accounts for just 7 percent of AIDS cases. For Puerto Ricans, drug use is culpable in 47 percent of infections.

Among the demands the Hispanic members of Congress will hear: a cry for the ouster of federal drug czar Barry McCaffrey, who prevailed upon the Clinton administration to keep intact a ban on allowing injecting-drug users to swap dirty, AIDS-tainted needles for needles free of the virus.

"We want him out, we want him away. He has done more than anybody to say drug users are not worthwhile," said deLeon, a New York AIDS activist.

Charged discussion

Sensitivities to the varying needs of Hispanic communities inspired some of the most-charged discussion at Monday's summit. Veterans of the AIDS battle urged strong pronouncements against homophobia and the federal government's ban on needle exchanges, while representatives of broad-based Hispanic groups counseled a more tempered approach to garner the widest support.

"We have a lot of similarities, but there are a lot of differences, too," said Dominick Maldonado, an AIDS educator from New Haven, Conn. "So a message for Puerto Ricans might be a lot different than a message for a Mexican, than a message for a Cuban, than a message for a Dominican."

Ultimately, an action plan was embraced that called for the drug czar's ouster while crafting messages aimed at Hispanics to have the broadest appeal.

"We're trying to get a lot of pieces of clothing in this luggage," said Moises Perez, executive director of the New York community group Alianza Dominicana. "But above and beyond all else, we're very concerned about what's going in our communities."

Absent voices

There was concern Monday, too, that some important voices were absent from the summit. No representatives of South Florida's Hispanic community were present, although invitations had been extended, an executive with the Harvard AIDS Institute said. And most troubling to the people present: Not a single elected official responded to pleas to join Monday's summit.

"If we are to call a meeting in D.C. and bring some of these people here to them and you're on their territory, then I think they will listen," said Ingrid M. Duran, director of the Washington office of the National Association of Latino Elected and Appointed Officials.

Her office, in conjunction with the Centers for Disease Control and Prevention, has pledged to rally Hispanic lawmakers. The 70 leaders hope their war plan reaches the halls of academe and drug development, too. They want more Hispanic researchers and patients included in campaigns to develop new drugs and a vaccine. By doing that, they hope to gain wider access to the powerful class of drugs called protease inhibitors that are given much of the credit for slowing AIDS' death march.

But, like all things in this epidemic, success is not evenly shared. The decline in deaths has been substantially lower among Hispanics and blacks than among non-Hispanic whites.

"I wish people realized that history is going to make accountable those who are avoiding us," said Moises Agosto of the National Minority AIDS Council. "Where are the leaders? We must be the leaders."

Rosie Perez battling AIDS among young Hispanics

The Miami Herald
May 6, 1998

By STEPHEN SMITH
Herald Health Writer

Maybe you noticed something missing at this year's Oscars shindig.

Sure, the duds of the stars still shimmered with the handiwork of Giorgio (as in Armani) and the house of Gianni (Versace, that is). But where was the sea of red ribbons, once affixed so devotedly to every lapel in Hollywood?

"Well," Rosie Perez is saying in that staccato, boom-boom, you-better-listen-or-else patter that's helped make her a star, "Hollywood is a superficial town, oriented to trends. You do one big monster film, and everybody wants to do monster films. Then, they're over that, and everybody is doing disaster films.

"There's still some people out there on a small scale working on AIDS. Like Elizabeth Taylor."

And, of course, Rosie Perez.

Been there, done that for a decade.

Rosie Perez

Going to keep being there. Too many people dead, too many people dying.

Which explains why she sat near the head of the table this week during an unprecedented summit of Hispanic leaders, summoned to Harvard University to craft a plan to combat an epidemic that has stalked their communities with particular fury.

Ask Perez why she continues to commit herself to battling AIDS, and

PLEASE SEE PEREZ, 2D

Rosie Perez keeps up AIDS fight

PEREZ, FROM 1D

she gives you that classic what-are-you-kidding New Yorker look.

"Because they haven't found a cure yet, that's why I'm involved," Perez says. "Why stop?"

Now, she wants to get other celebrities — especially other Hispanic celebrities — involved in the fight. Perez and other people from the arts who took part in the summit want to raise the money to produce a three-part TV film that would explore sexual attitudes and behavior in Hispanic communities. And they want to enlist celebrities in a one-day blitz that would provide messages of prevention and hope in the four states with the largest Hispanic populations — Florida, New York, Texas and California.

It helps, Perez says, if you try to understand how the star business works.

"Dealing with celebrities, they don't feel it's their fight," she says. "But we still need them. We can't use Gestapo tactics with them. You've got to say: 'Come on down there. MTV is going to be there, CNN is going to be there. This is going to be good for your career. Gloria Estefan is going to be there. *Wooooo.*' "

Dennis deLeon, a New York AIDS activist who was among

Rosie Perez and other people from the arts who took part in the summit want to raise money to produce a three-part TV film that would explore sexual attitudes and behavior in Hispanic communities.

those organizing the Harvard gathering and who isn't given to casual platitudes, describes Perez as "one of the most ardent fighters on behalf of AIDS."

Perez will tell you that kids today know about AIDS and know how you catch it. But they don't know the more subtle stuff, she says. They don't know how to say no when they're being pressured into having sex. They don't know how to negotiate with their partners to wear a condom.

"Young people, they're not stupid," Perez says. "They want the information."

At a press conference at the conclusion of the AIDS summit, Perez is invited to speak to the cameras. She starts out reluctantly, more reticent than anyone who has seen her screen persona could ever imagine Rosie Perez being.

"I'm *so* nervous," she says.

The case of nerves proves fleeting. Before long, the cameras are under her spell.

"It is time for us to take control," Perez says. "We need a lot more attention, and we need a lot more dollars because our numbers are rising.

"There still isn't a cure. Hel-*lo*."

HARVARD UNIVERSITY Gazette

May 7, 1998 Vol. XCIII No. 29

Hispanic Leaders Call For AIDS Action

By William J. Cromie
GAZETTE STAFF

Leaders of the U.S. Hispanic community met at Harvard on Monday to address the growing incidence of AIDS among Hispanics.

Although Hispanics represent 11 percent of the U.S. population, they account for 19 percent, or almost one in five, of AIDS cases reported in 1997. While cases of AIDS among whites have declined dramatically since 1986, cases among blacks and Hispanics have climbed steadily.

"Enough is enough," said Dennis deLeon, president of the Latino Commission on AIDS. "We cannot lose more people to AIDS." He called the meeting "a historic turning point, the first time so many Latino leaders have met to form a plan of action to deal with the crisis."

The Harvard AIDS Institute cosponsored the meeting, along with the Henry J. Kaiser Family Foundation and several Hispanic organizations that deal with AIDS and health issues.

At the conclusion of the meeting, called "Leading for Life," or "Unidos Para la Vida," deLeon announced the formation of the National Coalition of Latinos Responding to HIV/AIDS.

Actress Rosie Perez was on hand to call upon Hispanics to "mobilize" to support those with the disease and to promote education and other preventive efforts. She described a plan of action to bring the situation to the attention of the public at large.

A primary goal, Perez said, "is to produce a movie to explain the Latino culture and how it deals with sex and drugs. We want to reach out through the cable networks to tell people they must discuss such things as sex and drugs openly and honestly."

A major cause of AIDS among Hispanics involves men having sex with men. But "homophobia has forced this behavior underground, where it is harder for prevention programs to take hold," according to a Harvard AIDS Institute report. The report also notes more reluctance in the Hispanic community to use condoms and widespread misconceptions among women about how the infection is transmitted.

Perez noted that the action plan also calls for a national fundraising effort. She envisions an event held simultaneously in large cities of the four states with the largest Hispanic populations: California, Florida, New York, and Texas.

"It would include a concert and dance, with celebrity hosts," Perez said. "It's going to be great.

"We're looking for big, big bucks from industry to get enough money for us to take control of our situation," she added. Except for representatives from the media and entertainment industries, no Hispanic business leaders were listed among the meeting attendees.

The group also discussed convening a conference for elected officials to examine the "emergency." In 1996, for example, the annual rate of AIDS cases diagnosed among Hispanics was three times higher than that for whites. During the same year, whites experienced a 21 percent drop in AIDS deaths while the decrease among Hispanics was only 10 percent.

Hispanic children have been hit particularly hard. As of 1997, nearly one quarter of all children diagnosed with AIDS were Hispanic, according to the Centers for Disease Control and Prevention (CDC). Hispanic children are now almost six times as likely to be diagnosed with AIDS as white children.

Meeting participants also denounced the federal government's decision not to fund the needle exchange program for drug users. As among whites and blacks, infected needles constitute a major source of the AIDS virus among Hispanics. Participants also called for the resignation of Barry McCaffrey, who leads the nation's drug control effort, for "choking off the lives of thousands of Latinos in waging his war on drugs."

Helene Gayle, CDC's national director for HIV prevention, urged the group to concentrate on prevention. "Better drug therapies are reducing deaths from AIDS," she said. "That's good, but successful efforts at prevention are better."

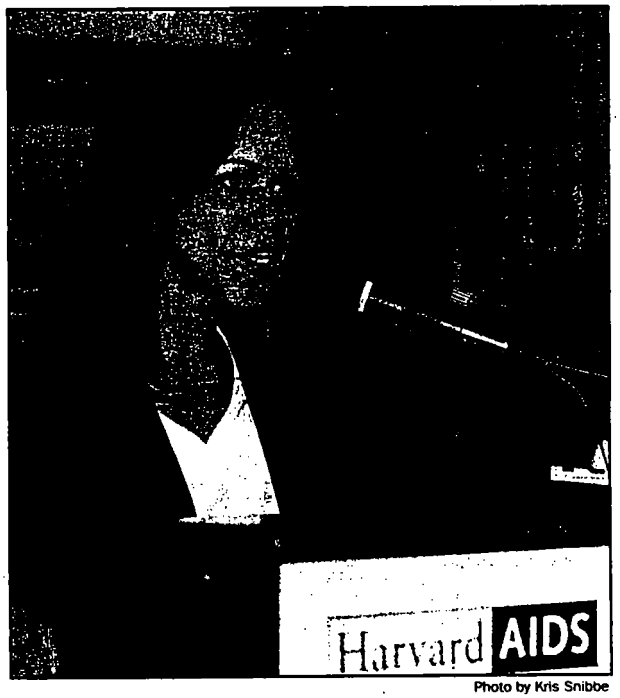
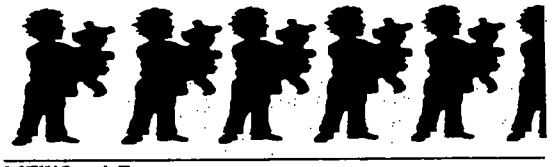


Photo by Kris Snibbe

Actress Rosie Perez joined leaders in a call for action to deal with the disproportionate number of AIDS cases among Hispanics.

AIDS Among Latinos

AIDS case rate per 100,000 population



LATINO = 1.7

WHITE (non-Hispanic) = **0.3**

Source: Centers for Disease Control and Prevention, 1997

CHILDREN WITH AIDS. According to statistics from the Centers for Disease Control and Prevention, Latino children are nearly six times as likely to be diagnosed with AIDS as white children.

The Washington Blade
SERVING THE NATION'S CAPITAL SINCE 1969
May 8, 1998• Vol. 29, No. 19

Latino leaders start work on national plan to fight AIDS

by Rhonda Smith

CAMBRIDGE, Mass.–A broad coalition of Latino leaders met at Harvard University on Monday, May 4, to hammer out a national strategy to stem the spread of AIDS. They prayed, listened to personal plights told by people living with AIDS, and then drafted a plan to help eradicate the public health problem.

The only real conflict in the process came in a brief debate over the group's mission statement and the role of Gay Latinos, some of whom feared that their involvement in this effort would be downplayed in order to recruit others to the effort.

"This was a chance to bring together Latino leaders who have not normally been involved with AIDS work," said co-facilitator Dennis de Leon, the president of the Latino Commission on AIDS, a New York-based organization. "The majority who came don't do AIDS work, but they know their communities."

There were many well-known national Latino organizations with representatives at the meeting as well. They included the National Council of La Raza, the National Association of Latino Elected and Appointed Officials (NALEO), the National Minority AIDS Council, the National Latina/o Lesbian, Gay, Bisexual and Transgender Organization (LLEGÓ), the Hetrick Martin Institute,

Continued on page 26

Latinos start work on national plan to fight AIDS

Some attending national conference clash over whether it needs to be 'Gay' explicit

Continued from page 1

and the International Association of Physicians in AIDS Care.

Ingrid Duran, director of NALEO's Washington, D.C., office, said the gathering was long overdue.

"AIDS really isn't an issue that NALEO has given much attention to," explained Duran, who also is a board member of Gente Latina de Ambiente, a community group for Gay Hispanics in Washington, D.C. "We did give it attention five or six years ago, but I think what has happened is that it's been seen as a Gay and Lesbian issue — not a Latino issue."

At the meeting, Duran said NALEO, a 5,400-member organization based in Los Angeles, would lead efforts to sponsor an AIDS education meeting for the 20-member Congressional Hispanic Caucus. The meeting would include representatives from the U.S. Centers for Disease Control and Prevention and the Latino Commission on AIDS, among others. In addition, she said NALEO plans to hold a workshop on HIV, AIDS, and the Latino community at its annual conference in 1999.

Dr. Helene Gayle, director of the CDC's National Center for HIV, STD, and TB Prevention, presented 1997 statistics at the meeting that indicated Hispanics make up 11 percent of the nation's population and 20 percent of the reported AIDS cases.

The CDC's figures indicate that 44 percent of the U.S. AIDS cases involving Hispanic men resulted from men who have sex with men, while 37 percent resulted from injection drug use. Among Hispanic women, 46 percent of the reported AIDS cases are a result of heterosexual transmission, and 43 percent resulted from injection drug use.

"Death rates as a result of AIDS are declining overall in the U.S., but at slower rates for black and Hispanic residents," Gayle said. "This reflects disproportionate access to treatment and therapies."

In response to a question about why the AIDS rates for white residents across the country are declining quicker than for the other two groups, Gayle said that when white Gay men began to get sick during the early 1980s, individuals in that segment of the population responded quickly.

"Gay white men mobilized and got their communities and resources on board," she said. "But also, this was a community that, relatively speaking, was already empowered. These were men who had educations and linkages to resources."

Gayle mentioned how U.S. Rep. Nancy Pelosi (D-Calif.) responded to the epidemic's impact on her constituents.

"She said that she had no choice but to view AIDS as important" because her constituents were dying, Gayle said. "That kind of clout really, really helps."

CDC officials say that the higher proportion of AIDS cases among Latinos is likely the result of underlying social and economic conditions, such as language or cultural barriers, higher rates of poverty and substance abuse, and limited access to health care.

Latinos at the Harvard AIDS Institute's "Leading for Life" conference — as well as African Americans who attended a similar event there in March — said that not enough funds have been forthcoming from private foundations and the federal government to fight AIDS in their communities.

"A lot of resources have been focused in the white community," said Victor Marquez, executive director of La Raza Centro Legal Inc., a nonprofit community law center in San Francisco.

Martín Ornelas-Quintero, executive director of LLEGO, agreed.

"Foundations say they've already given to a Gay, white agency, but those funds do not reach us," he said. "The challenge is for them to give to Latino-run and sexual orientation-appropriate agencies."

Gary West, deputy director of the CDC's Division of HIV/AIDS Prevention, Intervention, Research and Support, said the CDC is researching such complaints from agencies operated by Latinos and African Americans across the country.

"We are looking at our programs and the allocation of our funds and comparing them to trends in the epidemic," West said, from the CDC's headquarters in Atlanta, on Wednesday, May 6.

Another plan developed and presented during the conference resulted from an initiative spearheaded by actor and entertainer Rosie Perez and 19 other participants from the media and entertainment industry who attended the meeting.

Perez outlined a plan to create a movie trilogy that could highlight how various members of the Latino community are dealing with concerns about AIDS. The national coalition that met at Harvard plans to approach various cable networks to get assistance with this initiative.

"We also will establish a fundraising campaign to make sure the Latino community has its own money," Perez added, explaining that this would involve holding events simultaneously in California, Texas, Florida, and New York. The goal is to raise $150,000 to help produce the proposed events, she said.

"If [individuals and organizations] can give to the American Foundation for AIDS Research and the Gay Men's Health Crisis, they also have to give to us," Perez concluded. "What these other organizations do is great, but we need a lot more attention and dollars because the AIDS and HIV numbers in our community are rising."

Various other challenges make addressing AIDS issues in the Latino community difficult, participants at the meeting said. One obstacle is that the U.S. Latino community represents more than 30 regions of origin — about 62 percent Mexican, 13 percent Puerto Rican, 12 percent Central and South Americans, 5 percent Cuban, and 8 percent other Hispanic populations, according to the CDC.

CDC statistics highlighting the incidence of AIDS among Hispanics based on ancestry and exposure mode indicate that the dominant mode of transmission among Hispanic males whose ancestry is Central American, Cuban, Mexican, South American, and from the Spain/Portugal regions, is men who have sex with men. Among Hispanics with

by Clint Steib

Martín Ornelas-Quintero: "There are two key cultural values that have literally killed Latinos – shame about Gays and the way we define families."

Puerto Rican ancestry, however, CDC figures indicate that the dominant mode of HIV transmission is injection drug use. Participants at the meeting said that such demographic information is imprecise if it does not include similar data about U.S. Hispanics from the Dominican Republic.

Suggestions at the meeting about how to combat AIDS among Latinos nationwide varied.

Miguelina Maldonado, director of government relations and policy at the National Minority AIDS Council, suggested that AIDS data about Latinos depict information related to the influence of crack cocaine, inhalants, and alcohol, in addition to injection drug use.

The coalition called for the resignation of Barry R. McCaffrey, the retired general who oversees the Office of National Drug Contol Policy, because of his opposition to needle-exchange programs. Others mentioned the need for funds geared toward HIV prevention and treatment and for residential substance abuse programs for women.

More than one participant said homophobia remains a problem among many Latinos.

"There are two key cultural values that have literally killed Latinos — the issue of shame about Gays and the way we define families," said Martín Ornelas-Quintero, executive director of LLEGÓ, which is based in Washington. "Instead of being ashamed of us for being Lesbian, Gay, bisexual, and transgendered Latinos, they should be ashamed of themselves for neglecting us in the AIDS crisis for being who we are."

Ornelas-Quintero also said Latinos should use a more inclusive concept of "family" so that Gays are included as well.

The Kaiser Family Foundation presented a National Survey of Latinos on HIV/AIDS at the meeting that included interviews with 802 Latinos nationwide in 1997 about their level of knowledge and comfort in discussing issues related to AIDS. One question addressed whether Hispanics were comfortable being around Gays.

The results indicated that 24 percent said they were very comfortable with Gays, 19 percent said they were somewhat comfortable, 19 percent said they were somewhat uncomfortable, 33 percent said they were very uncomfortable, 2 percent said they had never been around Gays, and 3 percent said they didn't know or refused to answer the question.

"We do not have the skills to deal with issues related to sexual orientation," Ornelas-Quintero said later. "Even though *Ellen* has changed the cultural context, our community members overall still see her as a white Lesbian and homosexuality as a white phenomenon."

The issue at the meeting that triggered a brief debate among coalition members and some Gay Latinos involved drafting a mission statement that essentially said Hispanics should "rise to the challenge and address the health crisis created by AIDS."

The other option was a more specific statement that said communities and leaders should "speak out against homophobia, sexism, racism."

The Rev. A. Luis Cortés Jr., president of the National Hispanic Religious Partnership for Community Health, said the mission statement should not be too specific. The religious partnership is made up of a coalition of 5,000 Latino churches nationwide.

"We need to decide whether our agenda is AIDS or whether it is the affirmation or buy-in about sexual orientation," Cortés said, during a smaller meeting that day that focused on diversity issues. "The more we get into specifics, the more you risk losing certain groups."

Gonzalo Aburto Iniesta, editor-in-chief of the Spanish-language version of *Poz* magazine, took issue with this strategy.

"If we are trying to deal with AIDS, we can't just be politically correct," he said. "The crisis is getting worse because of stigmas associated with AIDS and Gays."

Pablo Colon, director of treatment, education, and advocacy at GMHC, agreed.

"Gay and Lesbian people were at the forefront of this, and that work needs to be recognized," he said later. "We owe that not only to Latino Gays but to white Gays and Lesbians who started the work. No longer can we negate our presence."

The meeting ended with Cortés and other coalition members clarifying that in addition to the broad mission statement various concerns would — and should — be addressed in separate statements.▼

HIV AMONG LATINOS

BABY BOTTLES, STATUES OF SAINTS, AND MARIGOLDS ARE AMONG THE OFFERINGS PLACED ON ALTARS HONORING THOSE WHO HAVE DIED of AIDS. "Making altars for people stems from the Mexican tradition of the Day of the Dead," says Maria Cristina Vlassidis of Boston's Latino Health Institute. "We have adapted an ancient tradition to respond to AIDS. The altars allow us to acknowledge our losses and to grieve as a community."

THE LATINO HEALTH INSTITUTE IS ONE OF SEVERAL ORGANIZATIONS around the country that now make *altares* as a way to honor the memory of Latinos who have died of AIDS. "For many people, the altars bring healing," Vlassidis says. "They also provide a safe place to talk about the epidemic."

Vlassidis believes that this outlet for grief—and this reminder of AIDS—is critical for Latinos, who are now incurring HIV infections at a rate faster than that of the general population.

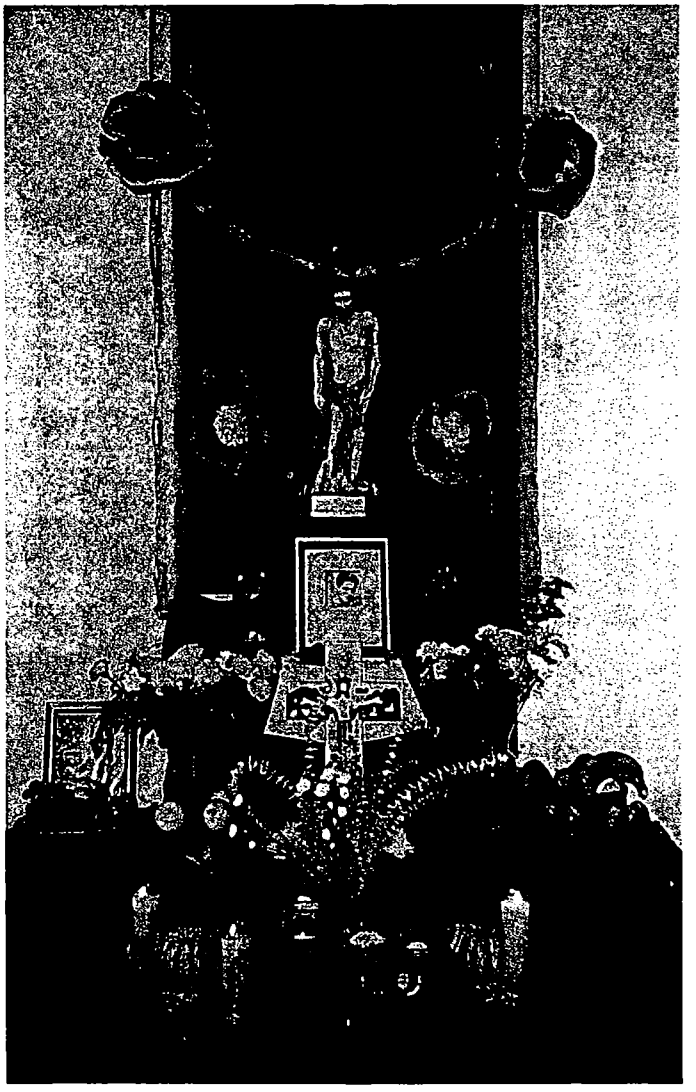
The Latino Community

The more than 27 million Latinos living in the United States comprise a community of communities. Approximately two-thirds are of Mexican descent, while the remaining one-third, or their ancestors, came to this country from Central or South America, Puerto Rico, Cuba, or Europe.

"For an example of the diversity of Latinos in this country—I am Chilean, but in making the altars, I was helped by Puerto Ricans, Guatemalans, Salvadorans, and Colombians—all in recreating a Mexican tradition," Vlassidis says.

Latinos do not share a single race, religion, or social class. Although few generalizations can be made, compared to non-Latino whites, Latinos tend to be younger, poorer, less likely to be high school graduates, and more likely to be unemployed.

These socioeconomic realities—often combined with language barriers, limited social supports, and little or no medical insurance—have placed many Latinos at relatively high risk of HIV infection. While Latinos account for less than 9 percent of the total U.S. population, they make up more than 17 percent of all cumulative AIDS cases.



Volunteers and staff members at Boston's Latino Health Institute built an altar to honor the memory of Latino men who have died of AIDS.

In a bilingual comic book produced by the New York City Department of Health, Rosa says, "No, Raul, I'm not well. That's why I came. I'm afraid, Raul, I'm...HIV positive."

Nearly 90,000 Latino AIDS cases have already been reported to the Centers for Disease Control and Prevention.

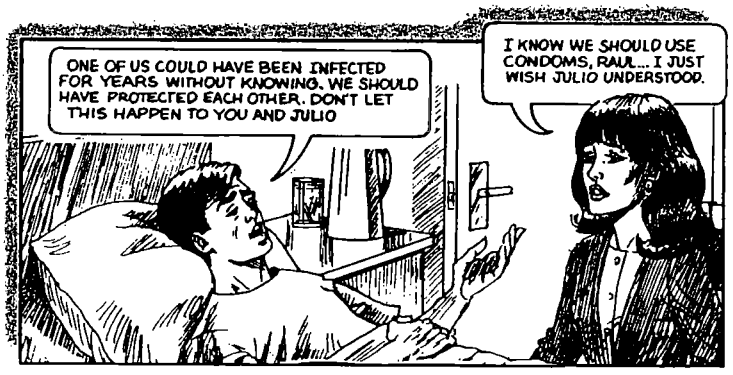
HIV infection rates among Latino men are highest among those who have sex with men and those who use injection drugs. Most Latinas are exposed to HIV either through their own injection drug use or—increasingly—through heterosexual contact. As more Latinas have become infected, the number of HIV-positive Latino children has also risen. In New York City alone, nearly 40 percent of infants with HIV are Latino.

A Multilingual Epidemic

Experts agree that new and redirected energies must be focused on HIV prevention among Latinos. Language barriers are often the first impediment to overcome. "Not all Latinos speak Spanish; many speak Portuguese or indigenous languages," Vlassidis says. "Moreover, Spanish speakers have hundreds of different dialects."

"When my cousin died of AIDS, his mother found it easier to think of him as having become infected through drugs rather than through sex with another man."

According to Heriberto Crespo, director of health education at the Latino Health Institute, prevention efforts need to be directed toward Latinos with limited English language skills. "Some institutions still provide AIDS brochures in English only," he says. "Spanish-language materials, when available, are often literal translations of English materials and therefore culturally inappropriate. Human reproductive anatomy, for example, may be discussed in ways that won't bother Anglos but will shock Latinos."



In another scene from the comic book, Raul—who has been diagnosed with AIDS—talks to Marisol about the dangers of unprotected sex.

Even within different Spanish-speaking groups, Crespo notes that it is important to use language carefully. "If I'm giving a workshop on HIV to Puerto Ricans, I can use the word *condones* for condoms. But if the audience is Dominican, I must use the euphemism *profilacticos.* Otherwise, they will be offended, and I will lose them."

In Austin, Texas, Elvia Mendoza begins conversations about AIDS in whatever language will get people to listen, whether English, Spanish, or Tex-Mex, a mixture of the two. "People are initially hesitant, so you have to gain their trust," says Mendoza, an HIV outreach educator at Informe SIDA. "You have to keep talking—not preaching—in a way that makes them feel like you're their next-door neighbor."

I Can Hear It in Your Voice

For Mendoza and other outreach workers, conversations about AIDS can be held anywhere—in homes, on street corners, in grocery stores, at religious festivals. This integration of HIV outreach within the Latino community must be carefully negotiated, however, as it links the fight against AIDS to traditions that can both help and hinder prevention and care.

"My mother called and asked, 'What's the matter? I can hear it in your voice,'" says Michael Melendez, president of the board of the Latino Health Institute. "I told her I have HIV. From that point, my parents' response couldn't have been better. My father told me, 'I don't ever want you to feel alone. You are never alone; you have your family.'"

Like Melendez, many Latinos retain close ties to their families, yet the very closeness of these bonds can make it difficult for some individuals to be open about their personal lives. "In immigrating here, many of us lost our countries, our land, our communities," Vlassidis says. "For many immigrants with HIV, family members are all they have, and they don't want to risk losing them by saying they're infected."

In addition, the centrality of the family to Latino culture has often served to reinforce traditional sex roles. People who either fall outside these roles—such as men who have sex with men—or are caught within them—such as young Latinas—may be at increased risk of HIV infection.

"When my cousin died of AIDS, his mother found it easier to think of him as having become infected through drugs rather than through sex with another man," Melendez says. "Because of homophobia, it's not uncommon for Latinos who have never done a drug in their lives to suddenly die of AIDS because of injection drug use."

Homophobia in the Latino community has forced same-sex behavior underground, where it is harder for HIV prevention programs to take hold. Moreover, the limited data available suggest that, among men who have sex with men, Latinos are more likely to have sex with women as well. Yet bisexuality is rarely discussed within the community, a silence that places both men and women at higher risk of HIV infection.

The Latinas with whom Mendoza works tell her that "the only women who get HIV are those who sleep around." Others have told her they thought that being married and having children made them immune to HIV.

Misconceptions are not the only source of vulnerability to HIV. Many Latinas may also be at risk due to traditional gender roles. "Machismo still lingers," Mendoza says. "If a Latina suggests using a condom, her partner may think she's implying that he's been sleeping around, or that he's gay."

These traditional gender roles can make the negotiation of safer sex more complicated, but not impossible. Working with women in Hartford, Connecticut, Carlos Toro, AIDS health educator at Latinos Contra SIDA, says, "It's give and take. We try to empower women, to get them to take a stance. If not just for their own health, then also for their kids. We try to get them to think about where their kids would be without them."

Dual Roles of the Catholic Church

Latinos Contra SIDA also targets adolescents, since much of the Latino population is in—or about to enter—the age groups in which most new HIV infections are now occurring. Moreover, studies have shown that young Latino males, in particular, are less likely than their peers to use condoms during sexual intercourse—a reluctance that may, in part, be attributable to machismo.

Condom use is further complicated for some Latinos because of the Catholic Church's stance on contraception. Although the expression of Catholicism is not monolithic across Latino cultures, the religion still influences the lives of millions of Latinos in both subtle and direct ways.

In terms of HIV prevention, Mendoza says, "Catholicism is a barrier in that you're not supposed to discuss sex, and if you do, you're admitting to feelings that are considered shameful. These feelings effectively close the door on our outreach efforts."

Yet to dismiss the Catholic Church simply as an obstacle is to deny the broader cultural role it plays in the lives of many Latinos and to overlook how it has supported Latinos with HIV and their families. "A lot of Catholic churches are really liberal," Toro says, "because their focus is on youth and they want to protect them."

Barriers to HIV Health Care

For many Latinos with HIV, obtaining the care they need remains a challenge. "Treating HIV is only part of the picture," Melendez says. "Latinos frequently face poverty, poor nutrition, violence in the community. Those with HIV are often very sick

by the time they seek treatment. Many have jobs that won't give them time off for medical or social service appointments. For some, the time off can become a survival issue—they can lose the income or even their jobs. One step providers might take in response to these problems would be to stand back and review clinic hours."

Communicating with physicians can pose further problems. "Hospitals don't have enough interpreters on staff," says the Latino Health Institute's Crespo. "I know of cases where doctors asked cleaning staff to interpret. While these interpreters may be bilingual, they don't have the skills necessary to convey medical information and choices. More importantly, their involvement presents a serious breach of confidentiality."

In some cases, Latinos are even asked to bring their bilingual children to interpret for them. "Perhaps the worst feature of this practice is that it makes the child responsible and the parent dependent, a reversal of the normal parent-child dynamic," Crespo says. In Boston, the Latino Health Institute provides treatment advocates who act as interpreters, maintain confidentiality, and inform clients of additional services.

Such advocacy is crucial, according to Jane Delgado, president of the National Coalition of Hispanic Health and Human Services Organizations. "Latinos don't have enough information about treatments, outcomes, or available options," she says. "Many people still believe HIV is a death sentence, when in fact it's slowly becoming more of a chronic disease, something that can be managed."

The political climate brings additional challenges, as some members of the Latino community are particularly affected by federal laws that restrict people with HIV from entering the country and demand the deportation of those found to be living here temporarily. The fear of deportation in particular may keep HIV-infected people without documentation from seeking health care.

Access to AIDS care may also become more difficult for Latinos who live and work here on a permanent basis. California's Proposition 187, for example—which was passed by a statewide referendum but is unimplemented pending a court challenge—would require agencies receiving state funds to determine the residency status of all clients. The agencies would then be forced to deny state-funded social services—including HIV services—to those without the appropriate documentation.

Forging a Different Future

"Latinos need AIDS programs that are located where people live, take their decision-making into account, and involve their family members," Delgado says.

Outreach workers such as Maria Cristina Vlassidis are incorporating AIDS education into people's lives. Last year, on World AIDS Day, Vlassidis's fourteen-year-old son helped her build an altar for Latino children who have died of AIDS. Together, they pinned up carousel horses, laid out baby shoes, and placed a teddy bear against a basket of fruit.

"What does our future hold if our children are dying?" Vlassidis asks. "Children are a symbol of hope. With these altars, we do more than acknowledge our losses. We express our hope and commitment to fighting AIDS as a community." ❦

—Paula Brewer is the editor and Christen Kaczanowski the assistant editor of the Harvard AIDS Review