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Keynote AIDS - New York State Conference of CBOs [Community Based Organizations] November 14, 1993

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IMMEDIATE ACTION REQUIRED:

The New York State Department of Health AIDS Institute Presents

The Fourth Annual Statewide HIV/AIDS Policy Conference

Issues on HIV/AIDS Policy and Programs

November 14, 15, 16 1993

The Omni Albany Hotel Albany, New York

State of New York
Mario M. Cuomo, Governor

Department of Health
Mark R. Chassin, M.D., Commissioner

AIDS Institute
Nicholas A. Rango, M.D., Director

SUNDAY DINNER
NOV. 14, 1993

MONDAY LUNCH
NOV. 15, 1993

MONDAY DINNER
NOV. 15, 1993

IMMEDIATE ACTION REQUIRED:

The New York State Department of Health AIDS Institute Presents

The Fourth Annual Statewide HIV/AIDS Policy Conference

Issues on HIV/AIDS Policy and Programs

November 14, 15, 16 1993

Schedule of Events

SCHEDULE OF EVENTS

Sunday, November 14

12:00 - 6:30 PM
Areas A & C, Level B

Registration and Information
Preview Exhibits

2:00 - 3:30 PM
Area G Ten Eyck Ballroom

Welcome/AIDS Institute Address

Dennis P. Whalen, Executive Deputy Director
New York State Department of Health AIDS Institute

Nilsa S. Gutierrez, M.D., Medical Director
New York State Department of Health AIDS Institute

3:30 - 4:30 PM

PWA Address

Larry Kramer
AIDS Activist & Playwright

Ilka Tanya Payan, New York City Human Rights Commissioner
Attorney, Actress

6:00 - 8:00 PM

Dinner
Keynote

Kristine Gebbie
National AIDS Policy Coordinator

8:00 PM
Poolside; Level A
Balcony; Level B

Candlelight Ceremony

Tato Laviera

Monday, November 15

7:30 AM - 6:00 PM

Registration and Information

9:00 - 10:30 AM
Area G Ten Eyck Ballroom

Opening Address

David E. Rogers, M.D., Chair
New York State AIDS Advisory Council

Mario M. Cuomo, Governor
State of New York

AIDS Research After Concorde

Fred T. Valentine, M.D., Professor of Medicine
New York University Medical Center

Gabriel Torres, M.D., Medical Director, AIDS Center
St. Vincent's Hospital

Maxine Wolfe, Ph.D.
ACT UP/New York

Daniel Stein, M.D., Medical Officer, Medical Branch, Division of AIDS
National Institute of Allergies and Infectious Diseases

10:30 - 11:00 AM

Break

11:00 AM - 12:30 PM

Concurrent Workshops

Area G Ballroom A

A. Mothers and Infants: How and When to Test for HIV
This session will explore the issue of testing newborns for HIV infection. Among the topics to be covered will be the controversial issue of mandatory newborn testing.

Cheryl Healton, Dr. PH Northern Manhattan Women & Children HIV Demonstration Project, Columbia University School of Public Health
Ronald Bayer, Ph.D., Columbia University School of Public Health

Ballroom B

C. Men on Men: Rainbow Prevention
HIV services for gay/bisexual men of color must take into account race, class, and culture as well as sexuality. Are current programs appropriately serving these men?

Julio Dicent-Taillepierre, Alianza Dominicana, Inc.
Nathan L. Kerr, People of Color in Crisis
John Manzon, Asian and Pacific Islander Coalition on HIV/AIDS, Inc. (APICHA)
Hon. Keith St. John, Esq., Albany Law School

Ballroom C

E. Continuous Quality Improvement (CQI) of Clinical Care
A forum for discussion of CQI with emphasis on the use of AIDS Institute Quality of Care Program reviews in the development of QOC programs by HIV providers. Audience participation will be encouraged.

Jose Belizario, M.D., South Brooklyn Neighborhood Health Center
Peter J. Karow, Ph.D., Terrance Cardinal Cooke Health Care Center
Dr. Sabrina Martin, Newburgh Family Health Center
Warren Morrisett, V.I.P., Inc.

Ballroom D

M. HIV Prevention Education in Our Schools - - Where Have We Been, Where Are We Going?
This workshop will provide a unique blend of panelists who will provide participants a glance at where New York State is in planning, implementation and formation of linkages needed to deliver HIV prevention education in our schools. Special emphasis will be placed on the role of the community provider, parents/guardians and adolescents in shaping the direction of local districts.

Mary Ellen Adams, Albany Medical Center, Pediatrics
Jacquee Albers, New York State Education Department
Brenda Ferreira, Alianza Dominicana, Inc.
Dr. Luis Reyes, New York City Board of Education Member
Radolfo A. Rivera, Action for a Better Community, Inc.
William Wallace, Peer/Youth Educator

Capitol Room Lobby Level

T. Free Access to Medications and Medical Care
This workshop will present information on the AIDS Institute's HIV Uninsured Care Programs (ADAP, ADAP Plus and Home Care). These programs seek to empower individuals with HIV to access health care, and provide a funding stream to maintain and expand health care services. The programs have expanded significantly in the past year. The workshop will provide an opportunity for attendees to learn more about the program and their services, as well as the expansion activities currently under way. The program is also seeking input from people living with HIV and service providers on needs and priorities for possible future expansion.

Lanny Cross, HIV Uninsured Care Programs, New York State Department of Health AIDS Institute
Daniel Tietz, HIV Uninsured Care Programs, New York State Department of Health AIDS Institute

Ballroom E

W. AIDS Services for Women: Taking Charge--Defining Empowerment
This session will focus on the impact of HIV on women of color and new strategies for empowering them to protect themselves from HIV infection. Panelists will discuss the following questions: the impact of the new CDC definition of AIDS on access to care for women; how to improve access to social services and care for women and their families; methods to encourage women focus on their own social service and health needs; and models of care for incarcerated and recently-released women.

Helen Daniels, Upper Manhattan Task Force
Norma Goodwin, M.D, Health Watch
Maria Hernandez, ACE OUT/Women's Prison Association
Myrna Jimenez, Life Force

12:30 - 2:00 PM **Box Lunch (Available on A, B or L levels of the Omni)**

2:00 - 3:30 PM **Concurrent Workshops**

Ballroom B

B. Men on Men: Closing the Generation Gap
The next wave of new HIV infections in the gay/bisexual population will be among men under 30. This session will examine sexual risk-taking among younger men and present cutting edge prevention strategies.

Andrew J. Humm, Hetrick Martin Institute for Lesbian and Gay Youth
Paul Postiglione, CSW, Choices Counseling Associates/GLYA
Margaret Rosario, Ph.D., Columbia University/HIV Center for Clinical and Behavioral Studies
John Wright, The Center for Children and Families

Ballroom E

F. For Her Own Good: Women and Men Keeping Each Other Safe
This session will focus on the roles of men and women in preventing the spread of HIV infection. Panelists will address the following questions: culturally-appropriate methods of educating men and women; steps needed to target injection drug-using African American and Latino women; non-traditional settings for the delivery of HIV prevention programs; the role of men in negotiating safe sex; and whether the range of prevention options for women are adequate.

Helen Daniels, Upper Manhattan Task Force on AIDS
Ruth John-Bonette, CNAP, New York City Department of Health
Dr. Zena Stein, Director, HIV Center for Clinical and Behavioral Studies

Ballroom A

G. AIDS Orphans and Their Families -- Another Epidemic in New York State

The results of a recent study conducted by The Orphan Project will be presented. This study estimates that 30,000 children and adolescents will be orphaned by AIDS in New York City by the year 2000. Panel participants will also describe service models that reach these children, adolescents and their families addressing permanency planning, legal assistance, bereavement counseling, and supportive service needs.

Ruth Bezares, Mothers of Children with AIDS (MOCA)
Jan Hubis, Division of AIDS Services
Carol Levine, The Orphan Project: The HIV Epidemic and New York City's Children
Mildred Pinott, Esq., Community Law Office, The Legal AID Society
Regina J. Prince, Child Welfare Administration/Human Resources Administration

Ballroom D

H. HIV Infection among Women Who Have Sex With Other Women

This session will discuss HIV issues for women who partner with other women, whether self-identified as lesbian/bisexual or not. Panelists will review recent data indicating that significant numbers of HIV infected women have (or have had) sex with other women, and discuss risk behaviors and service needs for the diverse population.

Joan Altman, Hettrick Martin Institute
Dana Greene, Lesbian Health Program, The Community Health Project
Amber Hollibaugh, Lesbian AIDS Project, Gay Men's Health Crisis
Telia Virgin, People with AIDS Coalition of New York
PWA Advocate

Capitol Room Lobby Level

I. AIDS Activism: Where to From Here?

After years of successes and failures, AIDS activists are asking questions. What's the best strategy for change: working on the "inside" with governmental officials, or staying on the "outside," using street tactics to continue building the grass-roots movement? Panelists representing both points of view will discuss the future of AIDS activism.

Terry Beswick, Human Rights Campaign Fund, ACT UP
Sally Chew, Freelance Journalist
Spencer Cox, Treatment Action Group, Community Research on AIDS
Keith Cylar, ACT UP, Housing Works
Kevin Frost, Treatment Action Group, ACT UP
Maxine Wolfe, ACT UP

Ballroom C

J. Alternative Approaches to Working With and Caring For HIV Infected Clients in Drug Treatment

The focus of this session will be on alternative and unorthodox approaches to enhance services for recovering clients who have the additional stressors of a positive serostatus. After a brief introduction, the entire session will be devoted to four workgroups: nutrition; recovery readiness; acupuncture, and cultural/spiritual aspects. Participants are invited to move among workshops attending as many as are of interest.

Richard Elovitch, Gay Men's Health Crisis
Vivica Ingrid Kraak, MS, RD, God's Love We Deliver
Ana Oliveira, Osborne Association
Tony Ortiz, Acupuncture and Holistic Approaches, La Feunte
Elliott P. Rivera, Lower East Side Harm Reduction Center
Michael O. Smith, M.D., Lincoln Hospital

3:30 - 4:00 PM **Break**

4:00 - 5:30 PM **Concurrent Workshops**

Ballroom B

D. Men on Men: Safer Sex/Healthy Sex

Why do some men-who-have-sex with men find it difficult to consistently practice safer sex? AIDS educators will offer some answers and will present new anti-"relapse" strategies.

Ramzi Abujawdeh, Office of Gay and Lesbian Health Concerns, New York City Department Of Health
Chuck Frutchey, San Francisco AIDS Foundation
Aldo Hernandez, New York City Healthy Sex Coalition
Ernesto Hinojos, Gay Men's Health Crisis, Inc.

Ballroom A

K. Managed Care, AIDS and Access to Care

Persons living with HIV/AIDS, providers of services and policy makers will discuss their experiences with managed care systems and the future of AIDS services in a managed care environment. Will access to comprehensive, quality care be assured? What are the implications of managed care for delivery of services? What can the AIDS community do to effectively address these issues?

Valerie J. Bogart, Esq., Legal Services for the Elderly
Trilby de Jung, New York State Department of Health AIDS Institute
Michael C. Ezie, M.D., Geneva B. Scruggs Community Health Center, Inc.
Ruth Finkelstein, Gay Men's Health Crisis, Inc.
James A. Spooner, Project Build of Richmond County
Karin E. Timour, Body Positive

Ballroom E

L. Needle Exchange: A Primary AIDS Prevention Strategy

This workshop will include a discussion of the various harm reduction and needle exchange models operating in New York State, an update of the first year evaluation of these programs, and future directions.

Alma R. Candelas, New York State Department of Health AIDS Institute
Francisco Paul Carvajal, RMN, New York Harm Reduction Educators, Inc.
Allan Clear, Lower East Side Harm Reduction Center
Denise Paone, Ed.D., Beth Israel Medical Center, Chemical Dependency Institute
Joyce Rivera-Beckman, M.A., St. Ann's Corner of Harm Reduction
Hector Garduno, ADAPT

Ballroom C

N. SSI and SSDI: Will the New Regs Make it Easier to Qualify?

The new HIV listings that are used by Social Security to determine eligibility of people with HIV infection for SSI and SSDI will be discussed.

Thomas Malvey, New York State Department of Social Services
Theresa McGovern, Esq., The HIV Law Project

Capitol Room Lobby Level

O. Are PWA's the Best Service Providers?

This workshop will look at the role PWA's play in today's AIDS service organizations. Are their voices being heard? Are their demands being met? How do we increase their role in setting the agenda of all service providers? Representatives from various organizations will take part in an open discussion of these issues.

Douglas Kenny, AIDS Activist, Broome County
Ben McDaniels, Gay Men's Health Crisis , Inc.
Kathy Pratt, By Women, For Women
Lisa Reid, New York City HIV Planning Council
Eric Sawyer, Housing Works, Inc.
Myrna Williams, APPLE, Inc.
Sunceray Coaxum, The Council on Alcoholism and Substance Abuse for Sullivan County

Ballroom D

U. Health & Human Services: Are They Accessible For High-Risk or Infected Youth?

Providers of health care to adolescents report that HIV infected youths are entering care with compromised immune systems, many with T-cell counts below 500 and some below 200. During this workshop, adolescents living with HIV infection and service providers will discuss their experiences with health and human service delivery systems. The session aims to provide a broad perspective on what we know and don't know about high risk and infected adolescents; how best to fill the gaps to access needed services; the role of counseling and testing; establishing linkages between human service providers and health care; and the extent to which current service models are or are not working.

Larry Abrams, Hetrick Martin Institute
Donna Futterman, M.D., Adolescent AIDS Program, Montefiore Medical Center
Roberta Marcus-Leiner, CSW, Peekskill Area Health Center
Rodolfo A. Rivera, Program Director, Action Front Center, Action for A Better Community
John Wright, Safe Space/Center for Children and Families

6:30 - 7:30 PM — **Reception**

7:30 - 9:30 PM
Area G Ten Eyck Ballroom

Dinner/Awards Ceremony

Mark R. Chassin, M.D., Commissioner
New York State Department of Health

Tuesday, November 16

8:00 AM - 1:00 PM — **Registration and Information**

9:00 - 10:30 AM
Area G Ten Eyck Ballroom

TB and HIV Plenary

Dr. George T. DiFerdinando, New York State Department of Health
Tom Frieden, M.D., New York City Department of Health
Nancy Mahon, Esq., The Correctional Association
John McAdam, M.D., St. Vincent's Charles Gay Shelter on Ward's Island

10:30 - 11:00 AM — **PWA Speakout**

11:00 - 11:30 AM — **Break**

11:30 AM - 1:00 PM **Concurrent Workshops**

Area G Ballroom C

P. TB Control in Non-Institutional Environments

Providers will discuss TB control issues that affect persons who work or volunteer in non-institutional settings where TB/HIV exposure may be a concern. Panel participants will discuss issues that are unique to these settings. Questions to be addressed include: mechanisms for triaging and sequestering suspected TB cases; criteria for client discharge following TB diagnosis; the use of respiratory protection; and TB screening of employees. The audience will be given the opportunity to ask questions concerning TB control issues at their worksites.

Linda Chiarello, R.N., M.S., C.I.C., New York State Department of Health AIDS Institute
Sharon Lebowitz, Office of Primary Care Serivces/Homeless Health Management, Health and Hospitals Corporation
Kathleen Rabbito, Division of Parole
Susan Rinder, Dominican Sisters Family Health Service
Hilda Roman-Nay, The Hispanic AIDS Forum
Rachel Stricof, M.P.H., New York State Department of Health

Ballroom E

Q. Coordination of Case Management for TB Patients

This informational workshop will provide participants with an understanding of the full continuum of care available and necessary for the successful management of TB patients. Panelists from institutional and community based programs will discuss techniques for coordination among agencies, integration of TB and HIV services, and review case management responsibilities by responding to specific questions from the moderator and the audience.

Tom Glaser, New York City Department of Health
Gaetana Manuele, M.S.W., St. Vincent's Hospital
Nicola Moore, Montefiore Medical Center
Alan Rice, M.S.W., Beth Israel Medical Center
Nadim Salomon, M.D., Beth Israel Medical Center
Meg Smirnoff, R.N., M.S., Mt. Sinai Hospital Medical Center
Public Health Advisor

Ballroom A

R. Components of Comprehensive Clinical Care for Women

Women comprise the fastest growing segment of the population affected by the HIV epidemic -- there has been more than a seven-fold increase in the number of reported AIDS cases among women in New York State since 1987. This workshop will include presentations on the clinical care of HIV infected women, including the recent CDC guidelines, a summary of clinical trials for women and results to date, and examples of comprehensive service delivery models for women.

Gina Brown, M.D., Columbia Presbyterian Medical Center
Rosemarie Colomaio, R.N., Erie County Medical Center Women's HIV Clinic
Mina Khorshidi, M.D., Suffolk County Center of Health Services
Louise Phillips, M.D., Special Treatment and Research (STAR) Clinic, SUNY Health Science Center at Brooklyn

Ballroom B

S. HIV Reporting

The CDC continues to promote HIV name reporting as the "gold standard" of HIV/AIDS surveillance. This session will explore the policy implications of CDC's position for New York State.

David Hansell, Gay Men's Health Crisis, Inc.
Stephen Shapiro, ACT UP/New York
John Ward, M.D., HIV/AIDS Surveillance Branch, Centers for Disease Control and Prevention

Ballroom D

V. Partner Notification: Increasing The Options

This workshop will present an overview of existing partner notification options with an emphasis on the process and desired outcome. Innovative partner notification strategies developed and implemented in community based settings will be described including PNAP, CNAP and physician disclosure. A client who has accessed these services will share their experience. The audience will be encouraged to join in a discussion of issues such as access and confidentiality.

Carol Budd, Middletown Community Health Center
Alan J. Dan, AIDS Services Activist
Yla Gallegos, HIV Program Coordinator, Family Health Center of Newburgh
Ruth John-Bonnette, HIV Counseling Programs-CNAP, New York City Department Of Health
Dennis Murphy, PNAP Program, New York State Department Of Health STD Control Program
Monica Sweeney, M.D., Bedford Stuyvesant Family Health Center

Exhibitors

AIDS Institute Educational Services
AIDS Institute Policy Unit
AIDS Institute HIV Uninsured Care Programs
AIDS Treatment Data Network
Albany AIDS Clinical Trial Unit
American Red Cross NYS-wide Network
Bristol-Myers Squibb
Burroughs Wellcome Co.
Calkins Value-Plus Pharmacy
Community Family Planning Council
NYS AIDS Coalition
NYS Office of Alcoholism and Substance Abuse Services
NYS Division of Human Rights
NYS Department of Social Services
Ortho Biotech
People with AIDS Coalition of New York
Public Employees Federation
Roche Biomedical Laboratories
Roche Laboratories
Rural Opportunities, Inc., AIDS Prison Initiative
The Learning Partnership
UMOJA SASA Condoms: "Protect the Blood!" Campaign
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THE FOURTH ANNUAL STATEWIDE HIV/AIDS POLICY CONFERENCE

is dedicated to the memory of

NICHOLAS A. RANGO, M.D.

AUGUST 2, 1944 — NOVEMBER 10, 1993

Innovator, Leader, Advocate, Friend

"The AIDS epidemic has claimed more than 200,000 lives in the United States, and now it has claimed another towering figure. Dr. Nicholas Rango's ferocious struggle against the disease has been a beacon in the storm. As Director of the AIDS Institute in the State Department of Health, Dr. Rango developed policy for the State and influenced policy for the nation. He created new medical treatment models, and sometimes by the force of his own personality forced into being new housing and community care programs. He has made an enormous difference in the lives of thousands of HIV positive New Yorkers, their families and friends, and his loss is a costly one indeed for the entire Family of New York."

Mario M. Cuomo
Governor
New York State

"Nick Rango was a passionate pioneer, a passionate physician who blended the doctor's caring and healing role with the policy-making role of a public health advocate and leader. Dr. Rango and the AIDS Institute he nurtured broke new ground constantly in the fight against the disease which took his life. The AIDS Institute itself is a living legacy, assuring that Nick's contributions will endure, helping thousands of others in the days and years ahead. Unorthodox, impatient and courageous in his public fight against the disease, he was equally valiant in his personal struggle. The Department of Health and the world of public health will miss him greatly."

Mark R. Chassin, M.D.
Commissioner
New York State Department of Health

New York State

HIV PROGRAM INITIATIVES

The AIDS Institute ■ New York State Department of Health ■ November 1993

Anonymous HIV Counseling and Testing Program
Criminal Justice Initiative
Women's Services: Obstetrical HIV Counseling/Testing/Care Initiative

HIV Test Counselor Training Program
HIV/AIDS Community Educator Initiative
HIV/AIDS Materials Initiative
HIV Clinical Scholars
Health Worker Training
Provider HIV Education Program
Infection Control Training Program
Legal Advocacy Initiative
Hotline Services

Community Service Programs
Community Based Organizations
Multiple Service Agency Initiative
Community Development Initiative
Peer Support/Education Programs
Women's Support Services
Community HIV Prevention and Primary Care Initiatives
Substance Abuse Initiative
Harm Reduction Initiative
Designated AIDS Centers (DACs)
Continuous Quality Improvement (CQI) Program
Pediatric/Maternal/Adolescent HIV Services
Nursing Facilities
Adult Day Care Program
Home Delivered Meals Program
AIDS Intervention Management System (AIMS)
Implementation of Ryan White Care Act (Title II)
COBRA Community Follow-Up Program
HIV Uninsured Care Programs: ADAP, ADAP Plus, Home Care

<u>POLICY UNIT</u>
Newborn HIV Testing
Nursing Home Initiative

ANONYMOUS HIV COUNSELING AND TESTING PROGRAM

Program

The Anonymous HIV Counseling and Testing Program provides HIV pre- and post-test counseling, free and anonymous HIV antibody testing, education about risk behavior and HIV prevention, skill development to negotiate safer sexual and drug use behaviors, partner notification assistance, demonstrations on condom use and cleaning of drug injection equipment, condom distribution, and referrals to medical care, drug treatment, and mental health and social services.

Program Status

During 1992, 28,015 persons were counseled and tested for HIV, an 18.4 percent increase over 1991. Although the rate of seropositivity has decreased every year since 1988, the 8.4 percent rate of HIV infection in New York City continues to be substantially higher than in the rest of the State (1.5 percent). The increased number of persons counseled and tested each year allows the program to reinforce prevention messages and tailor education to individual needs.

The following chart illustrates the statewide decline in seropositivity rates:

	1985	1991	1992	1993 (Jan.--July)
Persons Tested	**4,501**	**23,655**	**28,015**	**13,630**
HIV-Positive (%)	**14.3%**	**4.4%**	**3.1 %**	**1.8 %**

Program activities are currently being directed to areas of higher seroprevalence and at reaching and serving minority populations and individuals at high risk for HIV infection. The program's community-based strategy, developed in 1991, was implemented to reach more individuals at high risk for HIV infection through the establishment of new clinics in minority communities and areas of high seroprevalence, development of better referral arrangements among community agencies (including drug and alcohol treatment programs), and expansion of community outreach activities.

Between January 1 and June 30, 1993, 27.4 percent of all clients seen by the program were minority individuals; these clients accounted for 62.3 percent of all HIV-positive clients tested by the program. During the same time period, clients at high risk (men who have sex with men, injecting drug users, and the sexual partners of at-risk persons) made up 29.6 percent of the program's caseload and accounted for 76.8 percent of all HIV-positive cases.

Funding

The AIDS Institute's Anonymous HIV Counseling and Testing Program receives $3 million in combined Centers for Disease Control and Prevention funds ($1 million) and State funds ($2 million).

Future Directions

The AIDS Institute will evaluate clinic operations in view of epidemiological and seroprevalence data so that the Anonymous HIV Counseling and Testing Program can respond to the evolving HIV/AIDS epidemic. Evaluation efforts will identify both gaps in service delivery and underutilization of clinics. Outreach and program promotion activities, as well as the establishment and expansion of clinic sites, will focus on reaching underserved and high-risk populations. Additional program activities include the pilot testing of alternate approaches to service delivery in minority neighborhoods and areas of high seroprevalence, the pilot testing of strategies to increase return rates for post-test counseling, and the evaluation of various testing options for facilitating earlier entry into primary care and case management by HIV-infected clients.

For further information:
Barbara Greenberg
Anonymous HIV Counseling and Testing Program
(518) 473-1747

The AIDS Institute ■ New York State Department of Health ■ November 1993

CRIMINAL JUSTICE INITIATIVE

Program

The AIDS Institute's Criminal Justice Initiative provides HIV prevention, education, and supportive services for male and female prisoners, prison staff members, and parolees. The Institute targeted New York State's prison population for HIV services because of the high incidence of HIV infection and AIDS in correctional facilities and the presence of many individuals at risk for contracting HIV, primarily through injection drug use. An estimated 14 percent to 16 percent of the New York State Department of Correctional Services (DOCS) 63,542 inmates are HIV-infected, 8,172 of whom currently are being treated for AIDS-related symptoms.

In January 1990, through a collaborative agreement between the State Departments of Health and Correctional Services, the AIDS Institute established the Criminal Justice Initiative to:

- educate prison staff and inmates about HIV transmission, risk reduction, and the importance of early medical intervention for infected persons;
- provide anonymous and confidential HIV counseling and testing for inmates on a voluntary basis, with referrals to DOCS health services for treatment and follow-up;
- provide continuing HIV education and resource development at each DOCS facility through staff and peer education training.

Program Status

Two regional teams, located in Albany and Buffalo, each composed of four counselor/educators, are responsible for the provision of HIV/AIDS prevention and counseling and testing services. In the three years since the program has been in operation (April 1, 1990--March 31, 1993), the Criminal Justice Initiative staff have provided prevention education services to 6,960 DOCS staff members and 30,584 inmates at 16 facilities statewide and to the Ulster Reception Center. Almost one-third of the inmates requested additional counseling and/or testing services. Of the 6,952 inmates tested, 7.4 percent were seropositive. More than 50 percent of seropositive inmates chose confidential disclosure and referral to DOCS health services for early intervention treatment.

In April 1992, the AIDS Institute initiated a new program targeting HIV/AIDS prevention and support services to women incarcerated in State prisons and to HIV-infected women recently released from these facilities. In addition to offering prevention education, counseling and testing, and peer support activities, the program establishes linkages for HIV-infected women released from prison to community-based health care and case management providers. The AIDS Institute contracted with Rural Opportunities to provide these services at Albion and Groveland Correctional facilities, and with the Women's Prison Association for services at Bedford and Taconic Correctional facilities.

Most of the women incarcerated in DOCS facilities statewide are black or Hispanic (86 percent), between the ages of 20-34, and have a history of injection drug use. Most (80 percent) have children, and an estimated 25 percent were pregnant when arrested or gave birth shortly before or during incarceration. A blind HIV seroprevalance study of women inmates entering the DOCS system indicated that nearly 19 percent were seropositive.

In 1991 and 1992, the AIDS Institute contracted with two New York City-based organizations, the Fortune Society and the Osborne Association, to provide HIV prevention and support services for parolees at risk of HIV infection, those already infected, and their families. The Institute subsequently

solicited other eligible organizations to expand the initiative to the borough of Queens and to Western New York.

The AIDS Institute established the parolee program to:

- provide parolees and their families with the most current and complete information about HIV transmission, prevention, and health services;
- identify needs and help HIV-infected parolees and their families to obtain services;
- enable seropositive parolees to initiate and maintain behavior changes that will minimize the risk of further HIV transmission, and
- provide parole officers with the necessary knowledge and skills to assist seropositive parolees in making the transition from prison to community living.

Most parolees have participated in behavior that places them at risk for HIV infection. Division of Parole (DOP) data indicates that 75 percent of all parolees are current or former injection drug users. Of the 27,000 inmates that DOP estimates will be released during 1992-1993, 2,700 to 4,500 will be HIV-positive (based on anonymous seroprevalance studies conducted of entrants to DOCS facilities).

Funding

All Criminal Justice initiatives are funded through State and Department of Correctional Services (DOCS) grants.

Future Directions

In FY 1993-94, the AIDS Institute received $925,000 in State appropriated funds to expand services for inmates and correctional staff in additional State prison facilities. Four additional prison teams will be established to provide services in State prisons in the central and northern regions of New York State, as well as the prison reception centers at the Downstate and Elmira facilities. Plans are also underway to implement peer support programs at ten facilities statewide. In FY 1993-94, $400,000 in additional State funding was appropriated to expand the Parolee Initiative. A competitive solicitation has been issued to obtain two to three additional contractors to provide these services.

For further information:
Barbara J. Greenberg
Criminal Justice Initiative
(518) 474-1135

Women's Services
Obstetrical HIV Counseling/Testing/Care Initiative

Program

The Obstetrical HIV Counseling/Testing/Care Initiative began in August 1990 and, supported by the federal Centers for Disease Control (CDC), currently provides 24 hospitals in New York State with start-up funding for HIV services targeted to postpartum women who may not have been reached prior to delivery.

This Initiative is one of a number of programs created by the Department of Health to provide counseling and testing to women of childbearing age in New York State in response to data from the anonymous Newborn HIV Seroprevalence Survey which indicate that nearly 1,900 HIV-positive women give birth annually in the State. These programs encourage women to learn their HIV status and promote understanding of the benefits of early HIV-related medical interventions which may prolong life and improve the health status of both mother and child. Knowledge of serostatus and counseling may also influence future reproductive decisions and alter unsafe sexual and drug-related behaviors. In concert, the programs implement New York State policy advocating voluntary HIV counseling and testing in all preconception, prenatal, and obstetrical settings.

The Obstetrical Initiative supplements HIV counseling efforts in family planning and prenatal settings, and is particularly targeted to childbearing women who have limited contact with the health care system and who are at high risk for HIV infection. In addition, the initiative has focused on establishing systems of community follow-up for women who do not return for their results and on expanding access to ongoing services.

The initiative provides the following services:

- Counseling and voluntary testing for women in the postpartum setting
- Community follow-up through systems developed with participating hospitals
- Referral to case management and supportive and medical services on site or in the community
- Data collection to monitor hospital programs and increase understanding of clients' needs

New York State Designated AIDS Centers and municipal hospitals with high newborn seroprevalence rates were selected to participate in the Initiative. Funding has largely gone to supporting salaries of HIV counselors or community liaison workers. Counselors offer HIV counseling to women (and sometimes their sexual partners) in the postpartum setting; all testing is voluntary and, in accordance with State law, is performed only with written informed consent.

Funding

Current CDC grant funding for the Obstetrical Initiative is nearly $1.3 million annually. In addition, providers receive enhanced Medicaid reimbursement (under New York State's enhanced primary care rates) at a rate designated specifically for HIV pre-test counseling of women in the postpartum setting.

Program Status

Approximately 62 percent of HIV seropositive births in New York State occur at hospitals participating in the Obstetrical Initiative.

Through the end of March 1993, the program identified 53,979 women eligible for services through the Initiative. Of the eligible women, 34,706 (64.3%) received pretest counseling, and 13,046 (37.6%) were tested for HIV. Of those tested, 6,222 (48%) received posttest counseling and 302 (2.4%) tested HIV-positive. The demographics of women receiving services are shown below:

	Number Counseled	Number Tested[1]	Number Positive	Percent Positive[2]
Eligibility Criteria[3]				
Known HIV-Positive[4]	26	12	10	83.8
No Prenatal Care	2859	1367	118	8.6
Drug Use Noted	1919	895	50	5.6
Low Birth Weight	1145	343	11	3.2
STD	2802	1169	17	1.5
Partner at Risk	402	234	3	1.3
<5 Prenatal Visits	2891	1040	16	1.5
Patient Request	22558	7697	76	1
Other	104	37	1	2.7
Age				
Under 20	3295	1247	9	.7
20-29	19659	7506	143	1.9
30-39	10714	3696	137	3.7
40-49	306	100	100	7.0
Over 49	731	245	6	2.4
Race/Ethnicity				
Asian/Pacific	800	130	2	1.5
Black (Non-Hispanic)	14170	4920	167	3.4
Hispanic	17056	6955	117	1.7
Native American	52	19	1	5.3
White	2145	694	15	2.2
Other/Not Available	483	75	0	na
TOTAL	34706	12794	302	2.4

1 Number tested includes only conclusive (i.e. positive or negative) results; an additional 252 results were inconclusive, misplaced, or not reported.

2 Percent positive out of number of conclusive results.

3 Eligibility criteria focus programmatic effort toward women least likely to have had access to ongoing health care and therefore least likely to have been approached for HIV counseling.

4 Although women may report being known HIV-positive at delivery, they may elect to retest through this initiative.

Evaluation

AIDS Institute staff provide technical assistance in program development and implementation. An aggressive schedule of site visits, the development of methods for program analysis, and continued Institute staff involvement help program managers to assess and enhance program performance, particularly the identification of larger numbers of eligible women and improvement in post-test counseling rates. More recently, AIDS Institute staff have initiated a review of each site's quality assurance procedures with an eye toward ensuring adherence to New York State protocols as well as delivery of appropriate risk reduction messages. A data committee consisting of hospital and AIDS Institute staff was formed to improve the overall data reporting system of the Obstetrical Initiative and coordination among all counseling and testing programs in obstetrical settings.

For further information:
Helen Gasch,
Project Director
212-613-2488

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HIV TEST COUNSELOR TRAINING PROGRAM

Program

The HIV Test Counselor Training Program was established by the AIDS Institute in 1987 to train health and social service providers to counsel persons being tested for HIV and to refer them to additional needed services. The first year 250 persons took the training course; it was later extended from two days to three. In 1990 it was expanded to include an "Overview of HIV Infection and AIDS" course.

During 1992, 7,600 persons attended the courses offered by the Institute's Educational Services Section. During the first half of 1993, 878 persons attended the Overview of HIV Infection and AIDS and 1,300 persons attended the three-day HIV Test Counselor Training.

HIV Test Counselor training courses are provided by contractors and agencies authorized to conduct the courses after having a training team successfully complete the Rockefeller College HIV Test Counselor Train the Trainer Program.

Contractor Information

Registration for the HIV Test Counselor Training Courses has been decentralized. There are now five registration centers. Each center conducts registration for trainings conducted in their catchment area. Individuals interested in attending the one-day or three-day courses should contact:

PARTICIPANTS SHOULD CONTACT:	FOR TRAININGS CONDUCTED IN:
Terry Graff/(914)785-8364 Mid-Hudson Valley AIDS Task Force (ARCS)	**Dutchess, Orange, Putnam, Rockland, Sullivan, Ulster, Westchester, Albany, and Clinton counties.**
Rhoda Agran/(516)444-3199 or 7511 SUNY Stony Brook	**Long Island (Nassau and Suffolk Counties)**
Rhonda Braiser/(212)594-7741 Cicatelli Associates	**Manhattan**
Linda Couchon/(607)734-1574 Joint Education and Training (JET)	**Binghamton, Buffalo, Elmira, Ithaca, Rochester, Syracuse**
Sharon Toney/(212)966-8700 National Development and Research Institutes (NDRI)	**Bronx, Brooklyn, Queens, Richmond**

For Information on the HIV Test Counselor Train the Trainer Program, contact Rockefeller College at (518) 442-5731.

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HIV/AIDS COMMUNITY EDUCATOR INITIATIVE

Program

The Educational Services Section initiated the Regional Community Education Committees in 1991. The Committees meet in Western New York, Central New York, the Capital District Area and New York City (with participants from New York City and Long Island). The Committees serve as the AIDS Institute's link with HIV/AIDS educators in each region of New York State. The Committees share information with one another and focus on regional concerns. They receive current information on HIV/AIDS, prevention materials and policy updates from the AIDS Institute. Members have found the committees a valuable resource and opportunity to share ideas and problem-solve.

Membership

Membership is open to all HIV/AIDS Educators. For information about upcoming meetings, call Bonnie Kennedy at (518) 474-9866.

HIV/AIDS Community Educator Training

The Institute will coordinate an effort to establish Statewide training and periodic HIV/AIDS Informational Updates for HIV/AIDS Community Educators. There are many training programs for HIV/AIDS Community Educators in New York State but there is no Statewide effort to ensure the ongoing availability of consistent, high-quality training for educators.

The Educational Services Section of the AIDS Institute has begun working with agencies throughout New York State that conduct HIV/AIDS Community Educator Training to bring together effective elements of existing training programs in a model that can be utilized Statewide.

Through a contract with Rockefeller College, a one-day HIV Community Educator training program is currently being offered. The one-day HIV Community Educator training program will be available through Rockefeller College until May, 1994. In the Spring of 1994, the AIDS Institute will identify agencies to pilot the new course.

If you wish to be added to a mailing list to receive the training calendar for the four-day HIV/AIDS Community Educator Training that will be mailed out in the Spring of 1994, please call **Bonnie Kennedy (518) 474-9866**.

HIV/AIDS Community Educators have also indicated that there is a need for ongoing HIV/AIDS Informational Updates. In conjunction with the coordination of the four-day HIV/AIDS Community Educator Training Program, Educational Services will implement HIV/AIDS Informational Updates. The Updates will be conducted by Educational Services Staff at Regional Community Education Committee Meetings and will be open to members and non-members. Announcements of the schedule for the first Update Session will be mailed in February, 1994.

For further information:
Mabel Pruden
Educational Services Section
(518) 474-9866

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HIV/AIDS MATERIALS INITIATIVE

Program

The AIDS Institute's Division of HIV Prevention is responsible for the distribution of HIV/AIDS related informational materials, free of charge, for use in HIV prevention efforts. HIV/AIDS informational materials needs may include newsletters, brochures, posters, videos, PSA/video and audio tape scripts, etc. The Division of HIV Prevention maintains a warehouse ordering/distribution system from which the public can order HIV/AIDS informational materials. The Division has established a process to determine the HIV/AIDS informational materials needs and is responsible for locating existing materials for purchase or working on the development of materials to meet identified needs. In addition, the Division produces the newsletter, "Focus on AIDS in New York State" that provides contractors and the public with current HIV/AIDS information. The Division also maintains a listing of informational materials that have been reviewed for accuracy and make that listing available for those that want to purchase materials and need to know "what's out there".

To receive a copy of the HIV/AIDS Education and Prevention Publications and Videos Catalogue (order form is included), contact:

David Di Caprio
AIDS Institute
New York State Department of Health
Empire State Plaza, Corning Tower
Room 270
Albany, NY 12237-4635
(518) 473-7158

To receive a copy of the AIDS Institute Materials Listing or to be placed on the mailing list to receive the newsletter, "Focus on AIDS in New York State," contact:

Bonnie Kennedy
AIDS Institute
New York State Department of Health
Empire State Plaza, Corning Tower
Room 270
Albany, NY 12237-4653
(518) 474-9866

COMMUNITY-BASED SERVICES

Program

The Community Based Services Program is designed to facilitate early access to HIV prevention and the continuum of HIV care for people affected by HIV, including those who might not ordinarily seek these services until they become severely ill. Community-based HIV prevention services are provided through contracts with two major types of organizations:

- Comprehensive, multiple service providers: Community Service Programs (CSPs); Multiple Service Agencies (MSAs)
- Limited scope, specialized service providers: Community-based Organizations (CBOs)

The CSPs provide multiple services, including outreach, HIV prevention and risk reduction education, information and referral, case management, crisis intervention, counseling and other supportive services to individuals affected by HIV/AIDS within a borough of New York City or region of New York State.

The MSA Initiative provides the opportunity for CBOs serving communities of color to expand their service capacity to provide multiple HIV-related services within areas of high need. The service model has three components which are to be phased in over a three-year period: outreach and prevention education, client services, and program development.

The specialized service programs, or CBOs, provide a specific service or services such as transportation; HIV/AIDS education, prevention, outreach, support services to specific communities or populations; nutrition services; training, and case management.

Funding

The 1993-94 Aid to Localities budget includes two appropriations and Special Revenue, Other funds totaling $21,178,2000 for grants to community service programs including, but not limited to, community-based organizations and other organizations providing specialized AIDS-related services targeted to minority and other high-risk populations. The CSP initiative is allocated $12,174,555 of the above total appropriation.

The 1993-94 AIDS Institute budget includes two appropriations targeted to the MSA Initiative. One continues the 1992-93 appropriation of $3 million, and the second is the 1993-94 appropriation of $3.4 million to expand the number of MSA providers as well as to enhance the service capacity of existing MSAs.

Program Status

The Community Service Program was initiated in 1984 in response to a lack of interest from service providers in serving people with HIV/AIDS. There are now 14 CSPs serving the entire state. The success of this model has influenced the design of the MSA Initiative. The 14 MSA providers began providing services during the summer of 1993. In most cases these providers are currently developing their management and infrastructure. Prevention education/outreach, client services, and program development will begin or expand as the organizational infrastructure is developed.

The Community-Based Organization Initiative began in 1988 in response to the HIV epidemic's increased rate of expansion in racial/ethnic minority communities. There are now more than 100 CBOs

funded through the following initiatives: adolescent, legal, men who have sex with men, HIV+ support, women, homeless, minority, nutrition, and other specialties.

Future Directions

As the HIV/AIDS epidemic expands, the Community-Based Services Program will continue to establish initiatives to address the specific needs of target populations, communities or geographic areas. The program is committed to the continuation of funding or the establishment of new programs to:

- slow the spread of HIV/AIDS through education;
- provide direct client services or referrals to services;
- empower individuals infected with HIV;
- train health and human service providers;
- coordinate volunteers;
- form linkages among service providers, and
- raise funds for enhancing program activities.

To ensure that existing resources are used to address the most urgent needs in the most cost efficient manner the AIDS Institute will:

- emphasize rapid program development, implementation, and quality assurance, including frequent on-site monitoring and technical assistance;
- emphasize planning to best match limited resources to unlimited community needs, and
- involve members of HIV infected/affected communities in program planning and implementation.

For information:
Claudia Lee
Community-Based Services
(518) 474-4374

The AIDS Institute ■ New York State Department of Health ■ November 1993

MULTIPLE SERVICE AGENCY AND COMMUNITY DEVELOPMENT INITIATIVES

Program

New York State's HIV epidemic is growing most rapidly in minority communities. In 1988 -- for the first time -- reported AIDS cases among African American males surpassed those among white males. African American and Latino women currently account for more than 80 percent of female AIDS cases statewide. African Americans and Latinos also account for more than 80 percent of heterosexually-transmitted cases in the State. Among childbearing women, the seroprevalence rate continues to climb among African American women while declining among whites. African Americans and Latinos comprise more than 80 percent of reported AIDS cases among injection drug users. And overall, African Americans and Latinos represent 64 percent of the State's total reported AIDS cases.

In addition, HIV infection and AIDS is on the rise among Native Americans, Asians, and Pacific Islanders. Although actual case numbers are relatively small, case trends, HIV infection rates, and indicators of the potential for HIV infection (for example, sexually transmitted disease rates and teen pregnancy) signal a growing problem in these communities.

Empowering minority communities to combat the HIV epidemic through community-sponsored efforts is a top priority for the AIDS Institute. To address this urgent issue the Institute has developed two new initiatives to support such a response by communities of color: the Multiple Service Agency Initiative and the Community Development Initiative.

The **Multiple Service Agency Initiative (MSA)** will expand the capacity of organizations serving minority communities to provide comprehensive, "one-stop" HIV services within high-need areas of New York State. The MSA model is developmental, allowing organizations up to three years to phase in a comprehensive array of services, including HIV prevention, client services, and community development.

Grants under the initiative are sufficient to support infrastructure development -- including administration, fiscal management, and data collection -- that can't be covered by smaller grants. As a result, the MSA initiative will help minority community agencies build the programmatic and administrative capacity to provide quality, comprehensive HIV/AIDS services.

The **Community Development Initiative (CDI)** has been designed to enhance the ability of community-based organizations to develop the community infrastructure essential to combating the HIV epidemic. The lack of such capacity has meant that minority voices are frequently not heard by local, state, and federal policymakers. The drastic cutback in federal HIV prevention funds is just one example of how the exclusion from policymaking harms minority communities.

CDI funding has been granted to minority-run organizations with experience in serving communities of color, expertise in HIV service provision, and a proven ability to establish the linkages required for a community-based response to the HIV epidemic. CDI providers represent an essential link in the continuum of community-based services: organizing a community response among service providers and community leaders to increase the willingness and capacity of each to confront the HIV epidemic.

Program Status

The AIDS Institute has awarded 24 grants to community-based organizations statewide under both initiatives: 14 under the Multiple Service Agency Initiative, and 10 under the Community Development Initiative.

Funding

The two initiatives received a total of $3.9 million in State funds in FY 92-93: $3 million, Multiple Service Agency Initiative; $900,000 Community Development Initiative. The State legislature appropriated an additional $3.9 million in FY 93-94: $3.4 million, MSA; $500,000, CDI. These funds will expand services at existing programs and develop new programs.

Future Directions

The developmental nature of the Multiple Service Agency model will promote the enhancement and expansion of services in response to rapidly expanding AIDS caseloads in communities of color. The Community Development Initiative will enhance both community infrastructure and organizational support for HIV services in minority communities. The Initiative will also promote the organized involvement of minority communities in the development of AIDS policy for the State.

For information:
MSA: Claudia Lee,
(518) 474-1135
CDI: Elizabeth Dunn,
(518) 473-8484

Women's Supportive Services Initiative

Program

The Women's Supportive Services Initiative was inaugurated in 1992 to expand availability of HIV-related services for women and their families, and to strengthen the referral linkages between hospital HIV counseling and testing programs (e.g. the Obstetrical Initiative) and community-based health and social services. The initiative represents a unique public-private partnership, jointly funded, in which the AIDS Institute provides programmatic oversight and the United Way provides technical assistance and fiscal administration. Five community based organizations funded through this initiative provide family-centered case management, community follow-up and support services to HIV-infected women and their families. In addition, they provide a range of concrete services to clients such as: child care, 24-hour crisis intervention, emergency cash, housing assistance, individual and group counseling, peer support and HIV prevention education.

Program Status

- All five funded projects became fully operational providers of HIV Case Management and Community Follow-up services for HIV-infected women and their families as of October, 1992 and continue to expand their programs.

- By the end of the first program year, 1992-1993, these projects had reached 86% of their caseload capacity, providing case management services to 172 index clients and approximately 250 collaterals. As the second program year began, most agencies were experiencing substantial growth in caseload as referral linkages with hospitals strengthened. The demographics of women receiving services are shown below:

Demographic Information	Clients Served
Sex	
Male	23
Female	149
Race	
White	2
Black	74
Hispanic	79
Other	17
Stage of Disease	
AIDS	28
HIV+/symptomatic	49
HIV+/asymptomatic	52
Unknown	28
HIV-	14
Other	1

Total (Active cases through June 30, 1993)	172

Funding

Combined New York State and United Way funding for this initiative is currently $1,075,000, distributed among five programs which provide services in: the South Bronx, East New York, Central Brooklyn, Central Harlem, and the Lower East Side of Manhattan. (An expansion of the program through increased State funding is anticipated to take place with additional awards in early 1994.)

For further information:
Helen Gasch
Project Director
212-613-2488

The AIDS Institute ■ New York State Department of Health ■ November 1993

COMMUNITY HIV PREVENTION AND PRIMARY CARE INITIATIVE

Program

The Community HIV Prevention and Primary Care Initiative was established in 1989 with funding from the Centers for Disease Control (CDC) and the New York State Legislature. The Initiative was established to meet the growing need for community-based HIV services when preventive treatments became available for delivery in ambulatory care settings. AIDS Institute grants were targeted to local health departments and community health centers willing to develop or expand on-site HIV prevention and primary care services and to hire and train additional staff. Initially 17 facilities received grants. As a result of additional funding from the Ryan White CARE Act Title II and a State appropriation targeted to rural counties, the Initiative was greatly expanded. To date, community health centers, county health departments, and hospitals participate in the Initiative.

The goals of the Initiative are to promote the availability of HIV counseling and testing and to develop the capacity to deliver on-site HIV primary care services. In support of these goals, facilities are funded to develop the following services:

- Community outreach and education
- On-site patient education
- HIV counseling, testing, and partner notification
- Peer support
- HIV primary care
- Staff education
- Referral to services unavailable on-site
- Case management

Grant-funded programs are required to develop referral agreements with other HIV service providers including: Designated AIDS Center hospitals; community-based service organizations; drug treatment programs; county tuberculosis control programs; women's service agencies; parole offices; anonymous counseling and testing programs, and agencies providing services to adolescents. These linkages promote the continuous care of patients and their families.

Funding

The Community HIV Prevention and Primary Care Initiative in FY 92-93 received $5,969,370 in combined federal (CDC and Ryan White Care Act Title II) and State funding.

Program Status

Major accomplishments of the Community HIV Prevention and Primary Care Initiative in 1992 are as follows:

- More than 15,470 persons have received HIV antibody testing, with an overall seropositivity rate of 5 percent (12 percent in New York City).
- From 1/1/92 through 12/31/92, the number of persons receiving care through the grant-funded health centers increased by 820 (39 percent).
- The Initiative has succeeded in reaching the target populations. Blacks and Hispanics

accounted for more than 60 percent of those receiving counseling and testing and 79 percent of new primary care patients. Of the 1668 new patients enrolled in the initiative's various programs, 36.3 percent were women. Injecting drug users were 45 percent.

- The health centers are serving many people with symptomatic HIV disease (55 percent) who would otherwise seek care at overcrowded hospitals.
- Of the new patients receiving primary care services, 63 percent were covered by Medicaid and 29.3 percent were uninsured.

Future Directions

All contractors are evaluated through monthly data reports and site visits. AIDS Institute staff work closely with the programs to help them overcome barriers to service delivery, such as lack of administrative support and staff hiring difficulties. In the spring of 1993, the State legislature appropriated additional funding to both initiatives to expand the number of participating agencies and to offer a wide range of onsite services (subspecialty care, mental health care, drug treatment readiness counseling, and outreach to populations at high risk) at agencies that already receive grant funding.

For information:
Roberta Glaros
HIV Primary Care
(518) 474-7802;

The AIDS Institute ■ New York State Department of Health ■ November 1993

SUBSTANCE ABUSE INITIATIVE

Program

The New York State Department of Health AIDS Institute and the New York State Office of Alcohol and Substance Abuse Services (OASAS) have collaborated to develop a comprehensive continuum of HIV prevention and treatment services in substance abuse treatment settings across the State. To date, 25 drug treatment facilities of varied service models, including methadone maintenance, methadone-to-abstinence, drug-free residential, outpatient and detoxification, participate in this initiative.

The Substance Abuse Initiative, which was first developed as a program to provide counseling, testing, referral and partner notification services (CTRPN) in drug treatment facilities, has substantially expanded its goals and services since its inception in 1989. The CTRPN program currently includes 16 providers reaching 45 drug treatment programs at more than 80 sites. More than 25,000 clients are provided services under this program. At the end of 1990, primary care services were integrated with substance abuse treatment, CTRPN and case management. Sixteen drug treatment programs are currently funded under the primary care program to provide services to more than 16,000 clients. Also at the end of 1990, tuberculosis prevention and control was initiated in six drug treatment programs.

Facilities are funded to develop some or all of the following services:

- On-site client education
- HIV counseling, testing, and partner notification
- Individual and group counseling
- Peer education and peer support
- HIV primary care
- Staff education
- Referral to services unavailable on-site
- Case management
- Coordination of TB services and TB prophylaxis

Funding

The Substance Abuse Initiative in FY 92-93 awarded $7.5 million in total grants to Substance Abuse Settings. The CTRPN program receives $3 million from the Centers for Disease Control and Prevention (CDC). Primary Care receives $2.2 million in State funding and $1.4 million from the Alcoholism, Drug Addiction, and Mental Health Administration through OASAS. TB screening and preventive therapy is supported by $906,000 from CDC through the New York City Department of Health. In addition, programs receive reimbursement from enhanced Medicaid rates provided for HIV counseling and testing and primary care activities.

Program Status

Major accomplishments of the Substance Abuse Initiative include:

- Significant new growth of the Initiative occurred with one new counseling and testing program, six new primary care programs, and two new TB prevention and treatment programs becoming operational.

- To date, a total of more than 128,000 clients, collaterals and family members have received HIV prevention education through the CTRPN program. More than 50,000 clients have attended HIV-related individual or group counseling sessions.
- In 1992, more than 10,000 clients were tested for HIV, of whom more than 1,300 were HIV positive. The success rate for referrals for seropositive clients is well over 80 percent, which is largely attributable to the development of on-site medical services in many of the drug treatment programs participating in the Initiative.
- In 1992, the HIV primary care caseload grew to 1,174, an 85 percent increase from 1991; the case management caseload increased by 71 percent during the same period.
- The Initiative is effectively targeting clients at highest risk for HIV. Approximately 50 percent of clients served in 1992 had a history of injection drug use; these clients had a seropositivity rate exceeding 22 percent.
- The Initiative has reached traditionally underserved populations including minorities and women. Sixty-three percent of those counseled and tested and 78 percent of those provided medical care were African-American or Latino. Forty-one percent were women.
- To date, more than 60 clients with active TB have been identified through the Initiative. More than 750 clients have begun prophylactic treatment; 226 have successfully completed preventive therapy.

Future Directions

The AIDS Institute has requested applications from eligible organizations to fund HIV primary care services at substance abuse treatment programs. Approximately $600,000 was provided to two to four new programs and/or to enhance existing primary care programs. To further enhance program collaboration, the AIDS Institute and OASAS have initiated a series of workshops to improve administrative and programmatic coordination between the two agencies. As new or re-directed funds become available, the Initiative will continue to expand according to priorities jointly established by the two agencies.

For information:
Jeffrey Rothman
Director,
Substance Abuse Initiative
(518) 486-6806

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HARM REDUCTION INITIATIVE

Program

Since the Fall of 1987, injection drug use has been the predominant risk behavior for new AIDS cases in New York State. To date, more than 26,000 injection drug-using New Yorkers have been reported with AIDS. There are an estimated 260,000 individuals in the State at risk for HIV as a result of their drug use. In light of the impact of the HIV epidemic upon this population, the New York State Department of Health AIDS Institute recognized that new strategies were needed to prevent the transmission of HIV to substance users, as well as to their sexual partners and their children.

In May, 1992, the Department of Health filed emergency regulations authorizing the State Health Commissioner to exempt personnel and participants of approved needle exchange programs from the State's needle possession law as an HIV prevention measure. The regulations require that needle exchange services must be provided as part of a comprehensive harm reduction model. Within the harm reduction model, a client who will not or who cannot enter into treatment, or cannot abstain from drug use, is provided the means to reduce the risk of HIV infection and other harm to himself and his/her partners. In addition to the provision of clean injection equipment, harm reduction services include:

- information on risk reduction practices related to sexual and drug-using behaviors;
- distribution and demonstration of condoms and dental dams;
- distribution and demonstration of bleach kits and safer injection techniques; and
- direct provision or referrals to HIV counseling and testing, drug treatment programs, health care services, legal, housing and social services.

There are currently five approved harm reduction programs in New York State, four of which were authorized by the State in 1992. Additional applications from organizations wishing to provide these services are under review.

Funding

The Harm Reduction Initiative received $85,000 in State reappropriation money in FY 92-93 for program supplies and equipment. In FY 93-94, the New York State Legislature appropriated $500,000 to support harm reduction efforts, which the AIDS Institute used to develop contracts with the five approved programs to support the development of infrastructure for program development and expansion.

Program Status

Each of the approved programs utilizes a distinct model to conduct outreach to injection drug users and to operate needle exchange services within the context of a harm reduction model. The program employs street outreach and utilizes various settings for the provision of services, including vans, street-based fixed sites, store fronts, walking teams, and institutional settings. The programs continue to be volunteer-based and have undergone rapid expansion. To date, the approved programs collectively serve more than 10,000 injection drug users. The Institute continues to monitor the operations of the programs and provides oversight in accordance with State regulations.

Harm Reduction Initiative accomplishments during the past year and half include:

- The Initiative promulgated regulations for the implementation and operation of legal needle exchange programs in New York State;
- Five harm reduction programs were approved under the new regulations. All programs are operational and are actively engaged in developing organizational structures to support harm reduction activities, obtaining and training staff, developing referral agreements with health and human service providers, organizing advisory groups and working within their communities to broaden support for harm reduction services;
- The AIDS Institute has facilitated contacts between needle exchange programs and law enforcement representatives to ensure the latter's understanding of the public health benefit and to obtain support for the Initiative;
- The AIDS Institute has served as the liaison between City and State officials, community organizations, and activists to address the concerns of these disparate entities over the introduction of legal needle exchange services;
- The Institute continues to provide extensive technical assistance to approved programs on a variety of implementation issues and has helped the programs to develop referral relationships with other service providers; and
- The Institute and the American Foundation for AIDS Research (AmFAR), have formed a partnership to coordinate funding and support for the implementation of harm reduction programs including needle exchange in New York State.

Future Directions

The AIDS Institute will continue to provide regulatory oversight and technical assistance to programs participating in the Harm Reduction Initiative. Several applications for new programs from various locations around the State are currently being reviewed. The Institute will also continue efforts to support program infrastructure development and service delivery; work with community organizations, law enforcement representatives, and others to strengthen community acceptance of harm reduction programs; and continually assess program policies and procedures to ensure that the Initiative is meeting its goals.

For information:
Alma Candelas
Director,
Women and Substance
Abuse Section
(212) 613-2431

DESIGNATED AIDS CENTERS

Program

Designated AIDS Centers (DACs) are State-certified, hospital-based programs that serve as a hub for a continuum of hospital and community-based care for people with symptomatic HIV infection and AIDS. There are currently 26 DACs statewide (with four additional facilities pending certification by the State Department of Health) treating 50 percent of New York State AIDS patients. The Centers, established through emergency regulations enacted in 1985, provide state-of-the art, multidisciplinary care coordinated through case managers. At most facilities the Centers are organized into a central unit, with additional scattered beds as necessary.

Since September 1989, DACs with pediatric and obstetrical departments have been required to provide specialized HIV care to infants, children, and pregnant women. Pediatric/maternal services also are multidisciplinary and coordinated through case managers, but they are family-centered and have their own regulations and standards of care.

Standards of Care

Thirteen HIV-specific care standards have been developed for all Designated AIDS Centers. DACs are required to provide: specialized in-patient units and/or scattered beds; coordinated outpatient services; 24-hour emergency room coverage; longterm care as necessary; diagnostic and therapeutic facilities; in-service education to staff; crisis intervention services; public information and education for groups at high risk of contracting HIV, and in-patient and out-patient case management. DACs also must establish infection control policies and procedures and quality assurance mechanisms, make arrangements for patients' personal care or home care, and participate in clinical research.

These standards have been updated to reflect evolving HIV clinical knowledge and practice, and program experience. Compliance is monitored and evaluated through the AIDS Intervention Management System (AIMS).

Enrollment

The following tables compare demographics of patients admitted to DACs statewide and their HIV exposure categories, for 1990 and 1992.

Gender/Race	1990	1992*
Male	9,460 (79.6%)	10,298 (73.4%)
Female	2,273 (19%)	3,192 (22.8%)
Missing	150 (1.3%)	532 (3.8%)
African-American	3,222 (27%)	4,753 (33.9%)
Latino	3,180 (26.7%)	4,370 (31.2%)
White	4,045 (34%)	4,400 (31.4%)
Other/NA**	1,436 (12%)	499 (3.6%)

**Race not available

Exposure Category	1990	1992*
MSWM	4,134 (34.8%)	4,666 (33.3%)
IDU	4,664 (39.2%)	5,718 (40.8%)
MSWM/IDU	228 (1.9%)	288 (2.1%)
Pediatrics	184 (1.5%)	256 (1.8%)
Hetero.	821 (6.9%)	1,906 (13.6%)
Blood Products	168 (1.4%)	201 (1.4%)
Other	1,684 (14.2%)	987 (7%)

* 1992 data is understated due to reporting lag

Funding

Designated AIDS Center services are funded by two types of enhanced Medicaid rates: per diem in-patient rates, determined for each hospital based on staffing budgets, and seven-tier out-patient rates. Medicaid reimbursement provides stable, long-term funding for HIV services.

Future Directions

For information:
Ira Feldman
Assistant Director,
Bureau of HIV Health Care
(518) 486-1383

The AIDS Institute will coordinate changes in the DACs program with the Centers to meet the evolving needs of the HIV/AIDS epidemic. Program standards have been updated to emphasize HIV counseling and testing, substance abuse services, tuberculosis management, mental health services, community education, and dental care. The Institute will assist the Centers to organize and coordinate HIV services throughout entire facilities to accommodate expanding patient caseloads that exceed the Centers' current capacities. Also, the Institute will assure that the Centers effectively address the needs of women, children, minorities, persons co-infected with tuberculosis, and other populations.

The AIDS Institute ■ New York State Department of Health ■ November 1993

PEDIATRIC ADOLESCENT MATERNAL HIV SERVICES

Program

Pediatric Adolescent Maternal HIV Services incorporate several program initiatives for women, adolescents, children and families with HIV/AIDS. These programs have been designed to increase access to, and the range of, health care and supportive services for women, adolescents, and children who are infected or are at risk of infection. These programs fill service gaps left by other funding sources, provide start-up grants to develop services and develop pilot projects.

- **Pediatric Maternal HIV Services at Designated AIDS Care Centers and Care Criteria.** DACs regulations have been expanded to cover pregnant women, children, and adolescents with asymptomatic HIV infection and children whose HIV status is unknown; to provide family-based case management for medical and social service needs; to develop an interdisciplinary team approach to care, and to make services more accessible to families.

- **Grants for Hospital-Based Pediatric Maternal HIV Services.** Funding has been provided to hospitals to establish new models of family-centered, comprehensive services for HIV-positive, asymptomatic and symptomatic infants, children, adolescents, pregnant women, and their families. Developmental grants have been given to King's County Hospital Center, Harlem Hospital, and Woodhull Medical and Mental Health Center. A fourth grant is underway at Lincoln Medical and Mental Health Center.

- **Pediatric/Adolescent HIV Service Consortia.** New York City has almost 30 percent of the nation's AIDS cases in children. There are four pediatric consortia in the Bronx, Brooklyn, Northern Manhattan, and Staten Island funded by direct grants from the Health Resources Services Administration (HRSA). In addition, HRSA supports case management services by the New York City Human Resources Administration (HRA). The AIDS Institute has received HRSA funding to develop a Pediatric HIV Comprehensive Center in New York City encompassing 36 hospitals, community-based organizations, HRA, and the AIDS Institute.

The Center funds planning, coordination of services, and the implementation of a computerized clinical and case management system that integrates medical, social, and other services through the HRSA projects. The Montefiore Medical Center Adolescent HIV Program also participates in the Comprehensive Center. With HRSA funding, the Center has begun to develop a service consortium in the high need areas of Queens. New York State also supplements HRSA funding to the consortia for enhanced medical, dental and social services for HIV-infected children and their families.

During 1991, the State funded the development of an Adolescent HIV Prevention and Primary Care Initiative to enhance the capacity of HIV health service projects in New York City to provide comprehensive prevention and primary care to adolescents, in collaboration with community-based organizations serving youth at high risk of HIV infection.

- **Medical Respite for Families with HIV-Infected Children.** Medical respite care provides families and caretakers with some relief from the overwhelming demands of caring for children with serious physical and/or developmental HIV-related disorders. The Visiting Nurse Service Home Care Agency in New York City has received AIDS Institute funding to provide respite care for natural and foster families with HIV-ill children in the Bronx, Brooklyn, Manhattan, and Queens.

- **Specialized Day Care Services for HIV-Infected Children.** Specialized day care is needed

for children whose immune systems are so weakened by HIV that day care centers with large numbers of children pose serious health risks to them. Since the majority of symptomatic HIV-positive children have significant neurologic impairment, specialized day care programs must incorporate medical support and early intervention services. A pilot program at the Infant and Child Learning Center of the Kings County Hospital Center in Brooklyn provides medical services, psychosocial support services, transportation, and referral to other services.

Initiatives to be Developed in 1993-94 through New State Funding:

- **Comprehensive Health and Supportive Services for HIV Infected Women and Children.** Co-located HIV primary and gynecological care for infected women; health facility-based comprehensive health and related services for HIV infected women and children; and community-based women's and families' supportive services.
- **HIV Prevention, Health Care and Supportive Services for High-Risk and HIV-Infected Adolescents and Young Adults.** HIV prevention, peer support and skills development; comprehensive HIV prevention, primary care and supportive services in health care settings, and mobile medical vans reaching adolescents/young adults on the streets.
- **Orphans of the HIV Epidemic and their Families.** Legal assistance in child custody, guardianship, and wills; social support services including individual and group bereavement counseling, buddy programs, peer support, and age-appropriate activities to help children deal with the loss of a parent, and training programs for service providers who work with HIV-affected families in public and private agencies.

Funding

Pediatric Maternal HIV services are funded through several different sources.

- **Pediatric Maternal HIV Services at Designated AIDS Centers:** Enhanced Medicaid reimbursement.
- **Grants for Hospital-Based Pediatric Maternal HIV Services:** $112,500 for FY 93-94 in New York State funds.
- **Pediatric/Adolescent HIV Service Consortia:** $1.7 million annually in State funds; $900,000 in federal funds for FY 93-94.
- **Medical Respite:** $300,000 annually in State funds
- **Specialized Day Care:** $100,000 annually in State funds
- **FY 93-94 New State-Funded Initiatives:** $1.7 million, Comprehensive Services for Women and Children; $3.2 million for Prevention, Health Care and Supportive Services for Adolescents/Young Adults, and $350,000 for Orphans of the HIV Epidemic and Their Families.

All contractors are encouraged to apply for all available funding for services, such as COBRA case management and enhanced Medicaid rates for HIV primary care and Designated AIDS Center care. AIDS Institute grants fund the development and implementation of programs.

Future Directions

Evaluation studies help the AIDS Institute to develop new programs, such as a dental program in Northern Manhattan, following a study that demonstrated a lack of dental services for HIV-infected children. New HRSA-funded projects in New York will participate in the Pediatric Adolescent Family Comprehensive Care Center, as have the Lower New York Demonstration Project for Women and Children with AIDS, and the Queens HIV Women's and Children's Project.

For information:
Barbara Warren
Pediatric Adolescent Maternal HIV Section
(518) 486-6048

The AIDS Institute ■ New York State Department of Health ■ November 1993

AIDS NURSING FACILITIES

Program

After the AIDS Institute determined in 1988 that there was a need for long term care services for people with symptomatic HIV illness and AIDS, the State Department of Health issued regulations for the development of AIDS nursing facilities. With an estimated need for 1,551 nursing facility beds statewide by 1997, the State made enhanced Medicaid reimbursement available to attract service providers to AIDS long term care. The AIDS Institute also developed standards of care for persons with HIV illness, covering clinical care, substance abuse treatment, case management, HIV prevention, and staff education and training.

Over the next two years, 10 facilities were approved by the Public Health Council to provide 1,169 nursing care beds. The State also made loans through the Revolving Loan Fund to nine agencies to develop certificate of need (CON) applications for approximately 400 beds. Each of the State-approved facilities was required to sign a memorandum of understanding with the Department of Health to abide by the standards of care. All facilities are routinely surveyed and monitored by the Department of Health to ensure quality of care.

To date, four discrete AIDS nursing facilities are operating, with a total of 441 beds. Six additional facilities have provided a total of 39 scattered AIDS beds. Two more facilities opened 60 beds during the summer of 1992.

Funding

All AIDS nursing facilities are funded through Medicaid.

Future Directions

Four new facilities in Manhattan, Brooklyn, the Bronx, and Staten Island are expected to open in 1994, providing a total of 561 beds. Of the nine providers receiving revolving loan funds, one opened in September 1992, three have had certificates of need applications approved and two are awaiting financing, and three are pending certificate of need approval. Two providers are pursuing supportive housing. The AIDS nursing facility providers are varied and include substance abuse agencies, hospital-based nursing facilities, traditional nursing homes, and housing providers.

For further information:
Sherry Chorost
Chronic Care Section
(518) 474-8162

The AIDS Institute ■ New York State Department of Health ■ November 1993

AIDS DAY CARE PROGRAMS

Program

For people with symptomatic HIV infection and AIDS, day care programs provide a range of needed services that promote independence and delay institutionalization. AIDS Day Health Care comprises nutritional services, substance abuse and mental health counseling, medication management, nursing care, personal care, assistance with basic living skills, and case management.

The first such program in New York State opened in 1989 at the Village Nursing Home in New York City, serving approximately 100 HIV-ill persons. The program's clients, most of whom live in substandard housing, are capable of independent living and do not require continuous nursing home care. In 1993 the Jewish Guild for the Aged Blind opened their program in Yonkers, which serves up to 25 HIV-ill individuals.

To promote the development of new programs, the AIDS Institute has an annual appropriation of $500,000 in State funds for planning grants to service providers. New regulations promulgated in August 1991 created the new service category of AIDS Day Health Care for Article 28 diagnostic and treatment centers, enabling a wider range of providers to apply for Department of Health licensing. Two requests for proposals (RFPs) have been issued, and eight planning grants have been awarded. Eight programs are expected to begin operating in 1994.

Of the eight awards, six are for New York City providers, one for Long Island and one for Albany. Two other nursing facilities which have approved certificates of need (CON) also plan to operate AIDS day care programs. They also will provide after care services for residents of their health care facilities.

Funding

AIDS Day Health Care programs are funded entirely through Medicaid.

Future Directions

By 1997, an estimated 928 AIDS day care slots will be needed in New York State. The eight programs that have received AIDS Institute funding will create 360 slots; those, combined with the Jewish Guild for the Aged Blind and the Village Nursing Home program, total 405 day care slots. In addition, two AIDS nursing facilities plan to open Day Health Care programs to serve a total of approximately 90 clients per day.

Next year the Institute will seek to identify those areas of the State and those populations with the greatest need for such programs. The Institute also plans to develop Day Health Care programs for children with HIV illness.

For information:
Sherry Chorost
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(518) 474-8162

The AIDS Institute ■ New York State Department of Health ■ November 1993

HOME DELIVERED MEALS PROGRAM

Program

Good nutrition is essential to the management and treatment of HIV infection and AIDS. Lack of nutritious food profoundly affects the immune system, may affect disease progression and tolerance of medical treatments, and has a major impact on quality of life.

People with HIV/AIDS often have special dietary requirements that must be incorporated in their overall treatment plans. Many HIV-ill persons lack the means or physical strength to prepare food that can maintain or improve their health. Homebound PWAs can benefit from high-calorie, high-protein, and therapeutically-tailored meals based on individual nutritional assessments. Home care and home-delivered meals are often combined to meet the needs of homebound PWAs, replacing more costly home care meal preparation services.

The main goal of the Home Delivered Meals program is to increase access to such services. The New York State Department of Health seeks to ensure that existing services are coordinated and that providers have adequate resources and information to deliver the service. Reports from meal and AIDS service providers indicate a need to expand the existing meal delivery system to homebound persons with HIV/AIDS.

Funding

The Home Delivered Meals Program is funded for FY 92-93 through a State appropriation of $500,000. Continued funding for the program is anticipated.

Program Status

The AIDS Institute and the State Nutrition Assistance Program (SNAP) currently fund God's Love We Deliver, a New York City program currently providing home-delivered meals to 600 persons with AIDS. The AIDS Institute also funds the Momentum Project, Inc., which provides congregate meals to 200 persons with AIDS in Manhattan, Brooklyn, and the Bronx.

In July 1992, the AIDS Institute issued a request for applications (RFA) to expand home-delivered meals to other regions of New York. Selected contractors include: AIDS Community Services of Western New York; Visiting Nurse Service of Rochester; St. Peter's Community Outreach of Peekskill; Long Island Association for AIDS Care; Catholic Charities of Rockville, and Education and Assistance Corporation of Long Island. These organizations provide nutrition education and assessment as well as home-delivered meals to 300 persons with AIDS.

Future Directions

Based upon the performance of the pilot program and the availability of continued funding, the AIDS Institute anticipates expanding the Home Delivered Meals Program to additional regions.

For further information:
John W. Jack,
Health Care Consortium
(518) 486-6048

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AIDS INTERVENTION MANAGEMENT SYSTEM

Program

The AIDS Intervention Management System (AIMS) was created in 1986 to organize and evaluate data associated with the care of HIV-infected patients. AIMS encompasses a wide range of program areas, including acute care utilization and quality of care reviews at Designated AIDS Centers (25 centers statewide), and ambulatory care facilities (more than 200 providers statewide), quality of care reviews at chronic care facilities (11 providers to date), case management reviews at Designated AIDS Centers, and the analysis and reporting of data gathered through review activities and special studies.

Goals of the AIMS program, currently administered through a contract with the Island Peer Review Organization (IPRO), include:

- Creation of a review process that assures that services are necessary and appropriate and meet professionally-recognized standards of care;
- Development and management of a data system that supports review activities and permits program evaluation and policy development,
- Identification of service needs and development of mechanisms to address shortcomings or inefficiencies.

Funding

AIMS is funded through an annual State appropriation of $1.5 million.

Program Status

During 1992-1993 more than 1,500 inpatient charts at Designated AIDS Centers and more than 500 ambulatory care facility charts were reviewed. These reviews included both traditional utilization reviews, resulting in more than $1.5 million in Medicaid denials, and reviews conducted as part of a program of Continuous Quality Improvement (CQI). Reviews under the CQI process were piloted and implemented at acute, ambulatory, and chronic care facilities using algorithms developed by the AIDS Institute. Several data bases support program review and evaluation activities including information on utilization and CQI review results, case management findings, and demographic and clinical information regarding patients treated at Designated AIDS Centers.

Future Directions

The review and data analysis components of AIMS will be evaluated and refined in light of continually evolving HIV practice patterns, changes in the composition of the population being treated, and evolving research needs and priorities. Quality of care reviews will be refined to promote consistent and effective treatment practices. A longitudinal data base will be developed to follow patients throughout the health care system, and to assure continuity of care and appropriate linkages within the health care system and between health care and social service providers.

For further information:
Ira Feldman
Assistant Director,
Bureau of HIV Health Care
(518) 486-1383

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COMMUNITY FOLLOW-UP PROGRAM

Program

The Community Follow-Up Program, implemented in March 1990, is a statewide initiative of the AIDS Institute under the Comprehensive Medicaid Case Management Authority (COBRA). The program reimburses family-centered, intensive case management services for the following Medicaid-eligible populations:

- HIV-positive women of childbearing age;
- HIV-positive children and adolescents (to age 20);
- Women of unknown serostatus at high risk of HIV referred by a hospital-based program, such as the Obstetrical HIV Counseling, Testing, and Care Initiative, and
- HIV-positive persons in Community Service Programs and other community-based organizations under contract with the AIDS Institute.

The program is designed for persons who have not sought follow-up care, have comprehensive service needs, require frequent contact with care providers, and are unable to obtain care because of barriers to service delivery. Its goals are to provide access to services that foster independence and self-sufficiency; prevent or delay institutionalization; increase universal access to HIV-related services, and promote early medical intervention.

The Community Follow-Up Program encourages comprehensive case management by utilizing a team of paraprofessionals. Through the program the AIDS Institute has been able to increase the availability of community-based case management programs; provide stable funding for case management services through Medicaid; and enhance the continuum of services throughout the various stages of HIV illness. Case management continues for each client until such services are no longer needed; reassessments are required every 90 days.

Eligible providers include certified home health agencies, community health centers, community service programs, and other community-based organizations with two years experience in the care of and/or case management of HIV-positive persons. Also eligible are agencies with three years experience in serving drug-using populations or providing services to women and children, such as foster care prevention, child protection services, maternal/pediatrics, family planning, or other social services.

Case management services through the program are coordinated with other case managers who may be working with eligible persons; however, for reimbursement purposes, only one COBRA-funded provider can serve a client at any given time.

Funding

Medicaid reimbursement, the sole funding source for the program, is based on an approved hourly billing rate.

Program Status

There are currently 30 approved Community Follow-Up providers; 20 in New York City and 10 upstate. An additional 24 applications are pending review and approval. As of December, 1992, more than 1600

clients were served at a total cost to Medicaid of approximately $4.5 million.

Future Directions

The AIDS Institute will continue to promote the Community Follow-Up Program as a primary funding source for case management services for the targeted populations. In addition the Institute's Case Management Unit has developed a revised reimbursement rate structure which is pending Division of the Budget approval. Other proposed changes to the program include broadening eligibility to include all HIV-infected persons who need comprehensive Medicaid case management services.

For information:
Karen Savicki
Director, Case Management Unit
(518) 486-1323

The AIDS Institute ■ New York State Department of Health ■ November 1993

HIV UNINSURED CARE PROGRAMS
ADAP ADAP PLUS HOME CARE

Purpose

The New York State Department of Health AIDS Institute has established three programs for HIV Uninsured Care (ADAP, ADAP Plus and HIV Home Care Program). The mission of these programs is to provide access to medical services and HIV medications for all New York State residents with HIV/AIDS. The programs employ a dual approach to carry out their mission. First, the programs empower the individual to seek and access care by providing an "Enrollment Card," which allows the individual to choose an enrolled provider and receive medical services/drugs without cost.

Second, the programs supply a stable and timely funding stream to health care providers, enabling them to use the revenues to develop program capacity to meet the needs of the uninsured HIV population. The AIDS Institute has integrated the AIDS Drug Assistance Program (ADAP) with ADAP Plus (Primary Care) and the HIV Home Care Program to ensure cross-enrollment and continuity of services for participants in the programs. Individuals may apply for all three programs with a single application.

Population Served

The programs serve HIV-infected New York State residents who are uninsured or underinsured and meet established criteria. The programs can serve as a transition to Medicaid by providing interim assistance to persons eligible for, but not yet enrolled in Medicaid, or assist in meeting spend-down requirements.

Individuals with third-party insurance who cannot meet the deductibles or co-payments, or whose policies have waiting periods, may enroll and the programs will coordinate participant benefits with those of their insurance company. Adolescents who do not have access to the financial or insurance resources of their parents/guardians are eligible to apply for the program.

Eligibility Criteria

(1) Residency - New York State (U.S. citizenship is not required.)

(2) Medical -

- ADAP and ADAP Plus - HIV-infection (asymptomatics are eligible.)
- Home Care - AIDS or HIV illness and chronic medical dependency due to physical or cognitive impairment from HIV infection.

(3) Financial

- Income less than $44,000/year for a household of one, $59,200 for two, and $74,400 for three or more, and
- Liquid Assets less than $25,000

Funding

The programs are funded through a partnership between New York State, New York City, Long Island and the Lower Hudson Region using funds from Title I and Title II of the federal Ryan White CARE Act. The New York State Department of Health also uses state funds to help pay for administration of the programs.

Outreach/Provider Liaison

The programs use the AIDS Institute's network of programs and providers, and those of other New York State agencies as a comprehensive referral system and distributor for promotional materials. In cooperation with State, federal and local corrections authorities, program applications and information are provided to HIV-positive inmates nearing release from correctional facilities.

Other outreach efforts have included: transit poster campaigns; paid newspaper and radio ads; and TV, radio and newspaper public service announcements. Presentations on the programs, staff training and provider liaison services are available from program staff, including the program's New York City based Outreach/Provider Liaison Unit. The programs have also contracted with a community-based organization to conduct targeted outreach in New York City neighborhoods with a high incidence of HIV infection.

Clinical and Program Support and Policy Development

An Advisory Council including a Steering Committee, Clinical Subcommittee and a Reimbursement Subcommittee is used to provide recommendations and advice for the development of new service areas and resolution of ongoing policy issues regarding eligibility, provider enrollment, covered services, and service fees. The Advisory Council is comprised of a wide range of individuals who represent the geographic and demographic populations served by the programs. This group includes representatives from providers, community organizations, persons with HIV/AIDS, government, clinical specialties and reimbursement systems.

For further information:
HIV Uninsured Care Programs
Empire Station
P.O. Box 2052
Albany, NY 12220-2052
1-800-542-2437

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AIDS DRUG ASSISTANCE PROGRAM (ADAP)

Program

The AIDS Drug Assistance Program (ADAP) began in 1987 as part of a national program to provide free HIV/AIDS drugs to low-income individuals not covered by Medicaid or adequate third-party insurance. ADAP has grown tremendously in both enrollment and drug coverage. Participants may receive their prescriptions from over 1,800 local pharmacies statewide. The ADAP Formulary of 62 drugs includes prophylaxis for pneumocystis carinii pneumonia (PCP), anti-retroviral, anti-neoplastic, and opportunistic infection therapies.

New drugs are added to the formulary based upon the changing clinical profile of the epidemic and the most recent clinical trials data. The formulary, expanded from 15 to 62 drugs since June 1991, currently includes 3 anti-retrovirals (AZT, ddI and ddC), 13 drugs for treatment of AIDS-associated neoplasms, and 46 drugs to treat or prevent opportunistic infections and related conditions.

Enrollment

ADAP serves all populations affected by AIDS in New York State. The program's demographics, however, have changed over the years to reflect changes in the epidemic. Since the program began, there has been increased enrollment of blacks, Hispanics, women, low-income people and released prisoners. Cumulative ADAP enrollment is more than 20,000, with over 9,400 active participants. The program is expected to actively serve more than 14,000 individuals during 1993. New York City, with the State's highest incidence of AIDS, accounts for 70 percent of ADAP participants. Demographics of new enrollees during 1993 are: 20% Female; 35% African American, 32% White and 30% Hispanic; and 86% with annual incomes less than $20,000.

Funding and Expenditures

ADAP is funded through Titles I and II of the federal Ryan White CARE Act. For 1993-94, $7 million is available from Title II (New York State) and $8.25 million from Title I (New York City). Long Island and the Lower Hudson Region also contribute Title I funds to the program. ADAP receives reimbursement from drug manufacturer rebates and insurance companies. Fiscal growth of the program is illustrated in the following chart.

YEAR	PRESCRIPTIONS	EXPENDITURES	AVG COST
1991	50,909	$ 8,625,145	169
1992	84,757	$13,826,601	163

AZT is the most commonly provided medication, with an average monthly cost of $211, which accounted for 35% of the total expenditures for 1992. G-CSF has the highest monthly cost averaging $1,354.

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ADAP PLUS (PRIMARY CARE)

Program

ADAP Plus was implemented in October 1992 to provide access to primary care services to low income persons not covered by Medicaid or adequate third-party insurance. ADAP Plus covers a full range of HIV Primary Care services, provided on an out-patient ambulatory basis, including an annual comprehensive medical evaluation, clinical HIV disease monitoring, the administration of therapeutic medications and the treatment of both HIV related and non-HIV related illness. A nutritional component, consisting of nutritional assessment and counseling, vitamins and minerals, and oral supplements has recently been added to the program. ADAP Plus has enrolled over 110 hospitals, clinics and drug treatment programs (250 service sites), during the first year of operation.

Enrollment

ADAP Plus has enrolled over 7,800 participants in the first year with more than 6,500 currently active. Participant demographics include: 18% women; 62% minorities; 84% have an annual income less than $20,000; 43% have AIDS and 24% are symptomatic.

Funding

ADAP Plus was developed as a unique partnership between New York City and New York State. The NYC HIV Planning Council identified primary care for City residents with HIV as a high priority, and allocated Ryan White Title I funds to develop a reimbursement pool. The NYS Department of Health's AIDS Institute assisted Medical and Health Research Association (MHRA) and the NYC Department of Health in the design of a program based on the ADAP model. The AIDS Institute was awarded the contract for implementation and administration of the program for NYC residents. The AIDS Institute secured Title II funds to expand the program to the rest of the state. In 1993, the funding partnership between New York State and New York City continues, with the Long Island and Lower Hudson Regions joining in the partnership through an allocation of a portion of their Title I funds.

Future Directions

ADAP Plus is still a new program and in the developmental stage. ADAP Plus will begin to enroll private physicians as providers in November. In order to enroll, physicians must also be enrolled in the Medicaid HIV Enhanced Fees Program, to assure continuity of care and eligibility for enhanced rates. The program will also continue to identify gaps in services or provider coverage and develop appropriate responses to resolve identified problems.

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HIV HOME CARE PROGRAM

Program

The ADAP Plus (Home Care) Program, implemented in November 1991, provides home care services to chronically dependent individuals with HIV illness or AIDS, and who have no or limited insurance for home care. The program covers home health aide services, intravenous therapy administration, medication and supplies, laboratory tests, durable medical equipment and adult day health care. The program ensures statewide coverage through enrolled home care agencies. Currently 300 home care agencies are enrolled to provide services to eligible participants.

Enrollment

Between November 1991 and October 1993, more than 500 persons received home care benefits through the program. Enrollment is rapidly increasing with over 290 new enrollees since January 1993 and over 160 currently active. Participant enrollment is comprised of: 50% minorities; 17% female; 76% have an annual income below $20,000; and 90% have been diagnosed with AIDS, while the remainder are HIV symptomatic.

Funding

Home Care is supported for 1993-1994 through $630,000 in Ryan White Care Act Title II funds. Over $2 million in Ryan White Title I funding from New York City, Long Island and the Lower Hudson Region has been committed to the program. This unique partnership of Title I and II funding has allowed significant expansion of enrollment.

Future Directions

The program is conducting extensive outreach activities and anticipates rapid growth in enrollment. Program continue to recruit additional home care agencies and hospices to assure comprehensive access statewide. Adult day health care is a covered service that will become more widely available through the program as additional agencies implement new programs.

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NURSING HOME INITIATIVE

Policy Unit: *Nursing Home Initiative*

As HIV disease becomes more of a chronic condition and HIV-infected persons live longer, more of them will eventually need nursing home care. Nursing homes can provide long term care to support people with AIDS during the non-acute stages of their illness, as well as a range of non-medical services, including recreation, peer support activities, and counseling. Nursing home care also may be the best option for those individuals for whom home care is not feasible. Moreover, it is more cost-effective than hospitalization.

However, people with AIDS (PWAs) in New York State face difficulties in gaining access to nursing home care, according to complaints from AIDS service providers and persons with HIV/AIDS. Although there is an estimated need for 30 nursing home beds for persons with HIV in the Albany region, not one PWA has been accepted into a nursing home. Discharge planners at designated AIDS center (DAC) hospitals report that they are unable to place persons with HIV/AIDS in nursing homes, and reports received by the State Department of Health and the New York State Division of Human Rights indicate that nursing homes discriminate against persons with HIV in their admissions policies.

It is uncertain how many nursing homes statewide have actually accepted persons with HIV/AIDS because facilities, fearing negative publicity, will not disclose whether they have admitted PWAs.

The AIDS Institute developed a Nursing Home Initiative in 1991 to ensure that nursing home services are available to persons with HIV/AIDS, and that providers are prepared to accept and care for these patients. The initiative's objectives are to:

- Inform all New York State nursing homes about the need for nursing home care for people with HIV/AIDS, and the laws which ensure PWAs equal access to such facilities;
- Educate nursing home providers about HIV/AIDS and the service needs of persons with HIV;
- Encourage nursing homes to accept PWAs;
- Assist nursing homes to identify and address issues at their facilities that may hinder service provision to PWAs;
- Assist nursing home providers to develop sound policies on HIV/AIDS based upon the latest medical knowledge;
- Develop links between nursing homes and community service providers to enhance the ability of nursing homes to care for people with HIV.

To accomplish these objectives, the AIDS Institute Policy Unit has coordinated Nursing Home Initiative activities with the Institute's Chronic Care Unit, the Department of Health Bureau of Long Term Care, and the State Division of Human Rights.

Program Status

In 1991, the Nursing Home Initiative notified all 627 nursing homes in New York State by a letter co-signed by the Commissioners of Health and Human Rights that persons with HIV/AIDS who were in need of institutionalized long-term care had a right to receive nursing home services. As part of the Initiative, the Policy Unit has conducted regional meetings for nursing home administrators and staff in Albany, Buffalo/Rochester, Syracuse and New Rochelle (for nursing homes from Westchester County and Long Island). Meetings were also held with Designated AIDS Centers and Community Service Programs so

that hospital and community-based organizations were aware of the needs and rights of people with HIV/AIDS for nursing home care. On-site interviews with administrators from 61 randomly selected nursing homes outside of New York City also were conducted.

As a result of these efforts, eleven nursing homes have completed a limited review application process in order to provide care for people with HIV infection/AIDS. To date, more than fifteen individuals received nursing home care in institutions that previously were not providing care to people with HIV infection. The AIDS Institute continues to follow up with discharge planners at the Designated AIDS Centers throughout the state to monitor nursing home placement and to work with nursing homes who want to apply for a scatter site program.

For further information:
Mickey Gourlay-Doyle
Chronic Care Unit
(518) 474-8162

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NEWBORN HIV TESTING

Policy Unit: *Newborn HIV Testing*

AIDS in the United States has evolved over the past decade from a rare disease mainly affecting gay men to one of the leading causes of death among women in cities nationwide. In New York City, AIDS is the leading cause of death among women 20 to 39 years of age. As more women have become infected with HIV, the number of children with AIDS also has increased. There have been almost 4,000 cases of AIDS in children under 13 years of age. Approximately 85 percent of them have a mother with, or at risk for, HIV infection.

As the HIV epidemic spreads to different populations, the public health, medical and scientific community must continually question both assumptions and presumed care standards regarding HIV and AIDS. Providing appropriate HIV-related services to women and children has become a priority for the AIDS Institute.

Conferences on Women and Children with HIV/AIDS

At the request of the New York State Departments of Health and Social Services, the AIDS Institute held a conference on the care of women and children with HIV infection in January 1990 at Mohonk, New York. The conference issued a set of recommendations entitled "New York State Principles for the Care of Women and Children with HIV Infection," now known as the Mohonk Principles. The principles form the basis for New York State Department of Health Policy and programs for women and children with HIV infection.

The issue of routine or mandatory newborn screening for HIV emerged as a primary concern for many at the 1990 conference. Participants agreed that efforts should be made to improve early identification of HIV-infected infants and children, but, since identifying seropositive newborns necessarily identifies infected mothers, many were concerned about the potential impact of involuntary testing on women and their families. The conferees decided that New York State should not implement mandatory HIV screening of newborns at that time. However, the following criteria were included in the Mohonk Principles to provide a framework for reconsideration of newborn screening:

> Consideration of proposals for mandatory HIV screening of newborns must balance the involuntary, proxy testing of the mother against the State's *parens patriae* interest in safeguarding the health and welfare of the infant. Five conditions must be met before mandatory newborn screening would be ethically responsible: substantial clinical benefit of treatment in HIV-infected newborns has been demonstrated; appropriate clinical services are available to all HIV-infected family members regardless of family resources; a definitive laboratory test becomes available allowing for the detection of HIV infection in newborns (as opposed to the presence of maternal HIV antibodies), or the indicated clinical intervention for infants with HIV infection has been proven to be sufficiently non-toxic to uninfected infants who would receive it because of the presence of maternal HIV antibodies, and a system of voluntary counseling and testing of all women of reproductive age has failed to be effective.

In addition, the Mohonk Principles called on New York State to reconvene experts on a continuing basis to reevaluate the scientific and medical knowledge regarding diagnosis and treatment of

infection in newborns and children. In January 1992 the AIDS Institute held a second conference on the care of women and children with HIV infection to reconsider the issue of newborn screening in light of advances made during the past two years in both the diagnosis and treatment of HIV infection in infants, children, and women. The conferees did not achieve a general consensus on the issue; however, most participants concluded that the criteria developed in 1990 for changing the State's policy had not yet been met.

1993 Legislative Action

During the 1993 legislative session, Assemblywoman Nettie Mayersohn of Queens introduced a bill that would allow the Department of Health to release to parents the results of HIV tests given to all infants born in New York State, or, as it is commonly stated, to "unblind" the testing program. Currently the serosurvey of newborns is a "blinded" epidemiologic study, that is, all identifying information is removed before the sample of blood is tested. Hence, there is no way to notify parents or anyone else of test results. Since the study is "blinded," no written informed consent, which is required by law for all HIV antibody tests in New York, is obtained from parents.

Although this particular bill was not brought to the floor during the last legislative session, it, and possibly others, will be considered when the Legislature reconvenes. In the meantime, the New York State AIDS Advisory Council has established a blue ribbon panel to examine this issue. The Subcommittee on HIV Screening of Newborns meets this Fall and will report to the full Council at its December meeting. Dr. David Rogers, Chair of the AIDS Advisory Council, will report the subcommittee's findings and recommendations to the Legislature, the Governor, and Commissioner of Health.

For further information:
Eileen Tynan
Director,
Policy Unit
(212) 613-2427

The
AIDS
Institute | New York State Department of Health

FUNDING HIV PREVENTION AND HEALTH CARE

The AIDS Institute, created in 1983 as the central agency for coordinating New York State's response to the HIV/AIDS epidemic, has organized its programs to address the two most critical needs: prevention and health care.

Both tasks demand strategies unique to this epidemic. Prevention requires confronting the widespread denial, discrimination, and fear associated with AIDS in order to offer community education, counseling, and testing. Reimbursement mechanisms specifically for HIV care reflect the fact that HIV-infected people, whether symptomatic or not, make new and complicated demands on an already overburdened health care system.

To ensure access to care for virtually 100 percent of the HIV-infected population, New York State has established the following policies and funding mechanisms:

Enhanced Medicaid rates expand access to treatment for HIV/AIDS patients by fully reimbursing providers for the resource-intensive care of HIV-infected people, who have a wide constellation of medical and psychosocial needs. Use of the rates requires adherence to standards of HIV care devised by the Institute. Further, providers are encouraged, and in some cases directed, to add clinical and case management staff and otherwise strengthen infrastructure. The range of enhanced rates covers services from diagnosis through chronic care and terminal illness.

Private insurance is offered through private carriers, Blue Cross/Blue Shield, and COBRA continuation coverage. Insurance reform legislation passed in 1992 will prevent private insurers from overcharging or denying coverage to people with HIV or other illnesses.

Uninsured pools assure providers of reimbursement for treating all HIV-infected people and encourage the uninsured and underinsured to seek primary care, medications, and home care services. Further, they help to prevent the impoverishment of individuals and families already under stress and serve as bridges to Medicaid for difficult to reach populations, such as the homeless, parolees, and street adolescents.

Prevention, education and training, program start-up and development, as well as some capital financing, are funded by grants administered by the AIDS Institute.

The AIDS Institute | New York State Department of Health · November 1993

TYPES OF HIV FUNDING

ENHANCED MEDICAID RATES

PRIMARY CARE RATES
for clinics, hospitals, and private physicians

ACUTE CARE RATES
HIV DRGs for all hospitals
Enhanced inpatient and outpatient rates for Designated AIDS Centers

LONG TERM CARE RATES
Nursing facility rates
Home care rates
Day care rates
Hospice care rates

FOSTER CARE RATES
for foster parents and programs

COBRA FOLLOW-UP RATES
for case management services

PRIVATE INSURANCE

Private carriers
COBRA continuation coverage
Blue Cross/Blue Shield

UNINSURED POOLS

AIDS Drug Assistance Program
Home Care
ADAP Plus

GRANTS

Grants are awarded to encourage the initiation and development of new programs and to fund services not covered by enhanced Medicaid rates or other sources of funding.

Grants are available to health care providers, community organizations, and educational institutions. They are used particularly to improve services for high risk areas and populations.

Grants fund:

- Community education/outreach
- HIV counseling and testing
- Perinatal testing and follow-up
- Education/testing in prisons
- Supportive services
- Prevention and primary care in community health centers and substance abuse facilities
- HIV counselor training
- Clinical training (professionals)
- Occupational exposure training
- Pediatric/Maternal services
- Long term care, including nursing facilities, housing, home care, hospices, and adult day care
- Case management
- Ryan White planning networks
- Program evaluation/planning

New York State

ENHANCED MEDICAID RATES FOR HIV SERVICES

The AIDS Institute ■ New York State Department of Health ■ November 1993

PRIMARY CARE

ENHANCED PRIMARY CARE RATES FOR HOSPITALS AND CLINICS were established in 1989 to encourage earlier counseling and testing, clinical evaluation, and medical treatment. This five-tier rate structure is available to licensed hospitals and diagnostic and treatment centers who offer specified HIV services, care coordination, and referrals. Rates range from $60-398 (compared to the average New York City non-HIV clinic rate of $70).

- To encourage preventive education, facilities are reimbursed for pre-test counseling even if the client declines the test.
- Providers may bill for more than one patient visit per day, overriding previous Medicaid "threshold" rules and improving efficiency of service.

ENHANCED PRIMARY CARE RATES FOR PRIVATE PHYSICIANS were initiated on July 1, 1991, making New York the first state in the nation to appropriately reimburse physicians treating HIV-infected people. These fees ($25-84) are available to both primary care physicians and specialists.

ENROLLMENT: 205 clinics and hospitals; 360 physicians.
INFORMATION: 518-474-7802.

- In conjunction with the program, the AIDS Institute developed a series of HIV primary care treatment protocols and HIV clinical training programs to insure a single standard for the management of HIV infection.

ACUTE CARE

ENHANCED RATES FOR OUTPATIENT CARE AT DESIGNATED AIDS CENTERS (DACS), a seven-tier schedule instituted in 1986, were the first targeted reimbursement system for people with symptomatic HIV or AIDS. Rates range from $45-360 (basic NY City rate is $70).

- There is a rate specifically for case management and case management costs were built into all service categories.

PER DIEM RATES FOR DESIGNATED AIDS CENTERS, begun in 1986, were 40 to 50 percent higher than standard per diem rates. Currently, DACS receive $700-1,300 per day, depending on the size of the facility and program. DACS care for approximately 53 percent of New York State's HIV/AIDS patients.

ENROLLMENT: There are 25 Designated AIDS Centers. All other hospitals use HIV DRGs.
INFORMATION: 518-486-1383

- The outpatient and per diem rates for DACS were designed to enable them to meet AIDS Institute standards of care.

HIV DRGs FOR INPATIENT CARE were instituted for all licensed hospitals in 1988. Enhanced HIV DRGs are being planned for use in 1995 by the DACS (instead of per diem rates).

The AIDS Institute ■ New York State Department of Health ■ November 1993

HIV UNINSURED POOLS

AIDS DRUG ASSISTANCE PROGRAM

THE AIDS DRUG ASSISTANCE PROGRAM (ADAP) began in 1987 as part of a federally funded national program to provide free HIV/AIDS drugs to HIV-infected people not covered by Medicaid or adequate other insurance. The program coordinates benefits with other types of insurance and provides interim assistance to people eligible for but not yet enrolled in Medicaid, or have Medicaid spend-down requirements. ADAP currently offers 62 drugs to individuals who meet specific financial, residency, and medical criteria.

ENROLLMENT: 20,312 clients cumulative, with 9,829 active participants. More than 1,800 local pharmacies are enrolled.

ADAP Plus (PRIMARY CARE)

ADAP Plus (PRIMARY CARE), began in October 1992, to provide access to comprehensive ambulatory primary care services for HIV-infected low income people with inadequate or no insurance. The Program also serves as a transition to Medicaid. In the first year, the program enrolled hospitals and clinics to provide services, enrollment is now being extended to private physicians. A nutritional component including assessment and counseling, oral supplements, vitamins and minerals was recently added.

ENROLLMENT: 8,240 clients cumulative, with 7,058 active participants. Enrolled providers include 115 hospitals and clinics (254 sites).

HIV HOME CARE PROGRAM

THE HIV HOME CARE PROGRAM was implemented in November 1991 to provide care to any home bound HIV-ill person without Medicaid or other source of funding for home care services. Certified home health agencies, long term home health care programs, hospices, and licensed home care service agencies are enrolled to provide services. Services include skilled nursing, home health aides, intravenous therapy administration, medications, lab tests, durable medical equipment and adult day care.

ENROLLMENT: 543 clients cumulative, with 231 active participants. Over 300 Home Care Agencies are enrolled.

ADAP, ADAP Plus and HIV Home Care are integrated for coordinated services. Individuals may apply for all three programs with a single application. The programs are funded through a unique partnership using funds from the Ryan White CARE Act, Title II (State) and Title I (New York City, Long Island and Lower Hudson Region).

INFORMATION: (IN NYS) 800-542-2437 (OUT OF STATE) 518-459-1641

New York State

HIV PREVENTION GRANTS

The AIDS Institute ■ New York State Department of Health ■ November 1993

EDUCATION

COMMUNITY EDUCATION/OUTREACH services provide HIV/AIDS education, outreach, and training to the general public, to populations at high-risk of HIV infection, and to health and human service providers, including physicians, nurses, dentists, mental health professionals, and other practitioners. AIDS Institute education/outreach programs address such issues as occupational exposure to HIV, violence against persons with HIV/AIDS, and cultural barriers to HIV prevention messages.

COUNSELING TESTING

COUNSELING AND TESTING services include both anonymous and confidential HIV testing. Anonymous counseling and testing is available at 48 sites statewide, and from a mobile van in New York City. Sites include community organizations, drug treatment programs, housing projects, and soup kitchens. Programs provide referrals to medical and support services and follow State guidelines for partner notification. Confidential counseling and testing, with partner notification and referrals to medical and support services, are available at many locations, including community health centers, drug abuse programs, and county health departments, and from private physicians statewide. AIDS Institute grants also fund training of HIV test counselors.

SUPPORT SERVICES

SUPPORT SERVICES are designed to improve the quality of life of persons with HIV infection and AIDS. These activities include risk reduction counseling, peer support, case management, crisis intervention, transportation, nutrition, family services (child care, housing and job assistance) legal counseling, and referral to other needed services.

SUBSTANCE ABUSE

PREVENTION AND PRIMARY CARE IN DRUG ABUSE FACILITIES comprises a range of services offered at drug treatment sites including HIV counseling, testing, partner notification and referrals, HIV primary care, tuberculosis prevention, and case management. Primary care services, in addition to being offered on site by drug treatment programs, are available from primary care clinics that provide drug treatment either on site or through referrals. The initiative also requires ongoing HIV education and training for clinical and support staff at the facilities.

MULTIPLE SERVICE

THE MULTIPLE-SERVICE INITIATIVE is a new program aimed at providing comprehensive, "one-stop" HIV services to racial and ethnic minority populations living in high-need communities statewide. This new service model developed by the

New York State

HIV HEALTH CARE GRANTS

The AIDS Institute ■ New York State Department of Health ■ November 1993

PREVENTION/ PRIMARY CARE

PREVENTION AND PRIMARY CARE IN COMMUNITY HEALTH CENTERS comprises comprehensive HIV prevention and primary care programs including: community outreach and education; patient education; HIV counseling and testing; peer support; referral to additional services; staff training, and medical services for HIV-infected persons. These grant-funded programs are required to have referral agreements with drug treatment programs, community service organizations, women's service organizations, and acute care hospitals with experience in HIV treatment. The initiative funds programs at 134 community health centers, county health departments statewide and hospital based ambulatory care out patient clinics.

PEDIATRIC/ MATERNAL SERVICES

PEDIATRIC/ADOLESCENT/MATERNAL SERVICES comprise a range of programs for HIV infected children, adolescents, and their families. Eight projects in New York City, four of which are consortia of hospitals and community-based organizations, receive State and federal funding to provide medical and social services, including care by clinicians with expertise in HIV treatment, family-centered case management, developmental assessments of children and early intervention services, and dental assessments and care. Other grant-funded services for HIV-infected children include day care, home-based respite, primary care in rural counties, and family support services.

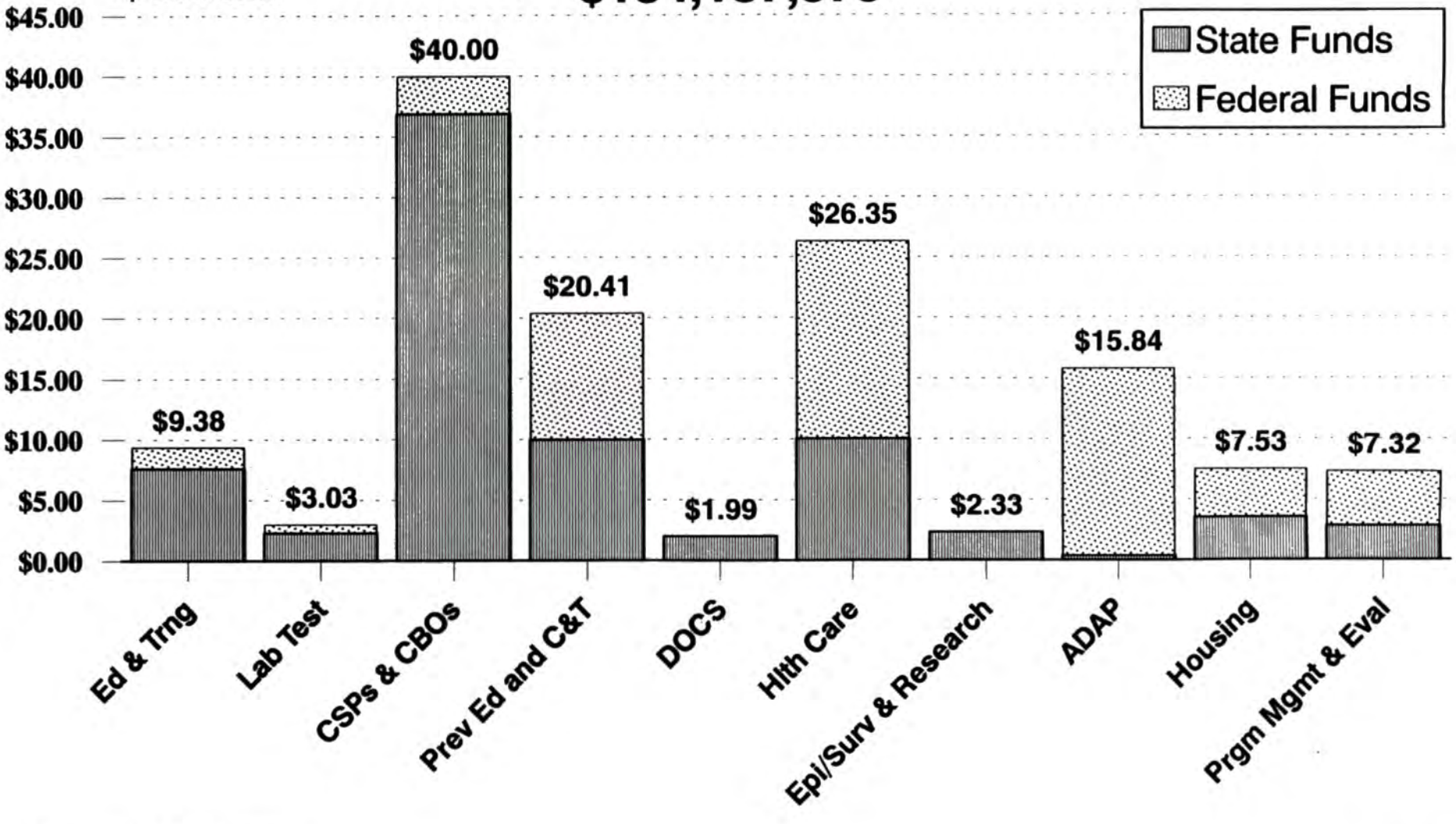
LONG TERM CARE

LONG TERM CARE comprises various programs designed to meet the complex needs of persons with chronic HIV illness. The AIDS Institute administers federal funds to provide home care for HIV-ill persons without insurance for this service, and funds adult day care, including health, mental health, and social services for people with HIV/AIDS. Grants also fund medical respite, short term medical care that relieves the burden on families of caring for HIV-ill children. The State established a revolving loan fund to develop residential nursing facilities to provide comprehensive clinical and supportive care for persons with HIV/AIDS, especially substance users. Grants also support housing for people with HIV/AIDS and hospice care for terminally ill AIDS patients.

CLINICAL EDUCATION

CLINICAL EDUCATION includes initiatives and programs to train health practitioners in HIV care. State funding to 16 hospitals supports instruction of community-based providers in HIV care, with training focusing on early intervention, diagnosis, and prophylaxis of HIV-related infections. The HIV Clinical Scholars program, based at five

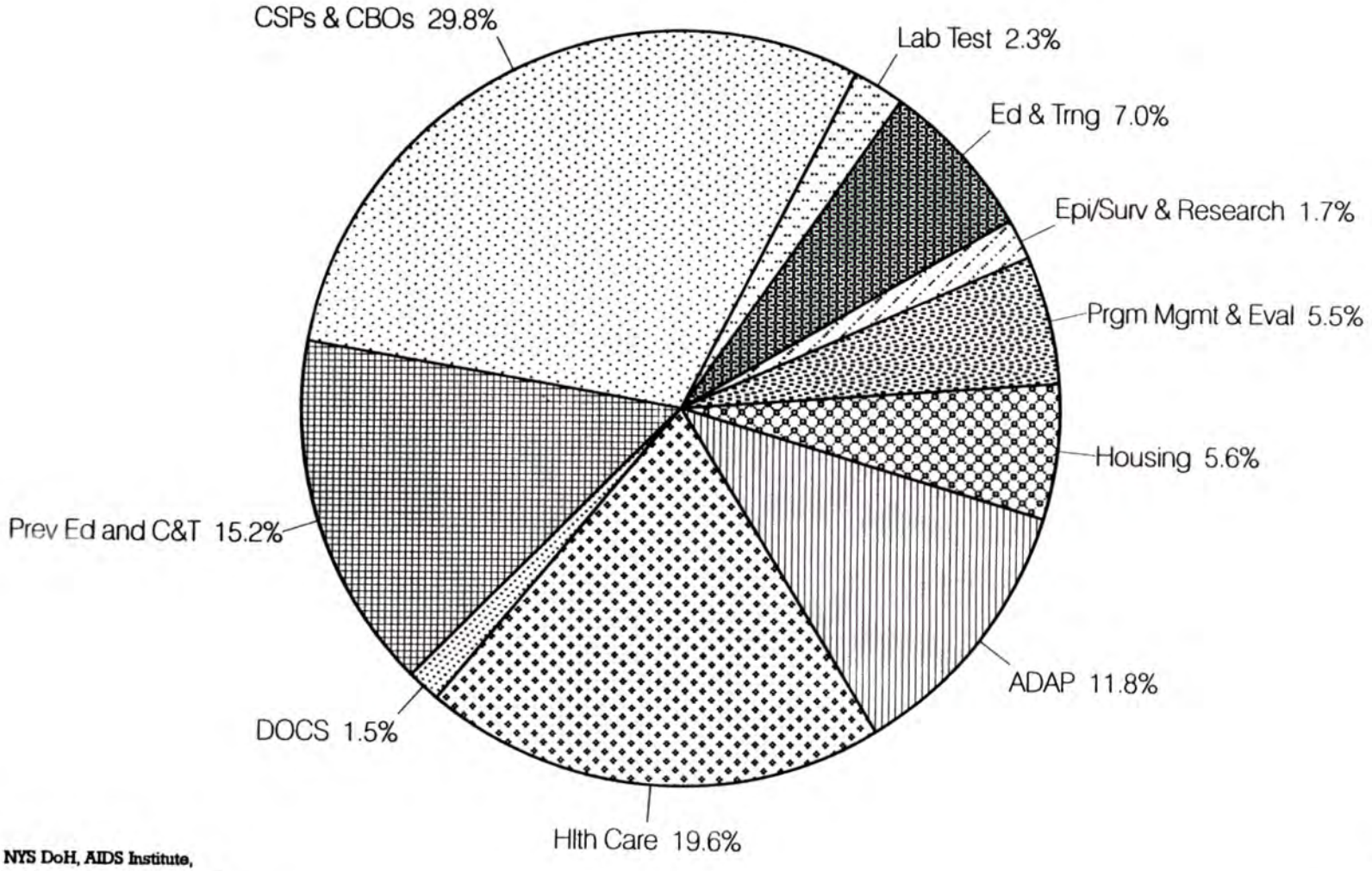
New York State Department of Health
AIDS Institute Funding Matrix
Fiscal Year 1993 - 1994
$134,187,579



Prepared by: NYS DoH, AIDS Institute,
Office of Information Resources Management

Novmber 1993

New York State Department of Health
AIDS Institute Funding Matrix
Fiscal Year 1993 - 1994
$134,187,579



Prepared by: NYS DoH, AIDS Institute,
Office of Information Resources Management

Novmber 1993

HIV/AIDS in the United States

September 1993 ■ The AIDS Institute, New York State Department of Health

Cumulative CDC Defined AIDS Cases

1988	1993	1994
82,764[1]	315,390[2] 49% reported since 12/90. 38% alive.	415-535,000 (projected by year end)

At least one million people are infected with HIV in the U.S.

Trends in the Epidemic

	1988	1992
Homo/bisexual (% of adults)	62%	55%
IDU-related[3] (% total cases)	25%	27%
Black+Hispanic (% total cases)	42%	47%
Women (% of adults)	9%	11%
Children	1,346 cases	4,249 cases

HIV infection is becoming less concentrated in urban areas. Last year, the rate per 100,000 population increased faster in small metropolitan regions (fewer than 1/2 million people) and in rural areas than in large metropolitan regions.

Nineteen percent of cumulative AIDS cases were diagnosed in people in their 20s, indicating a high rate of HIV infection among adolescents for the past decade.

[1] CDC AIDS Surveillance Report, cases reported as of December 31, 1988.
[2] CDC AIDS Surveillance Report, cases reported as of June 30, 1993.
[3] Includes adult cases with IDU as primary risk (20% in 1988, 23% in 1993), plus heterosexual adult cases attributable to sex with an IDUser, plus pediatric cases attributable to maternal IDU or sex with an IDUser.

HIV/AIDS in New York State

September 1993 ■ The AIDS Institute, New York State Department of Health

Cumulative CDC Defined AIDS Cases - New York

1988	1993	1997
20,476[1]	61,082[2] 43% reported since 12/90 30% alive	102,766[3] (projected by year end)

New York, with nearly 20% of the U.S. total, has more cases than any other state. It is estimated that **New York has 130-200,000 of the one million HIV-infected people in the U.S.**

Trends in the Epidemic - New York State

	Cumulative Dec.1988 (N = 20,476)	Cumulative Dec.1992 (N = 51,721)	Cases reported 1992 (N = 9,054)
Homo/bisexual (% of adults)	48.7%	40.8%	32.7%
IDU-related[4] (% total cases)	41.3%	47.4%	52.5%
Black/Hispanic (% total cases)	59.2%	64.2%	70.0%
Women (% of adults)	12.5%	16.2%	20.2%
Children	422 cases	1,161 cases	214 cases
Prison inmates	838 cases	1,956 cases	265 cases
NYS cases in NYC	84.6%	83%	83%

[1] New York State Department of Health AIDS Surveillance Update, as of December 31, 1988.
[2] New York State Department of Health AIDS Surveillance Update, as of June 30, 1993.
[3] This low-end projection (as of April 1993) does not attempt to account for the revised AIDS definition adopted by the CDC on Jan. 1, 1993.
[4] Includes adult cases with IDU as primary risk (37% in 1988, 43% in 1992, and 48% of cases reported in 1992), plus heterosexual adult cases attributable to sex with an IDUser, plus pediatric cases attributable to maternal IDU or sex with an IDUser.

STATEWIDE CONFERENCE HELPFUL HINTS

EMERGENCY PROCEDURES

Two case managers are on duty at all times during the conference to assist anyone with an emergency. Any conference participant in need of assistance should report to the registration desk, or see any conference staff person. For more information, please see the yellow "Medical Emergencies" sheet in your packet.

PWA REST AREA

A quiet, private rest area is available for any PWA in need of a break during the conference who is staying at another hotel. The rest area is located in Room 329 of the Omni Hotel.

MESSAGES

Messages for conference participants may be left on the message board located in the registration area.

PARTY MONDAY EVENING

A dance party will be held in Kelsie's, located on the main floor of the Omni, from 9:30PM-1:00AM Monday evening. Please come and relax with your friends and colleagues from around the state after a long day of work! A cash bar will be provided.

CONFERENCE NAME BADGE

Name badges must be worn at all times during the conference. Name badges are required for admittance to any Conference event. If you are attending more than one day of the conference, please be sure to bring your badge with you to each day's session.

MEAL TICKETS

Meal tickets are required for the lunch and dinners at the conference. Tickets are given to conference participants upon registration. Lost tickets cannot be replaced, so please be sure to keep your tickets in a safe place.

QUESTIONS FOR PLENARY SESSIONS

During the Monday morning Research plenary and the Tuesday morning TB plenary, conference participants can submit questions to be posed to the panel of speakers. Those wishing to submit questions can fill out the 3 x 5 index cards located on the conference room tables. Staff will collect these cards during each session, and questions selected at random.

CANDLELIGHT CEREMONY

A Candlelight Ceremony will be held beside the pool on Sunday evening after dinner. In addition to space around the pool's edge, the Level B balcony offers an excellent view of the ceremony.

AIDS INSTITUTE TRANSPORTATION SCHEDULE
NOVEMBER 14 - 16, 1993

ALL SERVICES WILL BE PROVIDED BETWEEN THE FOLLOWING PICKUP POINTS
HOST HOTEL: OMNI ALBANY HOTEL
CONVENTION HOTELS: THRUWAY HOUSE WASHINGTON AVENUE
BEST WESTERN WOLF ROAD
HOLIDAY INN TURF WOLF ROAD
AMTRAK STATION: RENSSELAER (DOWNTOWN ALBANY)
****INDIVIDUALS STAYING AT THE ECONO LODGE - THERE IS A HOTEL SHUTTLE RUNNING FROM THE HOTEL TO THE OMNI AND BACK. PLEASE CHECK WITH THE FRONT DESK FOR SHUTTLE HOURS.

SUNDAY NOVEMBER 14, 1993

1 COACH	11:00AM - 4:00PM	SHUTTLE FROM AMTRAK TO OMNI HOTEL
1 COACH	11:00AM - 6:30PM	CONTINUOUS SHUTTLE FROM OMNI HOTEL TO CONVENTION HOTELS
1 COACH	8:30AM - 10:00PM	CONTINUOUS SHUTTLE FROM OMNI HOTEL TO CONVENTION HOTELS

MONDAY NOVEMBER 15, 1993

2 COACHES	7:00AM - 10:00AM	CONTINUOUS SHUTTLE FROM CONVENTION HOTELS TO OMNI HOTEL
1 COACH	9:45AM - 11:30AM	PICKUP AT AMTRAK TO OMNI HOTEL
2 COACHES	12:00 NOON	SHUTTLE FROM OMNI TO CONVENTION HOTELS - 1 TRIP
2 COACHES	1:30PM	SHUTTLE FROM CONVENTION HOTELS TO OMNI - 1 TRIP
2 COACHES	3:30PM	SHUTTLE FROM OMNI TO CONVENTION HOTELS - 1 TRIP
2 COACHES	5:30PM - 8:00PM	CONTINUOUS SHUTTLES FROM CONVENTION HOTELS TO OMNI HOTEL
2 COACHES	10:00PM - 11:00PM	CONTINUOUS SHUTTLES FROM OMNI HOTEL TO CONVENTION HOTELS
1 COACH	1:00AM	FINAL SHUTTLE FROM OMNI TO CONVENTION HOTELS

TUESDAY NOVEMBER 16, 1993:

2 COACHES	7:00AM - 10:00AM	CONTINUOUS SHUTTLES FROM CONVENTION HOTELS TO OMNI HOTEL
2 COACHES	12:30PM - 4:30PM	SHUTTLES FROM OMNI HOTEL TO AMTRAK STATION

CONFERENCE EVAULATION FORM
THE FOURTH ANNUAL HIV/AIDS STATEWIDE CONFERENCE
NOVEMBER 14-16, 1993

Please help us improve this conference by completing all items on this form before leaving the conference and depositing it in any conference evaluation form box. Thank you.

Please tell us a few things about yourself. Circle the categories which best describe you.

Primary Occupation:

1. Social Worker
2. Administrator
3. Nurse Practitioner
4. MR/MH worker
5. Physician's Assistant
6. Criminal Justice/Law Enforcement
7. Nurse
8. Physician
9. Counselor
10. Government
11. Student
12. Therapist
13. Clergy
14. Educator
15. Outreach Worker
16. Advocate/PWA
17. Executive Director/Manager
18. Other

Primary Work Settings:

1. Family Planning/PCAP
2. Minority CBO Agency
3. Community Service Prog.
4. STD Clinic
5. Drug Treatment Clinic
6. Community Health Center
7. Nursing Service
8. Adolescent
9. Health Dept.
10. College/Univ.
11. Adult Care Home
12. AIDS Treatment Ctr.
13. Home Health Agency
14. Prim. Care Clinic
15. Corr. Facility/Jail
16. Diagnostic & Treatment
17. MR/MH Setting
18. Rape/Crisis Ctr.
19. Fire/Rescue
20. Hospital
21. Other _____

Gender: Male Female

Race/Ethnicity:
1. White
2. African-American
3. Latino-American
4. American Indian/ Alaskan Native
5. Asian/Pacific Islander
6. Other _____

Please indicate your degree of agreement with each of these items listed below:

		Strongly Disagree	Disagree	Average	Agree	Strongly Agree
1.	The Conference's format permitted participants to have adequate input into both policy formulation and future directions for programmatic activities?	1	2	3	4	5
2.	The session topics were relevant.	1	2	3	4	5
3.	Time allowed for discussion, question and answers was adequate.	1	2	3	4	5
4.	The Conference and its outcome will impact on government policies and legislative action.	1	2	3	4	5
5.	Do you think that, as a result of this conference, your views will be considered when government policies are made?	1	2	3	4	5

		Strongly Disagree	Disagree	Average	Agree	Strongly Agree
7.	Do you think the Conference and its recommendations will make government more or less responsive to the needs of your clients/patients?	1	2	3	4	5

8. What topics would your like to see on next years conference agenda?

_____

_____

9. Other suggestions/comments:

_____

_____

If you attended past statewide HIV/AIDS Conferences, please complete the following:

		Worse		About the Same		Better
10.	As compared to previous years, the meals were...	1	2	3	4	5
11.	As compared to previous years, the organization of the conference was...	1	2	3	4	5
12.	As compared too the Empire State Plaza, holding the conference at the Omni was...	1	2	3	4	5

Medical Emergencies

Call the following telephone numbers for help and assistance in the event of a medical emergency:

AT THE OMNI (Conference Site)

- Contact any OMNI Hotel Staff person. (They will notify paramedics and an ambulance if required.)

  (You can dial "0" at any house telephone (hotel phone) and ask the operator to contact the Albany Fire Department for medical assistance.)

- Contact any staff person from the AIDS Institute and they can assist with summoning help.

*If urgent or immediate medical care involving HIV disease is needed, go to the **Albany Medical Center Hospital.** 24-hour coverage during the entire conference is available through the **Emergency Department.***

IN THE CITY OF ALBANY

A number of hotels are located in the City of Albany:

OMNI (previously the Albany Hilton)
Econo-Lodge
Thruway Inn
Quality Inn

- Call the front desk and ask for an ambulance. If there is a problem, call for an ambulance directly by calling the following number on an outside line:

Albany Fire Department • 463-1234

IN THE TOWN OF COLONIE

A number of hotels are located in the Town of Colonie:

Best Western (formerly Sheraton)
Holiday Inn Turf on Wolf Road
Days Inn (Wolf Road)
Hampton Inn
Marriott
The Desmond
Red Roof

- Call the front desk and ask for an ambulance. If there is a problem, you can call for an ambulance directly by calling the following telephone number on an outside line:

Town of Colonie Emergency Number • 783-2811

Note: When calling for an ambulance, make sure that you know the exact room number and the name of the hotel. **Do not hang up until the emergency operator tells you he/she has all the necessary information.**

If assistance from a case manager is needed, there is 24-hour coverage through the entire conference. Any AIDS Institute staff person can help you make contact, or page Michael Nazarko by calling 1-800-347-2574. (When the operator answers, ask to page "82762" and give message.)

IMMEDIATE ACTION REQUIRED:
ISSUES ON HIV/AIDS POLICY AND PROGRAMS

AIDS INSTITUTE SURVEY ON TB/HIV EDUCATIONAL NEEDS

The dual epidemics of tuberculosis (TB) and HIV have generated a demand for training at community based agencies, especially for non-medical staff and volunteers who work with clients and population groups at high risk for TB. Although trainings have already been delivered at many agencies, the AIDS Institute wants to ensure that training is available to every agency in the state.

Due to limited resources, there is a need to target trainings to areas in which the need is greater. Please take a few minutes to fill out this questionnaire.

1. The agency you work with is a (please check):

___ Community-based organization
___ Community Health Center
___ Homeless program
___ Hospital
___ Community Service Provider
___ Substance Abuse Treatment Facility
___ Long term care facility
___ Other: _____

2. Your agency is located in (please specify by county): _____

3. What areas related to TB do you feel your agency staff needs training on?

4. Are there other clinical issues besides TB that you need training on?

(Please return to Registration Desk)

Rural Providers Meeting

When: Monday, 12:45 to 1:45 p.m.

Where: Room Two

Bring your lunch.

This is an informal gathering to share ideas, resources and materials that work in rural areas

ANNOUNCING

HIV/AIDS MATERIALS AWARDS PROGRAM

Recognition for contractor developed HIV/AIDS materials!

- **HIV/AIDS materials developed by contractors with AI funds are eligible.**
- **A "call for submissions" will be mailed to contractors each April (first mailing April 1994).**
- **Submissions will be accepted until June 30th each year.**
- **Submissions will be judged at 3 levels- HIV/AIDS educators, target audience focus groups and DOH/AI staff.**
- **Award winners will be notified prior to the Fall AI Statewide Conference. Award winning materials will be showcased at the conference each year.**
- **Award certificates will be presented to winning contractors at each Fall AI Statewide Conference.**
- **The names of award winners and materials' information will be publicized in AI newsletters and through Public Affairs Group (PAG) news releases.**

Please be thinking about HIV/AIDS materials your agency has developed in the past that should be considered for an award or about needed HIV/AIDS materials that your agency could develop.

Details about materials eligibility criteria, how materials will be judged and the materials submission process for the HIV/AIDS Materials Awards Program are available at the Educational Services Section Materials and Information Booth.

COMMISSION ON HUMAN RIGHTS
40 RECTOR STREET NEW YORK, NY 10006
Telephone: (212) 306-7500 TDD (212) 306-7686 Fax (212) 306-7658
DENNIS deLEON, Commissioner/Chair

Statement by Ilka Tanya Payan

October 14, 1993

I want to thank all those people who are here today to support me for saying publicly what I strongly feel should have been said privately, but that because of our social reality, I found imperative to do this way. Thank you again.

It wasn't the fear of transmission or the fact that we had lost over forty members of the Spanish theater community that led me to take the HIV test in 1986. It was my friend, Manolito Martinez, a young, talented actor and director who was, in August of 1986, devastated by AIDS-related complications. Manolito had come into my life from Cuba; he shared a room, clothes, music and laughter with my young daughter. He had a magical way with children, he had charm and musicality. He was the director of a children's theater company. He captivated my daughter. She now is a professional singer. I know that Manolito has left a strong legacy to my family. But that was not the only nexus I had with him -- we had a cosmic relationship. We were both Capricorns, born four days apart the same month, the same year -- he in Havana and I in Santo Domingo. Soon after we met we began to notice that similar events occurred to us almost simultaneously. We were hired for similar jobs at the same time. Once I fell in love with an Assyrian Christian Arab and, no sooner, Manolito had met another Assyrian Christian Arab, whom we later found out was my boyfriend's brother. There were many more coincidences. So, when in 1986 he finally, but reluctantly because he feared my reaction, admitted his condition to me, I had to be tested. The rest is history.

The HIV virus was sexually transmitted to me by a young Puerto Rican artist, whom I respected and loved dearly. It happened sometime between June 1981 and November 1981. Right after the last Fiesta de Loiza Aldea on Randall's Island and Thanksgiving, when I was sworn in as an attorney by a female judge in the Beverly Hills, California courthouse. I did not know at the time that he was or had been an IV drug user. He died a few years ago. He was my last love affair before I met my second husband in 1982.

On January 12, 1982, my dearest friend, Puerto Rican poet Victor Fragoso, also died of AIDS-related complications. Along with his mother and four friends, I traveled with his body from New York to Puerto Rico, where he was buried at the Caguas Cemetery on January 14, 1982. That day I met his nephew, who was destined to become my second husband for seven years, and my friend for life. Love, AIDS, Puerto Rico and gays still seem to have a deep connection to my life.

I am a women living with HIV since 1981, and with knowledge of this since 1986. My husband and I, because we did not know of my condition until 1986, had unprotected sex for almost five years, from 1982 to 1986, when I learned of my status. By mutual consent and with much love and no fears, we continued our healthy sex life with protection. He has never tested positive for HIV. A fact that tempts me to think that perhaps people with HIV don't have to be perceived as human lethal weapons, as some legal charges have sadly attempted to do.

I want to share with you some facts about my present health: I have not developed any opportunistic infections, although I have a very low T-cell count. These are the numbers that are supposed to measure the status of our immune system. I do not take

any chemical or pharmaceutical products for AIDS, I am under natural holistic therapies supervised by an army of naturopathic practitioners -- a Chinese doctor, acupuncturists, masseuses, a hypnotist and an Ohashi practitioner. These health professionals are from Miami, New York, San Juan and Santo Domingo. The traditional medical professionals who provide my allopathic medical care have been deeply and sincerely respectful of my decisions, and I want to acknowledge these forces: they are Amnerys Ley in Miami, Drs. Raymond K. Brown, Rona Vail, Wilfredo Manon Rossi, Jose Fernandez, Li Ying Wu and Ann Stuart all from New York; Drs. Gaspar Encarnacion and Servia Majia Lara from Puerto Rico; Dr. Frank Canelo in the Dominican Republic, my acupuncturist Walter Bosque, my masseuse David Westpal and my acupressurist Gloria Zelaya. To each and everyone of them I owe my present state of good health, but also to an unbending conviction that there is a divine force, that there are natural healing powers within my body, and that I have been lovingly nurtured by family and friends.

It's almost a cliche' by now, among some of us with HIV, to say that we have found a better and new life with this virus. I, personally, can tell you that I have been gradually transformed to health in body, mind and spirit. I have been exposed to human virtues of combat, such as, dignity, strength and courage and I work on cultivating the kind, loving virtues of mercy and compassion. It is indeed a wonderful life I now have sustained, by peaceful knowledge and acceptance of my mortality. I have experienced immeasurable joy by giving, living, sharing and serving others with HIV and AIDS, by receiving the unconditional love of my children and my ex-husband -- Gigi, Elizabeth and Gilberto -- and by the example set by remarkable individuals providing services in institutions like Gay Men's Health Crisis, Gouverneur's Leicht Clinic, Manhattan Center for Living, the Actors Fund, H.E.A.L. and Columbia School of Social Research. Even at government agencies like the

federal Immigration and Naturalization Service and New York City's Department of AIDS Services, I have found in many individual cases that people can act humanely and compassionately.

While speaking of government, I am proud that Mayor David Dinkins appointed me a Commissioner of Human Rights. His administration has been progressive in fighting for the rights of immigrants in New York City and compassionate in reaching out to people with HIV and AIDS. Although I cannot vote because all I have is a green card and a Dominican passport -- I have been a resident of New York City for more than 25 years -- I urge my family and friends to cast their ballot for David Dinkins, who has proven to be a humanist and a devoted public servant.

Aside from local politics, I am really here to share with you the fact that I have learned to gently practice the art of living, and to forcefully struggle against the common predictions of my imminent death and illness. This has made me a very happy woman. But if this is so, why is it, that if I have found all this clarity in my life and all this quietude of spirit on this journey of amazing discoveries with HIV, I am still terrified by the possibility of being found out to be a person with HIV? Why do I, almost irrationally fearful, insist on defending strict laws that will protect the confidentiality of my status? Why does my heart race uncontrollably whenever I suspect that I may be recognized at the clinic where I get my care? Why is it that even as a GMHC staff attorney, an employee of this safe place for people with this condition, I felt afraid of divulging my secret? Why did I die little deaths each time there was a rumor about my HIV status or someone directly confronted me? Finally, why did I suffer excruciating pain when I met a man I thought could be my future partner and I did not know when or how to reveal my condition? What is all this mortifying, horrifying fear in the midst of all this joy of living I am claiming to have found?

I think we all know the answer. Fear of discrimination, fear of rejection, fear of dishonor and disgrace. Why these fears? Because of rampant ignorance, especially in our Latino and immigrant communities, and painfully for me, in my own country, the Dominican Republic. Why this ignorance? Because we have frightfully failed to effectively educate about this epidemic, just like we have identically failed to eradicate it or to find ways in which we can live a full and complete life with HIV.

I cannot presume to have answers as to what we can do to solve the problem of ignorance, intolerance and inhumanity that surrounds us. But we all do know of some urgent things we do need to do: We need to develop better public policies. We need to allocate more monies to better health care services and holistic medical research budgets. We need to update AIDS education methodology and to establish programs that will ultimately eliminate the AIDS mass hysteria, the misinformation, the abuse of domination of people through fear and the greed of the health-related industries.

These major tasks appear before me as too monstrous for an individual with HIV to take on. And that is all I am: an individual with a serious medical condition that has compromised my immune system. Not someone with a religious, moral, social or economic class disorder. As a private persona I have had it! I will now open up the possibilities of acceptance and understanding of my condition. Living in fear does not allow me to do that and I refuse to continue living like this. It is not my style and it will never be. Making this decision has been very difficult. My family in the Dominican Republic fears reprisals. Yet, before their fear as people without HIV, is my fear living with it. I have had to choose not to be silent and frightened anymore. If I continue to do this, it will only mean that I agree with the discrimination. Having to keep this secret is collaborating with the intolerable social

abnormality of treating a health problem as a moral and political issue. I want to give all the people in my life the opportunity to come to me with the privilege of having an opportunity to solve for themselves a serious and confusing social issue of health and discrimination. As a bonus they could get to know the wonderful person I have become because of HIV.

As a public persona I will not become a poster girl or an official spokesperson in the struggle for dignity for people with HIV. I am not a Magic Johnson or an Arthur Ashe. I am choosing a private and personal life to do the things I've always wanted to do--write a book, learn how to sing, slow down the New York rat race for the benefit of my immune system, dance more salsa, and yes, why not, take more seriously the search for a life partner. I can plan all this because I am still alive. I need to continue to live and thrive with my condition, not die of it. In spite of the super struggle to ignore all the news about my impending death and devastation. I sincerely hope that this public act on my part, where I painfully risk hurting my family, will at least serve other people living in fear of disclosure of HIV to make an informed decision about their privacy, and not one based on fear and shame.

This country blows a loud horn about the Declaration of Independence and our right to liberty and the pursuit of happiness. I must say that I find it extremely oppressive and sad to have to resort to this: treating this information as a news item after 13 years of living with this epidemic. There is something simply embarrassing about this. But because of it, it is still the most effective way, in one clean sweep, to be able to tell my family and friends that I am only an individual with a serious medical condition not unlike diabetes, leukemia and other forms of cancer. ***I have the right to my life*** and with this confession, which should have been intimate and private, I have chosen to exercise it.

10/14/93

COMMISSION ON HUMAN RIGHTS
40 RECTOR STREET, NEW YORK, NY 10006
Telephone: (212) 306-7560 TDD (212) 306-7686 Fax (212) 306-7658
DENNIS de LEON, *Commissioner Chair*

ILKA TANYA PAYAN REVELA SU SEROPOSTIVIDAD VIH

No fue la posibilidad de la transmisión del virus, ni la pérdida de un incontable número de amigos desaparecidos a causa de la epidemia, lo que me llevó en agosto de 1986 a hacerme la prueba de anticuerpos del VIH, el virus que supuestamente causa el síndrome de inmunodeficiencia. Tuve que hacerme la prueba por razones que creo estaban mas bien relacionadas con el cosmos. Cuando Manolito Martínez, talentoso actor, cantante y director de teatro infantil, llegó de Cuba y entró en mi vida, inmediatamente se incorporó como miembro de mi familia. Vivió en mi casa compartiendo la hahbitación de mi hija, quien encontró en Manolo un duende celestial que usaba la misma talla de ropa y que, con su capacidad extraterrenal para la gracia y la musicalidad, cautivó a mi hija. Estoy convencida que no es casual el que mi hija haya escogido una carrera musical. La convivencia delicada, amorosa y creadora con Manolito Martínez dejó una deleitosa herencia.

Pero el nexo entre Manolito y yo era mas particular aún. Nacidos bajo el signo de Capricornia, el mismo año, con cuatro días de diferencia, él en la Habana y yo en Santo Domingo, notamos desde un principio que los eventos de nuestra vida se sucedian casi idéntica y simultáneamente: nos caían al mismo tiempo trabajos actorales similares, conocí y me enamoré una vez de un árabe-cristiano descendiente de asirios, y no mucho después Manolito se enamoraba de otro jóven árabe-cristiano descendiente de asirios, que pronto descubrimos era el hermano neoyorquino de mi novio residente en California. Cuando me casé con un hombre más jóven que yo, Manolito esperó pacientemente

hasta mudarse con un jóven que le regaló un perrito miniatura, al mismo tiempo que, sin saberlo, mi esposo me regalaba un perrito shitzu que nunca pesó más de ocho libras. Esas son sólo unas cuantas de las muchas casualidades ocurridas en lo que hoy parecen ser muy pocos años de profunda amistad. Por lo tanto, cuando en agosto de 1986 Manolo, temiendo mi reacción, finalmente pudo confesarme lo que yo ya sabía sobre su salud, me hice la prueba. El resto es historia.

En algun momento, entre finales del mes de junio de 1981 y el mes de noviembre del mismo año, justo entre la última Fiesta de Loiza Aldea en Randalls Island y el Dia de Accion de Gracias, mes en que fuí juramentada como abogada ante una mujer juez en una corte de la ciudad de Beverly Hills, California, el virus VIH me fué transmitido sexualmente por el último novio que tuve antes de casarme por segunda vez. Aquel talentoso y joven artista puertorriqueño, a quién y amé tiernamente, era usuario de drogas intravenosas, algo que yo desconocía. Murió hace unos pocos años de complicaciones relacionadas con el SIDA.

Unos meses despues de terminar esa relación, el 12 de enero de 1982, murió Victor Fragoso, también de complicaciones relacionadas con el SIDA, otro jóven puertorriqueño, poeta, abiertamente homosexual, a quién yo contaba orgullosamente entre mis mejores amigos. Despues de su muerte en el Sloan Kettering Hospital de Nueva York, su madre y cinco amigos residentes en esta ciudad viajamos con su cadáver a Puerto Rico. Fue enterrado en el cementerio de Caguas el 14 de enero. Ese mismo día conocí al sobrino de Víctor, quien estaba destinado a ser ese segundo esposo por más de siete años y mi amigo de toda la vida.

El amor, los homosexuales, Puerto Rico y el SIDA han tenido, y continúan teniendo, una íntima conección con mi vida.

He vivido con VIH desde 1981, y con conocimiento de esto desde 1986. Mi esposo,

con quien tuve relaciones sexuales sin protección alguna por casi cinco años, de 1982 a 1986, porque ambos ignorabamos mi condición, ha sido y continúa siendo negativo a la prueba de anticuerpos del VIH. Esto me indica con más certeza que las historias sensacionalistas en la prensa, que tal vez no sea un arma mortal humana y altamente infecciosa, como temen los que ignoran los hechos sobre esta condición.

La verdadera condición de mi salud es la siguiente: No he sufrido ninguna de las enfermedades oportunistas asociadas con el síndrome, aunque tengo extremedamente bajo el contéo de las Celulas T, las supuestas indicadoras del funcionamiento del sistema inmunológico; no tomo, ni he tomado aún, productos químicos o farmacéuticos para el SIDA, estoy bajo diversos tratamientos naturales supervisada por un ejército de amorosos médicos naturópatas, una doctora china, acupunturistas, masajistas, un hipnotizador y una practicante de digitopuntura. Los médicos y profesionales practicantes de medicina alopata tradicional que me atienden han sido dignos amigos que han respetado mis decisiones acerca del cuidado de mi salud por medios naturales. Aprovecho este medio para agradecerle individualmente a todos y a cada uno de ellos: Amnerys Ley en Miami, los doctores Raymond K. Brown, Rona Vail, Wilfredo Manon Rossi, Jose Fernandez T., Li Ying Wu, Ann Stuart y Pamela J. Dole, todos de Nueva York, los doctores Gaspar Encarnación y Servia Mejía Lara de Puerto Rico, el Dr. Frank Canelo de la Republica Dominicana, mi acupunturista Walter Bosque, mi masajista David Westphal, mi acupresionista Gloria Zelaya y mi hipnotizador Michael Ellner. A cada uno de estos decicados individuos le debo mi presente estado de buena salud, pero se lo debo también a una convicción inquebrantable de que hay una fuerza divina desconocida por nuestra limitada mente humana y unos poderes naturales en mi propio cuerpo para la sanación tanto corporal como espiritual, y se lo debo también a mis familiares y amigos que me han nutrido de amor y de fé.

Desde que conozco mi condición seropostiva me he decidado a practicar el arte de vivir con VIH, dándole frente a una dificultosa lucha para ignorar las terribles predicciones noticiosas de una muerte inmnediata y desgarradora. Me he encontrado con una nueva vida, donde me sostiene el conocimiento y la aceptación pasiva de mi mortalidad. He sido expuesta a las virtudes de combate humano como la valentía, el poder y la dignidad y al mismo tiempo trato de cultivar las virtudes amorosas de la compasión, la miserciordia y la bondad. He encontrado un gozo infinito al compartir, y recibir de otras personas afectadas por el VIH y por el SIDA, al recibir el amor incondicional y el apoyo de mis hijas Gigi y Elizabeth, de mi ex marido, de antiguos novios como el asirio-árabe-cristiano, y de una legión de amigos, amigas y clientes muy especiales. Eso gozo también lo he tenido al estar asociada con los servicios humanos que proveen individuos extraordinarios, que se dedican a servirnos en instituciones como Gay Men's Health Crisis, la Clinica Leicht del Hospital Gouverneur, Manhttan Center for Living, the Actors Fund, H E.A.L, y el colegio de estudios salud de Columbia University. Hasta en agencias gubernamentales como el Servicio de Inmigración y el departamento de Servicios para el SIDA de la ciudad de Nueva York, en muchos casos individuales he tambien encontrado demostraciones de humanismo y compasión ante esta devastadora epidemia.

Pero, a pesar de toda esta aparente felicidad y paz lograda después de siete años aprendiendo a vivir con VIH, esta semana, provocada por una serie de circunstancias personales, me tuve que preguntar seriamente que, ?cómo era posible, que en este nuevo camino abierto para mi por el VIH, que había iluminado mi vida, pudiera aun sentir tanto terror, tanto pánico, ante la posibilidad de que se descubriera mi condición? ?Cómo era que yo aun mantenía un temor irracional que me provocaba a creer en la necesidad de unas leyes estrictas para proteger la confidencialidad de esta condición? ¿Como era que mi corazón latía incontrolablemente ante el pánico de ser reconocida en la clínica donde

regularmente recibo mi atención medica? ?Cómo era que aún en mi posición de abogada, empleada en una organización como GMHC, que presta servicios exclusivamente a personas con esta condición, yo temía revelar la mía? ?Cómo era posible que sufriera una muerte chiquita cada vez que se rumoraba o se me confrontaba con la posibilidad de descubirme? y, finalmente, al estar cara a cara con la posibilidad de haber encontrado a un compañero para mi vida y mi futuro, viví los dias más tormentosos y dolorosos al no saber la respuesta a cuándo y cómo le revelaba mi condición. ?Qué era esa mortificación, ese horrible miedo en medio de toda la profunda felicidad, paz y gozo que hoy declaro he encontrado como resultado del VIH?

Creo que todos tenemos la respuesta: El gran miedo es a esas reacciones acerca del SIDA que todos tenemos cuando lo encaramos. Miedo a ser rechazado, miedo a ser cruelmente discriminados, miedo al señalamiento de infamia y deshonra. Pero ?Porque tenemos estos temores? Porque la ignorancia sobre esta epidemia es vergonzosa, especialmente en nuestras comunidades latinas e inmigrantes y, tristemente para mi, en mi propio pais, la República Dominicana. Y, ?Porque existe tanta ignorancia? Porque hemos fallado de una manera espantosa al no proveer la educación necesaria sobre este problema de salud, al igual que hemos fallado al no encontrar en 13 años, que lleva esta epidemia devastando a nuestra juventud, a nuestras mujeres, a nuestros niños, una cura o una esperanza de vivir una vida plena conviviendo con esta condición.

Yo no pretendo proveer una respuesta que solucione esta terrible situación. Solo se que es obvio -- que se cae de la mata, como decimos en nuestro deliciosa lengua -- que se necesita desarrollar una política pública efectiva, se necesita aumentar los presupuestos de servicios de salud y de investigación de tratamientos naturales, se necesita poner al día la metodología educativa sobre el SIDA. Hay que crear los medios para que finalmente eliminemos la histeria masiva, la falta de información, el abuso que

crea la dominación de la gente por medio del miedo, y la avaricia de las industrias de la salud.

Todas estas son tareas demasiado monstruosas para que una persona con VIH pueda emprenderlas. Y esto es lo que yo simplemente soy: Una persona que vive con VIH, que claramente no está muriendo de VIH. Una mujer sana, excepto por esta condición, que ha decidido que no va a vivir en secreto el papel equivocado que la sociedad quiere imponer: de pecadora, víctima o enferma aterrorizada. Valga esta aclaración. Yo tengo una seria condición médica, que afecta mi sistema inmunológico, pero definitivamente no tengo un desórden de órden religioso, moral o de clase social. Por lo tanto, no me ha quedado otra opción que la de divulgar mi condición médica. No voy a continuar colaborando con mi silencio y con mi miedo a que se preserve y se perpetúe esta injusta e innecesaria anomalía social, tan inhumana e intolerable.

Mi persona privada se hartó ya de esta situación. Y es con profunda humildad que pretendo con esta acción quizás crear posibilidades a los que son parte de mi vida privada para que acepten y comprendan mi condición. Ojalá tambien la de otros tantos miles y miles de seres con VIH que viven en estado de opresión y pánico en nuesta sociedad. Creo que sólo así puedo retomar las riendas de mi vida. Rehuso vivir con secretos y temores sin fundamento, no ha sido mi estilo de vida ni lo será jamás. Espero tambien que desde ahora, cualquier persona que se acerque a mí, entienda que al relacionarse conmigo la vida le está ofreciendo el privilegio de encarar y tal vez resolver consigo misma un importante y serio problema social de salud y discriminación que es endémico en esta sociedad. Voy a tener la arrogancia de tambien predecir que al mismo tiempo tendrán otro privilegio, el de conocer a la hermosa persona en la que me he converido como resultado de mi relación con el VIH. Estas oportunidades y posibilidades no las tendríamos en un ambiente de misterio y temor. Un peso enorme y desgarrador se ha

desprendido de mis hombros con esta decisión.

Como persona pública, no voy a dedicarme a ser vocero oficial en la lucha por la dignidad de las personas con VIH o SIDA. No soy Magic Johnson ni Arthur Ashe. He llevado esta labor en los ultimos años. Hoy decido escojer mi vida personal y privada y llevar a cabo proyectos íntimos como escribir un libro de cocina en honor a cuatro generaciones de mujeres dominicanas: mi abuela, mi madre, mi hija y yo. Me gustaría aprender a cantar, bailar más salsa, reducir la velocidad de una vida en Nueva York, y sí, porque no, tomar mas en serio la búsqueda de un compañero para el resto de mi vida. Felizamente puedo hacer estos planes porque aun estoy viva.

Declaro nuevamente que hago esta confesión, que continúo creyendo es de índole muy personal, con la única esperanza de que, al divulgarla, pueda inspirir a otros en situaciones similares a que hagan decisiones sobre su privacidad de una manera informada y no bajo el velo cegador del miedo y la verguenza.

Este país dice ofrecer el derecho a la libertad y a la búsqueda de la felicidad, pero temo decir que se hace extremadamente opresivo y triste el tener que aceptar que todavía, despues de trece años de esta epidemia, se tiene que tratar este tema como si fuera noticia. Pero esta es la realidad: Sin lugar a dudas, la forma en que lo estoy haciendo sigue siendo la mas efectiva para dejarle saber a todo aquel a quien verdaderamente le importe, de una sola vez, que como persona viviendo con VIH soy, vuelvo a repetir con sólida convicción, un ser humano con una condición médica que seriamente ha comprometido mi sistema inmunológico, muy parecida a la diabetis, la leucemia o cualquier otro tipo de cáncer. Tengo derecho a mi propia vida, y con esta confesión estoy ejerciendo este bién-ganado y herederado derecho humano.

14 octubre 1993

THE CITY OF NEW YORK
OFFICE OF THE MAYOR
NEW YORK, N.Y. 10007

October 14, 1993

Honorable Ilka Tanya Payan
Commissioner
New York City Commission on Human Rights
40 Rector Street
New York, New York 10006

Dear Commissioner Payan:

I commend and respect your courageous decision to reveal your HIV status.

Your determination to illustrate that people with HIV are productive members of society will serve as a source of inspiration to all, but particularly to the women and members of the Latino community who are struggling with the terrible impact of this disease. You will serve as proof that people with HIV are the professionals we work with, the public officials who serve the community, the advocates who fight for our rights, the neighbors we trust, and the friends and family we love.

I am proud to have appointed you to the City's Human Rights Commission. I knew then that you brought a wide array of talents and experience as an actress beloved by thousands of Spanish-speaking New Yorkers, as an ardent activist fighting discrimination against immigrants and people with HIV, as an attorney working in civil rights law, and as a Latina dedicated to the cause of justice for all. You have served the Commission with great vigor for the cause of fairness. You symbolize the diversity and tolerance that makes New York City great.

I look forward to continue working with you in your role as a Human Rights Commissioner and in your fight against HIV. I wish you well. Keep the faith!

Sincerely,

David N. Dinkins
MAYOR

I M A N

INTER-CITY MUSLIM AIDS NETWORK

Anyone interested in issues relating to Muslims and AIDS is invited to attend the IMAN* meeting on Monday, November 15, from 12:45 to 1:45 in Meeting Room 4.

This will be an opportunity to review IMAN's activities, help set goals for the future and identify needs to address.

Please pick up your box lunch and bring it to the meeting, so we can talk over lunch.

**IMAN is a voluntary network of Muslims who are concerned about the impact of HIV and AIDS in their community and non-Muslims who provide services to Muslim and share these concerns.*

REGIONAL COMMUNITY EDUCATION COMMITTEE MEMBERS:

You are invited to a meeting/ reception with your fellow members from across the state.

*Compare notes on activities

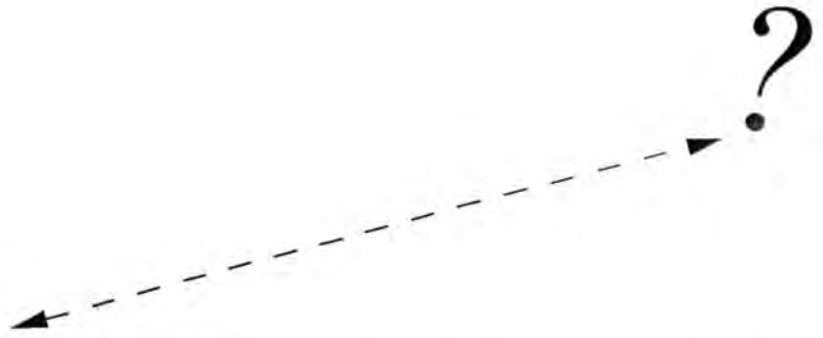
*Meet the staff who work behind the scenes

*Find out about the changes in the facilitation of the Regional Meetings

*Give us feedback on your Regional concerns

WHERE: Meeting Room 4

WHEN: Monday, November 15, 5:30-6:30



What about

Health Care Reform & People Living With HIV?

3 Corners Community Initiative, Inc., Hosts

A PUBLIC FORUM

At the The 4th Annual Statewide HIV / AIDS Policy Conference

Monday, November 15th, 1993

~ 12:45 to 2:00 pm - Ballroom C, Omni Albany Hotel ~

12:45 - **Opening & Overview** - Darren Britton, Moderator
3 Corners Board of Directors, president

12:50 - **Options for Reform: Single Payer and the Clinton Plan**
- M. J. Van Loon, RN, MPH, 3 Corners Board of Directors
Village Nursing Home, & The Association of Nurses in AIDS Care

1:05 - **What about HIV Care in Health Care Reform?**
- Karin Timour, Director of Education, Body Positive

1:15 - **HIV+ Women's Issues in Health Care Reform**
- Sue Simon, Planned Parenthood of New York (tbc)

1:25 - **What are New Yorkers doing about Health Reform *now*?**
- Mark Hannay, Policy Department, Gay Men's Health Crisis

1: 35 - **Open Discussion**

Anyone attending the New York State Department of Health AIDS Insitute Statewide HIV / AIDS Policy Conference in Albany is welcome and encouraged to attend this forum with brief presentations followed by Questions & Answers. Pre-registration is not required, but space is limited to 90 people. **Pick up your box lunch, & come to BALLROOM 'C'.**

Organizing Social Hour

~ 5:30 to 6:30 - Ballroom C, Omni Albany Hotel ~

Δ An organizing & networking social hour will be held later, also in **Ballroom C**. Light healthy refreshments will be served. These sessions are sponsored by 3 Corners Community Initiative, Inc., 121 West 20th Street, Suite 3C, New York, NY 10011-3600. (212) 727. 9579.

The Board of Directors of 3 Corners would like to express our sincere gratititude for the generous, anonymous donation that made these sesssions possible. 3 Corners, Inc., is a fully tax exempt public charity under IRS 501(c)3.

Networking Reception Meeting

for

All those interested in HIV Infection Among Women who have Sex with Women

♀♀♀♀♀♀♀

Monday November 15th, 1993
5:30-6:30

Meeting Room 2

Refreshments will be served

Co-sponsored by:
AIDS Institute and
Bronx Lesbian AIDS Task Force

ATTENTION!
THE CASE MANAGEMENT RECEPTION WILL BE ON

MONDAY, NOVEMBER 15
FROM 12:45 - 1:45
IN THE OMNI BALLROOM D

(The date was erroneously listed as 11/16 in the letter of invitation.)

THE WHITE HOUSE

WASHINGTON

November 10, 1993

Hope Goldbaer
New York Department of Health
AIDS Institute
Room 384 Corning Tower
Albany, NY 12237-0658

Dear Hope:

This letter confirms Kristine Gebbie's appearance at the New York State Conference on "Issues on HIV/AIDS Policy and Programs" on Sunday, November 14, 1993 in Albany, NY at the Omni Hotel.

Ms. Gebbie will arrive on USAir Flight 438 at 3:50 p.m. and will be driven to your event by Darren Britton. Her speech, "AIDS Policy: A National Perspective," will begin at approximately 6:00 p.m. and you will see that she gets to the Albany Airport in time for her 7:50 p.m. flight.

Please call me at (202) 632-1090 with any questions or for further clarification. I am enclosing a biographical sketch and curriculum vitae for your reference. Thank you for your work on this event and the best of luck with the conference.

Sincerely,

W. Steve Lee

W. Steve Lee, Executive Assistant to
National AIDS Policy Coordinator

Enclosure

STATE OF NEW YORK - DEPARTMENT OF HEALTH

AIDS INSTITUTE FAX

GOVERNMENT RELATIONS & STRATEGIC PLANNING
ROOM 384 CORNING TOWER
EMPIRE STATE PLAZA
ALBANY, NEW YORK 12237-0658
PHONE: (518) 473-8484
FAX: (518) 486-1317

12 PAGES TO FOLLOW

TO: Steve Lee

FROM: Hope Goldhaber

DATE: 10/29/93

_____ AS REQUESTED

_____ REVIEW AND COMMENT

X AS DISCUSSED

_____ FOR YOUR INFORMATION

COMMENTS:

STATE OF NEW YORK
DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.
Commissioner

Paula Wilson
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH
Lloyd F. Novick, M.D., M.P.H.
Director
Diana Jones Ritter
Executive Deputy Director

October 29, 1993

Steve Lee
750 17th Street NW
Suite 1060
Washington, DC 20500

Dear Mr. Lee:

We are honored that Kristine Gebbie has agreed to present at our fourth annual HIV/AIDS policy conference on Sunday, November 14, 1993. As requested, I have enclosed informational materials on this three day event.

Allow me to confirm with you that Ms. Gebbie will arrive in Albany on Sunday afternoon (arrival time to be determined). We will arrange to have someone from the AIDS Institute meet her flight and transport her to the conference site, the Omni Albany Hotel, approximately 15-minutes away. Participants will be seated for dinner at 6:00 PM, and we ask that Ms. Gebbie present at approximately 6:45 PM. This would leave ample time for Ms. Gebbie to be escorted to the airport for her return flight at 7:50 PM.

Please forward to me a biography or introduction for Ms. Gebbie and a list of any audio/visual equipment she will need. You are welcome to include an item in our registration packet or in our press release, if applicable.

I can be reached at (518) 473-8484 and my fax number is (518) 486-1317. Please contact me if I can be of further assistance. Thank you.

Sincerely,

Hope Goldhaber
Conference Coordinator
NYSDOH AIDS Institute

IMMEDIATE ACTION REQUIRED:

Issues on HIV/AIDS Policy and Programs

IMMEDIATE ACTION REQUIRED:

Issues on HIV/AIDS Policy and Programs

About the Conference

The HIV/AIDS epidemic has become a pandemic of global proportions. New York State remains the epicenter of the United States, with more than 59,000 cumulative AIDS cases and the nation's highest numbers of new cases. Moreover, HIV/AIDS has manifested itself in New York as several epidemics, affecting gay/bisexual men, IV drug users, women, children, and adolescents. The impact of this disease has been felt in all communities, across racial, ethnic and cultural lines.

The spread of HIV/AIDS throughout New York State presents extraordinary challenges in the areas of policy development, program implementation, and funding of services. The New York State Department of Health AIDS Institute, the lead agency for coordinating the State's response, faces a health crisis that is a moving target. New issues and concerns arise that demand innovative thinking and creative planning. Other issues that had seemed resolved take on new twists, requiring a reevaluation of past approaches.

The Fourth Annual Statewide HIV/AIDS Conference will spotlight these "hot topics" in a series of plenary sessions and workshops.

Emerging issues:

- Health care reform and its implications for HIV/AIDS services;
- New Federal regulations affecting disability coverage for people with AIDS;
- Heterosexual intercourse surpassing IV drug use as the primary HIV risk factor for women;
- Lesbians and HIV/AIDS;
- Children orphaned by AIDS

Issues that have taken on new dimensions or have resisted resolution:

- AIDS treatment research in the wake of the Concorde study of AZT;
- A second wave of HIV infection among gay/bisexual men, especially young men and men of color, and "relapse" into unsafe sex;
- Guidelines for the treatment of HIV-infected women;
- HIV screening of newborns;
- Harm reduction, including needle exchange, for drug injectors;
- HIV reporting issues;
- HIV education in public schools

The conference format will promote information exchange, debate, and strategic planning. Participants are urged to express their opinions and share their experiences in their chosen sessions. As in the past, such active involvement will directly contribute to the shape of future HIV/AIDS policy and programs.

Who Should Attend

The conference seeks participants from all levels of government and elected officials; health care, substance abuse treatment, and other HIV service providers; HIV educators and other community-based providers; AIDS advocates; representatives of the private sector, the media, and religious groups; and persons living with, or affected by HIV/AIDS.

Speakers

Invited speakers include political leaders, government officials, HIV health care and community-based service providers, AIDS educators and advocates, and persons with HIV/AIDS. All invited speakers possess unique qualifications and have extensive experience in the subject areas they will address.

PWA Informal Gathering

People with HIV/AIDS, their significant others, and their families are invited to attend a pre-conference meeting from 11:30 A.M. to 1:30 P.M. on Sunday, November 14, 1993. This session will be organized by PWAs for conference participants to meet each other, review the Sunday afternoon PWA Address, learn more about the conference, and strategize about their contribution to the plenary sessions and workshops. Information will also be provided at the informal gathering about access to emergency care in the Albany area and other conference services available to HIV-infected participants. To register for this session, please call, or ask your HIV service agency to call, (518)473-8484.

Networking Sessions

Free meeting space is available during the conference to persons who wish to meet with others in their specific field or coalition. Advertisement and refreshments are the sole responsibility of the host organization and must be coordinated with the AIDS Institute. No solicitation or product demonstrations will be permitted. If your organization would like to host a network session or reception, please call (518)473-8484.

60's Dance Party!!

You've worked hard - now play hard. Take a break, recharge and let loose with friends old and new on Monday night after the dinner program. "Fun" is the only key word you need to know. Absolutely everyone is welcome. Details to be announced in the final program.

November 14, 15, & 16, 1993

Location

The Fourth Annual Statewide HIV/AIDS Conference will be held in downtown Albany at the Omni Albany Hotel. Recently and beautifully renovated, this facility, the former Albany Hilton, is now home to a new restaurant, gift shop, and expanded meeting center. Conference participants will enjoy the benefits of having every workshop and activity in close proximity. The Albany Medical Center (an AIDS Designated Care Center), 10 minutes off-site, is able to provide a full spectrum of HIV/AIDS medical services including urgent and emergency care.

Travel

By Plane: Albany County airport is located 15 minutes by car from the conference site. For travel on USAir to Albany, from the Continental US, Canada, The Bahamas and San Juan, between November 11 and 19, conference participants are eligible for discounted airfares. Contact Phillips World Travel at (518) 383-0100; they will be happy to arrange your flight.

By Bus: Albany's bus depot is four blocks from the conference site. Call your major bus company of choice for information on transportation services to this terminal. Local bus service is provided by the Capital District Transportation Authority (CDTA). Schedule information will be available on-site or call CDTA at (518) 482-8822.

By Train: Amtrak provides direct inter-city rail passenger service to Albany from several New York cities. The station is located in Rensselaer, NY, a 10 minute drive to the conference site. The conference shuttle will meet trains arriving on Sunday between 11:00 AM and 1:30 PM, and carry passengers to the Omni Albany Hotel. Phillips World Travel can help you obtain the lowest Amtrak fare possible; call (518) 383-0100.

By Car:

From New York City and points South: Take I-87 North (NYS Thruway) to Exit 23. Proceed on I-787 North, exit at Route 20 West (Downtown Albany), turn right onto Broadway, left onto State Street, right onto Lodge Street.

From points North: Leave I-87 South (Adirondak Northway) at Exit 1E, proceed East on I-90 toward Albany. Exit at I-787 South. Exit at Clinton Avenue. At second light, take left onto North Pearl Street, right onto State Street, right onto Lodge Street.

From points West: Take the NYS Thruway East to Exit 24, continue East on I-90, exit at I-787 South. Exit at Clinton Avenue. At second light, take left onto North Pearl Street, right onto State Street, right onto Lodge Street.

From points East: Due to construction on I-90 West at the Patroon Island Bridge (the interchange between I-90 and I-787), it is suggested that travelers take the Thruway Spur from I-90 East to Exit 21A, then proceed North on the Thruway to Exit 23. Proceed on I-787 North, exit at Route 20 West (Downtown Albany), turn right onto Broadway, left onto State Street, right onto Lodge Street.

Parking: Free parking validation will be available to conference participants using the Omni Albany Hotel's parking garage.

Shuttle Service: Shuttle bus service will be provided on a limited schedule from the Amtrak Station to the Omni Albany Hotel and from the Omni Albany Hotel to outlying hotels. If you wish to use this service, you must complete the shuttle service section of the registration form. Shuttle service requested on-site is not guaranteed. There is no additional fee.

Lodging

A limited number of rooms have been reserved for conference participants. Hotels will accept telephone registration. MAKE RESERVATIONS BY THE DATE INDICATED TO RECEIVE THE RATES LISTED BELOW AND SAY THAT YOU ARE REGISTERING AS PART OF THE NYS DEPARTMENT OF HEALTH AIDS INSTITUTE CONFERENCE. All listed hotels offer on-site parking and a limited number of non-smoking or handicapped-equipped rooms. Contact the hotel of your choice directly for information regarding check-in/check-out times, required deposits, cancellation policies and complimentary transportation to the airport. Tax exempt certificates are required at check-in.

HOTEL	Indoor Pool	In-room Fridge	Distance (from conference)	Rates	Reserve By	Wheelchair Accessible
Omni Albany Hotel State and Lodge Streets Albany, New York 12207 1-800-THE-OMNI 518-462-6611	Yes	Upon Request	On-Site	s=$89 d= 99	11/1	Yes
Econo-Lodge 300 Broadway Albany, New York 12207 1-800-333-1177	No	Upon Request	5 Blocks Uphill	s=$46 d= 51 t= 57 q= 62	10/31	No
Best Western (formerly Sheraton) Albany Airport Inn 200 Wolf Road Albany, New York 12205 518-438-1000	Yes	No	15 min by car	s=$63 d= 73 t= 83 q= 93	10/21	Ground Floor Only
Holiday Inn Turf on Wolf Road 205 Wolf Road Albany, New York 12205 518-458-7250	Yes	Upon Request	15 min by car	s=$85 d= 85	10/25	Yes
Thruway Inn 1375 Washington Avenue Albany, New York 12206 518-459-3100	No	No	15 min by car	s=$49 d= 54 t= 59	11/5	Ground Floor Only

A Special Thank You to Our Sponsors:

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IMMEDIATE ACTION REQUIRED:

Issues on HIV/AIDS Policy and Programs

Sunday, November 14

12:00 - 6:30 PM Registration and Information
Preview Exhibits

2:00 - 3:30 PM ***Opening Session***
Welcome
Insights and Perspectives

3:30 - 4:30 PM ***PWA Address***
This traditional conference program provides an opportunity to hear those most affected by the epidemic present their perspectives on the impact of HIV/AIDS.

6:00 - 8:00 PM **Dinner**

Keynote Address

8:00 PM ***Candlelight Ceremony***
Light a candle during this uplifting event to signify the common goals we share and our unified efforts in the battle against HIV/AIDS. A brief ceremony will be held to commemorate those we lost to this devastating disease and to inspire renewed strength and vigor for our continuing fight. An area prohibiting photographs will be designated.

Monday, November 15

7:30 AM - 6:00 PM Registration and Information

9:00 - 10:30 AM ***AIDS Institute Address***
AIDS Research After Concorde
The Concorde Study raised questions about the direction and structure of AIDS research in the United States. Will current research mechanisms give us answers fast enough? Are we asking the right questions? Discussion will focus on the problems with the current research effort and ways it might be improved.

10:30 - 11:00 AM Break

11:00 - 12:30 PM **Concurrent Workshops**

A. Mothers and Infants: How and When to Test for HIV
This session will explore the issue of testing newborns for HIV infection. Among the topics to be covered will be the controversial issue of mandatory newborn testing.

B. Men on Men: Closing the Generation Gap
The next wave of new HIV infections in the gay/bisexual population will be among men under 30. This session will examine sexual risk-taking among younger men and present cutting edge prevention strategies.

C. Men on Men: Rainbow Prevention
HIV services for gay/bisexual men of color must take into account race, class, and culture as well as sexuality. Are current programs appropriately serving these men?

D. Men on Men: Safer Sex/Healthy Sex
Why do some men-who-have-sex-men find it difficult to consistently practice safer sex? AIDS educators will offer some answers and will present new anti-"relapse" strategies.

E. Continuous Quality Improvement (CQI) of Clinical Care
A forum for discussion of CQI with emphasis on the use of AIDS Institute Quality of Care Program reviews in the development of QOC programs by HIV providers. Audience participation will be encouraged.

12:30 - 2:00 PM **Box Lunch**

2:00 - 3:30 PM **Concurrent Workshops**

F. For Her Own Good: Women and Men Keeping Each Other Safe
This session will focus on issues involved in shaping an HIV prevention message and developing a strategic response to the rise in heterosexual transmission. The first segment will provide an update of the impact of AIDS on communities of color as felt by heterosexual couples and family units. The second segment explores how men and women negotiate gender roles and safer sex practices. Discussants will review questions such as how the FDA approved female condom fits into the range of personal protection choices for women and how prevention messages for men and women should differ. Women's concerns about disclosing their HIV status to present and former lovers/husbands will be the focus of the third segment, including the threat of domestic violence.

G. AIDS Orphans and Their Families — Another Epidemic in New York State
The results of a recent study conducted by The Orphan Project will be presented. This study estimates that 30,000 children and adolescents will be orphaned by AIDS in New York City by the year 2000. Panel participants will also describe service models that reach these children, adolescents and their families addressing permanency planning, legal assistance, bereavement counseling, and supportive service needs.

H. HIV Infection among Women Who Have Sex With Other Women
This session will discuss HIV issues for women who partner with other women, whether self-identified as lesbian/bisexual or not. Panelists will review recent data indicating that significant numbers of HIV infected women have (or have had) sex with other women, and discuss risk behaviors and service needs for this diverse population.

I. AIDS Activism: Where to From Here?
After years of successes and failures, AIDS activists are asking questions. What's the

SCHEDULE OF EVENTS

best strategy for change: working on the "inside" with governmental officials, or staying on the "outside," using street tactics to continue building the grassroots movement? Panelists representing both points of view will discuss the future of AIDS activism.

J. Alternative Therapies for Drug Addiction and HIV

Topics to be discussed include: acupuncture; massage; healing and recovery; and nutrition.

3:30 - 4:00 PM Break

4:00 - 5:30 PM **Concurrent Workshops**

K. Managed Care, AIDS and Access to Care

Persons living with HIV/AIDS, providers of services and policymakers will discuss their experiences with managed care systems and the future of AIDS services in a managed care environment. Will access to comprehensive, quality care be assured? What are the implications of managed care for delivery of services? What can the AIDS community do to effectively address these issues?

L. Needle Exchange: A Primary AIDS Prevention Strategy

This workshop will include a discussion of the various harm reduction and needle exchange models operating in New York State, an update of the first year evaluation of these programs, and future directions.

M. HIV Prevention Education in Our Schools - - Where Have We Been, Where Are We Going?

This workshop will provide a unique blend of panelists who will provide participants a glance at where New York State is in planning, implementation and formation of linkages needed to deliver HIV prevention education in our schools. Special emphasis will be placed on the role of the community provider, parents/guardians and adolescents in shaping the direction of local districts.

N. SSI and SSDI: Will the New Regs Make it Easier to Qualify?

The new HIV listings that are used by Social Security to determine eligibility of people with HIV infection for SSI and SSDI will be discussed.

O. Are PWAs the Best Service Providers?

This workshop will look at the role PWAs play in today's AIDS service organizations. Are their voices being heard? Are their demands being met? How do we increase their role in setting the agenda of all service providers? Representatives from various organizations will take part in an open discussion of these issues.

6:30 - 7:30 PM **Reception**

7:30 - 9:30 PM **Dinner**
Dinner Speaker
Award Ceremony

Tuesday, November 16

8:00 AM - 12:30 PM Registration and Information

9:00 - 10:30 AM ***TB and HIV Plenary***

In the past ten years, tuberculosis (TB) has re-emerged as an important communicable disease, occurring more frequently today in both the general population and in people with HIV infection. This session will review the TB/HIV epidemic with emphasis on epidemiology and impact on health care programs and prevention activities. Background information for the TB/HIV workshops at 11:00 AM will be provided.

10:30 - 11:00 AM Break

11:00 AM - 12:30 PM **Concurrent Workshops**

P. TB and HIV: What Community Based Providers Need to Know

This workshop is designed to provide information about TB and TB transmission, the effect of TB on people with HIV and the community at large and strategies for reduction in TB transmission in community based HIV programs. Participants are encouraged to discuss the concerns of their particular organizations.

Q. TB in Health Care Settings

This session will present current guidelines for infection control with an emphasis on practical applications in health care facilities and agencies. Participants are encouraged to discuss the concerns of their particular facilities.

R. Components of Comprehensive Clinical Care for Women

Women comprise the fastest growing segment of the population affected by the HIV epidemic — there has been more than a seven-fold increase in the number of reported AIDS cases among women in New York State since 1987. This workshop will include presentations on the clinical care of HIV infected women, including the recent CDC guidelines, a summary of clinical trials for women and results to date, and examples of comprehensive service delivery models for women.

S. HIV Reporting

The CDC continues to promote HIV name reporting as the "gold standard" of HIV/AIDS surveillance. This session will explore the policy implications of CDC's position for New York State.

CONFERENCE REGISTRATION:

Questions? Call (518) 473-8484

Registration Fees

Full	$150.	Includes conference materials, two continental breakfasts, box lunch, two dinners, shuttle service and participation in all sessions.
Monday Only	$ 75.	Includes conference materials, continental breakfast, box lunch, dinner, shuttle service, and participation in sessions offered on Monday, November 15.
Sunday OR Tuesday Only	$ 45.	Sunday Registration includes conference materials, dinner, shuttle service, and participation in sessions and activities offered on Sunday, November 14. Tuesday Registration includes conference materials, continental breakfast, shuttle service and participation in sessions offered on Tuesday, November 16.
Group Rates		
Full	$135.	Four or more staff/clients from the same agency, submitting registrations at the same time with total payment, are eligible for this discounted full conference rate per person.

All registrations must be postmarked by October 22, 1993.

Late Registration

Registrations **postmarked after October 22 or paid on-site** are considered late registrations and participants will be charged as follows:

Full:	$200.
Monday Only:	$100.
Sunday OR Tuesday Only:	$ 60.

There are no Group discounts after October 22.

Payment

ONLY checks or money orders payable to **Health Research, Inc.** will be accepted as payment of the registration fee. NO VOUCHERS OR PURCHASE ORDERS WILL BE PROCESSED OR HONORED AS PAYMENT OF REGISTRATION FEE. Participants will not be registered until payment is received. Certification of registration payment for reimbursement purposes is available upon request.

Cancellation

Cancellation of conference registration must be made in writing and postmarked by October 22, 1993 for a full refund. Written cancellations postmarked between October 22 and November 7 will be refunded at 50% of fee. Refunds will not be made to participants who cancel after November 7 or who register but do not attend.

PWA Scholarship Program

A limited number of scholarships are available for PWAs across the state. Each scholarship recipient is afforded lodging, a waiver of the registration fee and is reimbursed for travel expenses. Scholarships are awarded by lottery from a pool of nominated candidates, and are available only to PWAs. For information on how to nominate a PWA from your region, please call (518) 473-8484.

Registration Form

Instructions: Please type or print clearly all information. Use one form per registrant; photocopies accepted. Space is limited. In order to guarantee your participation, please return your registration with payment, postmarked by October 22, 1993, to: Health Research, Inc., HIV/AIDS Statewide Conference Registration, Corning Tower Room 359, Empire State Plaza, Albany, New York 12237-0658, Attn: Hope Goldhaber.

Employees of the NYS Department of Health, Conference Speakers, or Scholarship Candidates should NOT use this form. Please call (518)473-8484 for the correct registration form.

NAME: _____
(as to appear on name badge)

TITLE/POSITION: _____

AFFILIATION: _____
(as to appear on name badge)

ADDRESS: _____

PHONE: (____)_____ FAX: (____) _____

SESSION REGISTRATION:

Please refer to the Schedule of Events for workshop titles and descriptions. **Check one session in every column.** If left blank, workshops will be chosen for you. Workshop changes requested on-site will made to the extent possible but are not guaranteed.

Monday , November 15

11:00 AM - 12:30 PM

	1st choice	2nd choice
A.	___	
B.	___	
C.	___	
D.	___	
E.	___	

2:00 - 3:30 PM

	1st choice	2nd choice
F.	___	
G.	___	
H.	___	
I.	___	
J.	___	

4:00 - 5:30 PM

	1st choice	2nd choice
K.	___	
L.	___	
M.	___	
N.	___	
O.	___	

Tuesday, November 16

11:00 AM - 12:30 PM

	1st choice	2nd choice
P.	___	
Q.	___	
R.	___	
S.	___	

Shuttle Service Requested?

❑ Yes From Omni to Which Hotel? _____
❑ No

Special Arrangements Required?

❑ Yes Check materials and services needed (guaranteed only if registration postmarked by October 22).

____ Interpreter Services
Specify: oral, ASL, voice, signed English

____ Assistive Listening Devices
Specify: audio loop, FM system

____ Printed Materials
Specify: large print, braille, cassette

____ Wheelchair Use On-site

____ Wheelchair accessible transportation

____ Dietary Requirements
Specify: _____

❑ No

Check or Money Order enclosed for:

❑ **Registration**
____ Full registration, postmarked by October 22, 1993
____ single - $150.
____ group - $135. per person, for groups of four or more.
____ Sunday Only $45.
____ Monday Only $75.
____ Tuesday Only $45.

❑ **Late Registration, postmarked after October 22 or paid on-site**
____ Full $200.
____ Sunday Only $ 60.
____ Monday Only $100.
____ Tuesday Only $ 60.

I will attend (check all that apply):
❑ Sunday Dinner 11/14 ❑ Monday Lunch 11/15
❑ Monday Dinner 11/15

Total Enclosed: _____
(if applicable, use group total)

IMMEDIATE ACTION REQUIRED:

Issues on HIV/AIDS Policy and Programs

The Fourth Annual Statewide HIV/AIDS Policy Conference November 14 - 16, 1993 at the Omni Albany Hotel

Tuesday, November 16, 11:30 - 1:00

V. PARTNER NOTIFICATION: INCREASING THE OPTIONS

This workshop will present an overview of existing partner notification options with an emphasis on the process and desired outcome. Innovative partner notification strategies developed and implemented in community based settings will be described including PNAP, CNAP and physician disclosure. A client who has accessed these services will share their experience. The audience will be encouraged to join in a discussion of issues such as access and confidentiality.

Two Workshops Are Revised:

Monday, November 15, 2:00 - 3:30

J. ALTERNATIVE APPROACHES TO WORKING WITH & CARING FOR HIV INFECTED CLIENTS IN DRUG TREATMENT

The focus of this session will be on alternative and unorthodox approaches to working with recovering clients who have the additional stressors of a positive serostatus. Speakers will present their experiences conducting innovative projects with recovering users in treatment. Topics to be covered include holistic approaches to care, acupuncture, and cultural/spiritual aspects. The second half of the session will break into discussion groups on these topics.

Tuesday, November 16, 11:30 - 1:00

Q. COORDINATION OF CASE MANAGEMENT FOR TB PATIENTS

This informational workshop will provide participants with an understanding of the full continuum of care available and necessary for the successful management of TB patients. Panelists from institutional and community based programs will discuss techniques for coordination among agencies, integration of TB and HIV services, and review case management responsibilities by responding to specific questions from the moderator and the audience.

NETWORKING OPPORTUNITIES

Be sure to take the time to meet with those who share your interests. Already scheduled are networking sessions for rural agencies; a discussion on AIDS treatments; regional community education members; the Intercity Muslim AIDS Network; and more.

ATTENTION NON-PROFIT EXHIBITORS!

Burroughs Wellcome Company has once again provided a corporate endowment to assist non-profit agenices with the exhibition rental fee. Please call (518) 473-8484 if you would like to apply for this program.

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IMMEDIATE ACTION REQUIRED:

Issues on HIV/AIDS Policy and Programs

The Fourth Annual Statewide HIV/AIDS Policy Conference
November 14 - 16, 1993 at the Omni Albany Hotel

HAVE YOU REGISTERED?

Pre-registration ends October 22nd!! Don't miss your opportunity to join 1,000 of your collegues in addressing some of the most critical AIDS policy issues.

Speakers Include:

Kristine Gebbi
National AIDS Policy Office

Larry Kramer
AIDS Activist & Playwright

Gabriel Torres, MD
St. Vincent's Hospital

Nancy Mahon, Esq
The Correctional Association

Zena A. Stein
The HIV Center for Clinical & Behavioral Studies

John Wright
Safe Space/Center for Children and Families

Chuck Frutchey
San Fransico AIDS Foundation

Donna Futterman, MD
Montefiore Medical Center

Carol Levine
The Orphan Project

Mark R. Chassin, MD
NYS Department of Health

David E. Rogers, MD
AIDS Advisory Council

Andrew Humm
Hetrick Martin Institute

Carolyn Britton, MD
Columbia Presbyterian Hospital

John Manzon
APICHA

Michael Ezie, MD
Geneve B. Scrugge CHC

Waffa El-Sadr, MD
Harlem Hospital

Denise Paone, PhD
Chemical Dependency Institute, Beth Israel Medical Center

And MORE

PROGRAM UPDATE

Please refer to the full conference brochure and the enclosed revised agenda.

Three New Workshops Are Added:

Monday, November 15, 11:00 - 12:30

T. FREE ACCESS TO MEDICATIONS AND MEDICAL CARE

This session will encompass the concepts, structure, and scope of services available from the AIDS Institute's HIV Uninsured Care Programs (ADAP, ADAP Plus, and Home Care.) Expansion activities underway and the possible future directions will be discussed.

Monday, November 15, 4:00 - 5:30

U. HEALTH & HUMAN SERVICES: ARE THEY ACCESSIBLE FOR HIGH-RISK OR INFECTED YOUTH?

Providers of health care to adolescents report that HIV infected youths are entering care with compromised immune systems, many with T-cell counts below 500 and some below 200. During this workshop, adolescents living with AIDS and service providers will discuss their experiences with health and human service delivery systems. The session aims to provide a broad perspective on what we know and don't know about at risk or infected adolescents; how best to fill the gaps to access needed services; the role of counseling and testing; establishing linkages between human service providers and health care; and the extent to which current service models are or are not working.

Continued...

1993 REVISED AGENDA

Sunday, November 14

12:00 - 6:30 PM Registration

2:00 - 3:30 PM Opening Session/Welcome

3:30 - 4:30 PM PWA Address

6:00 - 8:00 PM Dinner/Keynote Address

8:00 PM Candlelight Ceremony

Monday, November 15

7:30 - 6:00 PM Registration

9:00 - 10:30 AM AIDS Institute Address/AIDS Research After Concorde

10:30 - 11:00 AM Break

11:00 AM - 12:30 PM Concurrent Workshops

- A. *Mothers and Infants: How and When to Test for HIV*
- C. *Men on Men: Rainbow Prevention*
- E. *Continuous Quality Improvement (CQI) of Clinical Care*
- M. *HIV Prevention Education in Our Schools — Where Have We Been, Where Are We Going?*
- T. *Free Access to Medications and Medical Care*

12:30 - 2:00 PM Box Lunch

2:00 - 3:30 PM Concurrent Workshops

- B. *Men on Men: Closing the Generation Gap*
- F. *For Her Own Good: Women and Men Keeping Each Other Safe*
- G. *AIDS Orphans and Their Families – Another Epidemic in New York State*
- H. *HIV Infection Among Women Who Have Sex With Other Women*
- I. *AIDS Activism: Where to from Here?*
- J. *Alternative Approaches to Working with & Caring for HIV Infected Clients in Drug Treatment*

3:30 - 4:00 PM Break

4:00 - 5:30 PM Concurrent Workshops

- D. *Men on Men: Safer Sex/Healthy Sex*
- K. *Managed Care, AIDS and Access to Care*
- L. *Needle Exchange: A Primary AIDS Prevention Strategy*
- N. *SSI and SSDI: Will the New Regs Make it Easier to Qualify?*
- O. *Are PWAs the Best Service Providers?*
- U. *Health & Human Services: Are They Accessible for High-Risk or Infected Youth?*

6:30 PM - 7:30 PM Main Reception

7:30 PM - 9:30 PM Dinner/Award Ceremony

Tuesday, November 16

8:00 AM - 1:00 PM Registration

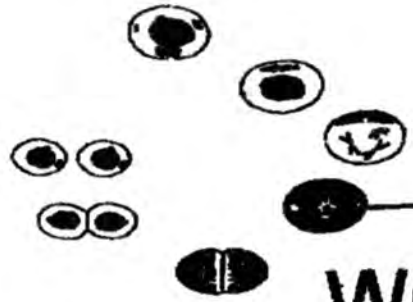
9:00 - 10:30 AM TB and HIV Plenary

10:30 - 11:00 AM PWA Speakout

11:00 - 11:30 AM Break

11:30 AM - 1:00 PM Concurrent Workshops

- P. *TB Control in Non-Institutional Environments*
- Q. *Coordination of Case Management for TB Patients*
- R. *Components of Comprehensive Clinical Care for Women*
- S. *HIV Reporting*



NOVEMBER 15, 1993
12:30 TO 1:45

WHAT ARE THE ALTERNATIVES?

A Discussion of Traditional and Alternative Treatments for AIDS

Individuals and organizations attending the New York State Department of Health AIDS Institute Statewide HIV/AIDS Policy Conference in Albany are encouraged to come hear about new and approved treatments for AIDS. Registrants will receive Treatment Review. Issues # 8 and 9 contain a special two-part review of acupuncture as a complementary treatment for AIDS. Call to register. Space limited to 50 people.

•

Phone 212.268.4196 Fax 212.268.4199• Español 212.643.0870

AIDS Treatment Data Network

259 West 30th Street - 9th Floor
New York, NY 10001-2809

Stop by our booth and receive a free copy of
The Experimental Treatment Guide

Darren J. Britton
St. NY Outreach
HIV/Ped AIDS
212. 613. 4962

BD

10/28

MEETING INFORMATION FOR KRISTINE M. GEBBIE

ONAPC STAFF CONTACT: Steve Lee

DATE/TIME EVENT: NY Statewide AIDS Conference - 11/14 @ 6:00

LOCATION: Albany, NY - Omni

ORGANIZATION: State of NY Department of Health

CONTACT: Vince Marrone, Dir. Government Relations - AIDS Institute
(212) 613-4359 Hope Goldbaer. (518) 486 1317 fax
AIDS policy: A National Perspective 473 8484 phone

TOPIC: policy, programs re newborn HIV screening, partner notification or needle exchange, IV drug use, women

FORMAT: keynote speech 800-1000, many PWAs

BACKGROUND: John has worked on this and Dr. Elders' office asked for you to stand as surrogate. CBO, service providers, local officials

CONFLICTS: Trying to schedule a meeting in Columbia, SC

Darren Britton, NY State Dept of Health - PED AIDS 212.613.4962
pickup KGT, brief

DIRECTION TO STAFF

SCHEDULE ✓ SCHEDULE FOR OTHER TIME ____ REGRETS ____

SEND SURROGATE (who?) ____

COMMENTS: ____

- They will help w/ ground transport. (bio, etc.), press release

STAFF CHECKLIST: CONFIRMED ____ CALENDAR ____ TRAVEL ____ HOTEL ____

Be sure to follow up with Elders office.

U.S. Department of Health and Human Services
Public Health Service
Office of the Surgeon General
200 Independence Avenue, S.W., Room 736-E
Washington, DC 20201

Telephone: 202-690-8335
Fax: 202-690-6498

DATE: 10/27/93

TO: Steven Lee

FAX: 202-632-1096

FROM: JAMES JOHN BEMBERG
202-690-8335

ADDITIONAL MESSAGE: please leave a message that you received this FAX Thanks James

Total number of pages this transmission (including cover): 2

(782)

STATE OF NEW YORK
DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.
Commissioner

OFFICE OF PUBLIC HEALTH
Sue Kelly
Executive Deputy Director

September 21, 1993

Dr. M. Joycelyn Elders
Surgeon General
United State Public Health Service
5600 Fishers Lane
Room 1866
Rockville, MD 20857

Dear Dr. Elders:

I'm writing to invite you to give the keynote address at the Fourth Annual New York Statewide AIDS Conference in Albany, New York.

The New York Statewide AIDS Conference is the largest of its kind in the country, attracting nearly 1,000 people from across New York and the nation. This year's conference will focus on a variety of pressing policy and programmatic issues, including screening newborns for HIV infection, partner notification, and TB. The conference will take place Sunday, November 14, through Tuesday, November 16, at the Albany Omni Hotel in downtown Albany, New York.

Each year, state and national leaders in the fight against AIDS are invited to address the conference. We would be honored to have you present the keynote address this year. Your comments could focus on any of a number of issues under discussion at the conference, or an issue of your choosing.

For your information, other invited speakers include Gov. Mario M. Cuomo (who has addressed the conference each of the last two years), Dr. David Rogers, former Vice-Chair of the National Commission on AIDS; National AIDS Policy Coordinator Kristine Gebbie; and New York State Commissioner of Health Dr. Mark Chassin.

I hope your busy schedule will allow you to attend this important event. I will contact your office in the near future to discuss the possibility of your attending, and I look forward to seeing you in Albany.

Sincerely,

Vince Marrone

Vincent N. Marrone
Director, Government Relations
AIDS Institute

NEW YORK STATE DEPARTMENT OF HEALTH
AIDS INSTITUTE

M E M O R A N D U M

November 4, 1993

TO: Steve Lee
Office of Kristine Gebbie, AIDS Policy Coordinator

FROM: Vincent N. Marrone
Director
Government Relations and Strategic Planning

RE: **November ~~13~~ 14 Speaking Engagement**

I wanted to provide you with some background on AIDS in New York State that may be helpful in preparing Ms. Gebbie's remarks before our statewide AIDS conference.

In brief:

Harm Reduction:

The New York State Department of Health (DOH) has approved six harm reduction programs under a state law that allows the Commissioner (Dr. Mark Chassin) to exempt classes of individuals from the state's prescription law (which prohibits over-the-counter (OTC) sale). Five of the programs are in New York City; the sixth (on the verge of starting up) is in Buffalo. There has been a bill before our state Legislature for the past 4-5 years to make OTC sale legal in NYS. This bill has never passed either house (Assembly or Senate), though it has made it to the floor of the Assembly two years straight. The bill is sponsored by the Chair of the Assembly Health Committee (Dick Gottfried), who is from Manhattan.

IVDU-related HIV infection is really the engine driving HIV in NYS today--numbers among gay men have leveled and begun dropping (in terms of new cases per year). As a result, cases among women and infants have increased as well.

The community is very interested in expanding our state's harm reduction efforts, and as such would be interested in the prospects for Surgeon General Elders rescinding the prohibition on the use of federal funds for harm reduction programs.

Newborn Screening

There is currently a bill before the NYS Legislature to mandate that all infants born in NYS be tested for HIV at birth and, for those found to be HIV-positive, to require that such information be given to the parents. Currently, no one

in NYS is tested without written, informed consent, with the exception of donors of blood, semen, etc. NYS currently conducts a blinded newborn seroprevalence study that tests every infant born in the state for HIV. As this study is conducted under a research protocol, no names are attached to the test results, although we can identify in which hospital the possibly-infected infant was born.

Our state AIDS Advisory Council (Chaired by Dr. David Rogers, formerly co-chair of the National AIDS Commission), has convened a subcommittee to review this issue and make recommendations to the Legislature by January 1, 1994. The Legislature postponed action on the proposed bill in order to allow the Advisory Council to conduct this study.

The AIDS community is opposed to this change in policy, although a number (but not all) of NYS pediatricians favor it. Confidential, voluntary HIV testing is near-sacred in NYS, with our voluntary testing and counseling policy extensively outlined in law.

This is certain to be the biggest AIDS policy issue under debate in NYS next year.

Lab-Based Reporting

In order to more accurately gauge the number of AIDS cases in NYS, DOH has proposed moving to a lab-based AIDS reporting system. Under this system, labs would report to DOH any CD4 count of less than 200. DOH would then contact the patient's physician to determine if the person is HIV infected and, therefore, qualifies as an official AIDS case.

Most members of the AIDS community have opposed this step, primarily on the grounds that DOH does not need patient names from the labs in order to conduct this review. The community has proposed the use of a system of "unique identifiers" (UI) as an alternative. Under this system, physicians would send tests to labs with a UI. The labs in turn would report the UI for patients with CD4s of less than 200--along with the referring physician's name--to the state for further investigation.

Their fear of this system is, in my estimation, closely linked to a larger fear of HIV-name reporting, which is currently not done in NYS. (AIDS is a reportable condition in NYS, with names sent to the state DOH.)

Funding

As you might expect, Ryan White, CDC prevention, housing, TB, and AIDS research funding are always on people's minds when federal issues are discussed.

The City's Supplemental Award under Title I of the CARE Act was a disaster in 1993, with the City getting approximately $20 million less than they had expected. Needless to say, the staff at HRSA who administer this program are not very popular in NYS, and the process used for reviewing Supplemental Grant requests has come under intense

scrutiny. A number of City and Planning Council members have met with representatives of HRSA, as well as HHS (including Dr. Lee), but to no avail thus far. HRSA claimed that NYC did not deserve more money, as they could not spend what they received in the previous year. NYC countered that the money was spent, but a significant portion of it was NYC tax levy (in anticipation of receiving federal funds) because HRSA refused to "front" the money to NYC. This controversy continues.

Under Title II, Upstate NY areas, with no Title I city, feel shorted in the funding process. They also complain that case counting in inaccurate, as folks identified in an area become, forever more, the "property" of the city/county where the identification took place. Their experience has been that significant PWA migration occurs, resulting in a demand for services that is effectively hidden in the case counts.

With regard to prevention, the ability to spend federal funds on harm reduction is a major issue in NYS, as previously cited. The state currently spends $500,000 to support our existing programs, but this is woefully inadequate to meet their needs, let alone expand beyond our modest start.

TB is a major issue in NY, especially in NYC, where HIV and TB are seen as one. Paying for DOT and providing housing for those who are homeless and sick with TB are the primary concerns.

Housing issues in general are a big problem in NYC, where the City is involved in long-standing court battles over their housing policies for homeless people with a variety of serious medical needs, including HIV and TB. The court cases have yet to be resolved, with the City reluctant to establish a standard of care (housing and related services) that would obligate them to establish a new and potentially expensive service for sick homeless people. HOPWA and other housing programs provide significant resources for HIV housing in NYC, so a review of where they stand might be useful.

Future Directions:

Where we stand with regard to the re-authorization of the Ryan White CARE Act, health care reform and HIV, and efforts currently underway to reform the CDC prevention program would all be of interest. Community planning is generally supported in NYS, but creating further planning bodies has met with some resistance from those involved in the extensive network of councils, networks, and task forces that currently exist.

Please accept these suggestions as only that. I'm certain that whatever Ms. Gebbie decides to discuss will be of interest to our conference attendees.

Please feel free to contact me at 212-613-4359 (NYC) or 518-473-8484 (Albany) if you have any comments or questions.

Changing the paradigm of national debate

~~debate~~

consequences of national denial

November 12, 1993

MEMORANDUM

TO: Kristine M. Gebbie

FROM: W. Steve Lee W.S.L.

SUBJECT: Nicholas Rango

I spoke with David Rogers and he thinks it would be a very good idea to say a few words about Dr. Rango on Sunday. The NY Times obit has some good stuff (attached). In addition he suggested that you mention that he was the architect of the NY state AIDS program. FYI -- David is introducing you on Sunday.

Deaths

Mabel M. Beloved wife Sidney. Loving mother and Lynda and the late rol. Devoted sister of nstein. Loving grand- f David P. Berrol, Amy sa Berrol and Barry A. id Beth P. Rothman. Ser- / 12 Noon at Riverside Chapel, 21 West Broad unt Vernon, NY.

Mabel. The Board of of the Mamaroneck Yacht Club announces g of Charter Member ember of the Board of Mabel Posner. We ex- eepest condolences to , daughter-in-law Lin- ved grandchildren. Rosenshein, President, Board of Governors

holas. It is with deep he clients, volunteers, taff of Gay Men's te the death of our d and colleague, le brought an un- rity and a relentless the personal and allenge of fighting e New York State ader in innovative, d intelligent respon- emic. He and his le- nue to inspire us to to achieve a world and until then, a ch all people with ted with dignity and His personal battle engthened his com- ompassionate care with AIDS, whatever der or sexual orien- s a fireless fighter, d friend, inspiring mpassionate care- is a loss to us all deeply missed. His ve on in our work, s.

eff Soref, President son, Exec. Director sell, Chief Counsel as, M.D. The ectors, staff and Community Family ll join the rest of in mourning the nd "Nick" Rango. AIDS Institute he t it is possible to within a bureauc- oming a heartless ntellect, strength l compassion al- ate policies and have placed New lead in the fight . His humanity used him to be spected even by eed with him. He and a real hero. who achieved hort life and n iron fist with of humor and left us a legacy We will do our oint him.

B. Dunlop, Chair oard of Directors is, Exec. Director A., MD. With we record the ctor, a true lead- Outraged by in- scrimination, he nagine a world demanded that s completely to geous, uncom- reless, he fought t improved the n living with HIV ate and initiated national impact. nmitted to the for the highest lic service in the DS. Our deepest family.

The AIDS Institute ate Dept of He-

Dr. Nicholas A. Rango, 49, Dies; Built New York's AIDS Program

By BRUCE LAMBERT

Dr. Nicholas A. Rango, who built New York State's AIDS Institute into the nation's largest state AIDS program while struggling with the illness himself, died on Wednesday at home. He was 49 and lived in Manhattan.

The cause was AIDS, the State Health Department said.

Dr. Rango publicly acknowledged his illness and his homosexuality. He ran the agency from his sickbed during medical relapses. In June he said, "When you're aware the clock is ticking, it focuses your attention."

Through his work in New York, he exerted national influence on AIDS issues. He also organized his counterparts from other states into a coalition to lobby for Federal money and policy changes.

Recruited in 1987

Dr. Rango was recruited to his post as director of the AIDS Institute in 1987 as the epidemic worsened in New York, which has the most AIDS cases in the country. His mission was to plan treatment and prevention and to get services delivered.

During his tenure, the AIDS Institute quadrupled its budget to $120 million and expanded into a wide array of programs.

Dr. Rango broadened services to people other than gay men who were increasingly afflicted by AIDS, including heterosexuals, women and babies. New programs were begun for teenagers, minorities, prisoners and addicts.

Advocates for AIDS programs, even while complaining about the state's shortcomings, considered him a friend behind the scenes. Once, when the group Act Up disrupted a State Public Health Council meeting by blowing deafening horns, Dr. Rango confided to a bystander that he was glad the protesters kept the pressure on.

"We are moving too slow," he said in 1989, repeating a frequent theme. "We have done a lot, but we have not done enough." Sometimes acerbic, he said at a 1990 seminar on lobbying: "On the issue of AIDS, the New York Congressional delegation is somewhere between stage three and four of a coma."

Dr. Rango assembled the state's first long-range plan on AIDS. It called for action by 18 agencies, including those dealing with human rights, the courts, schools, mental health, youths, parolees, addicts and welfare recipients.

He initiated AIDS medical care standards, a wider definition of AIDS entitling more patients to receive care, special nursing homes and residences, higher reimbursements to encourage doctors and clinics to treat AIDS patients, housing aid, prison health programs, home care, tuberculosis programs, care for the uninsured, research to prevent accidental exposures like needle sticks and special training for doctors and nurses.

Dr. Rango advocated giving clean needles to drug users to curb infection, a measure resisted by many state and local officials. He also expanded preventive education, voluntary testing, confidentiality protection, subsidized medications for 7,300 patients and a network of AIDS treatment centers in 23 hospitals across the state.

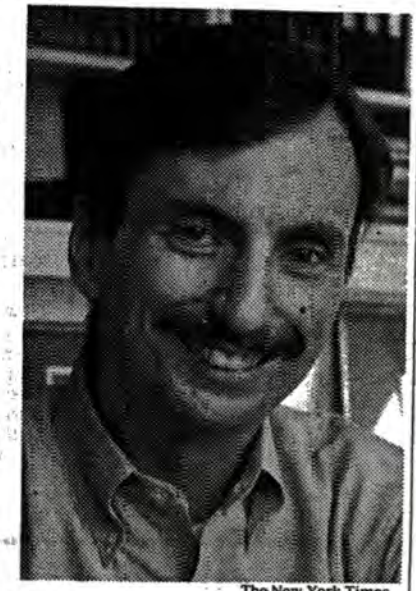
Nationally, he led the opposition to mandatory testing of health care workers and to the barring of infected people from doing invasive medical procedures.

> Advocates saw a friend behind the scenes.

In New York he worked with State Health Commissioners David Axelrod and Mark Chassin and with the State AIDS Advisory Council and its chairman, David Rogers. With Gov. Mario M. Cuomo, they forged the administration's AIDS programs and sought support from the Legislature.

Getting money for the agency was a constant struggle, and Dr. Rango was quick to defend its semi-independent status within the Health Department.

He did not win every battle. He failed in an attempt to require Roman Catholic-run AIDS nursing homes to give preventive education on safe sex and the use of condoms. When the recession hit, AIDS funds and staffing did not rise so quickly as the epidemic, which by June 30 reached 61,082 cases with 42,567 deaths.



The New York Times

Dr. Nicholas A. Rango

Trained in gerontology and sociology, Dr. Rango was the director of the Village Nursing Home in Manhattan before joining the AIDS agency. In AIDS work he faced many of the same terminal-care issues but in much younger patients, he said.

An Ohio Native

Dr. Rango was born in Youngstown, Ohio. He graduated from St. Louis University in Missouri and earned his medical degree at Northwestern University. At Cook County Hospital in Chicago, he was president of the Residents and Interns Association, a union with more than 500 members.

He earned a doctorate in sociology at Columbia and for nine years taught health at Barnard College, where he developed a health policy and medical ethics program for premedical students.

Dr. Rango won awards for his work, published research in medical journals and assisted on the federally sponsored National Hospice Study and the Hasting Center's project on Termination of Treatment and Care of the Dying.

His survivors include his mother, Doris, of Manhattan; a brother, Arthur, of Manhattan, and a sister, Ann Ursula Watkins of Warren, Ohio.

A Mass will be held at 12:45 P.M. on Wednesday at the Church of St. Francis Xavier at 30 West 16th Street in Manhattan.

Mauri Brito On F

By W

Maurice sor who wa the politica and 18th cer London. He

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Professor C his wife of 35 miliana von u had two sons,

Tadeusz Pankiewicz, 85, Pole Who Helped Jews

By RICHARD E. LYON

been the only P the destru rman

e the era. After the war he returned to his work as a pharmacist, retiring a decade ago.

s survived by his wife.

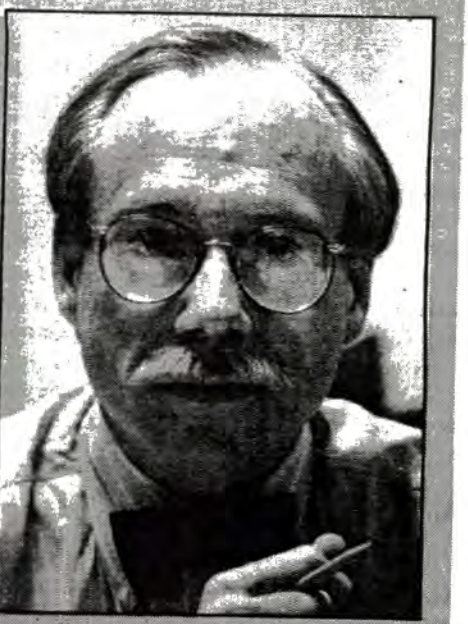
Brown, 76,

Mary A. Volunt

Mary Agnes devoted more volunteer worl home on the U hattan. She wa

Obituaries

Jeff Schmalz, respected AIDS reporter, dies at 39



Jeffrey Schmalz, 39, a *New York Times* reporter who won national recognition for his extensive coverage of AIDS and Gay issues, died Saturday, November 6, at his home in New York City. According to the *Times*, he died of complications associated with AIDS.

Schmalz's two-decade career included serving as regional editor, metropolitan news reporter, bureau chief in Albany, N.Y., and Miami, Fla., and deputy national editor.

He was diagnosed with AIDS in 1990, after suffering a brain seizure in the newsroom. Returning to work a year later, he came out as a Gay man and a person with AIDS, and persuaded his editors to switch his news focus from politics to AIDS and Gay civil rights.

"I feel an obligation to those with AIDS to write about it, and an obligation to the newspaper to write what just about no other reporter in America can cover in quite the same way," he wrote in a *Times* article about living with AIDS last December. He rejected questions about his journalistic integrity as a Gay man with AIDS who wrote about Gays and AIDS.

"Some people think that it is the journalism that suffers, that objectivity is abandoned," he wrote. "But they are wrong. If the reporters have any integrity at all, it is they who suffer, caught between two alliances."

Coworkers credited Schmalz with a "finely honed news sense, a devotion to accuracy, a sharp-edged writing style, and an innate sense of politics," the *Times* reported.

"The healthy Jeff was an outstanding correspondent and editor with a great future in American journalism," the *Times* quoted Max Frankel, its executive editor, as saying. "Jeff in illness plumbed the depth of his experience and applied it brilliantly to his coverage of the plague, producing a remarkable bequest to American journalism."

In September, Schmalz served as a keynote speaker at a National Lesbian and Gay Journalists Association conference, according to Leroy Aarons, president of the organization.

"Jeff spoke of the great success of Gay and Lesbian journalism in the mainstream over the last few years, and spoke of the tremendous contrast between the *New York Times* of today and the *New York Times* of years ago," Aarons said. By coming out to his editors as a Gay man with AIDS, Schmalz opened the way for the respected *Times* — which only a few years ago would not print the word "Gay" — to begin extending its coverage of AIDS and Gay news affairs.

"He did some of the best writing on the topic of AIDS," Aarons said. "He was able to demonstrate that you could not only be a Gay journalist writing about Gay topics, but a Gay journalist with HIV writing about HIV, and still be able to do a credible job."

"The *Times* was the center of his life," said Richard Mieslin, a close friend. "His professional life and his personal life were hugely intertwined."

"He was a very different person after he became sick," Mieslin said. "He became much more comfortable with himself ... much more contemplative and much more philosophical."

Survivors include a sister, Wendy Wilde of New York City. A memorial service is being planned for December.

—Aras van Hertum

NY - 11/14

Natl Perspective - Future Directions

Work so far
Local in much of its nature - natural in impact -
Wide Range - architect of ny state progs
natural voice / prod / leader
Problem - "natural" sometimes switches so
it's unrecognizable -
doesn't adequately provide for variation
"on average" describes no one quite,

issues confronting us - ny & nationally
1) continuing to understand the epidemic
seroprevalence
reporting issues - CD4 and HIV
pathogenesis / natural history

2) serving those infected & research on treatment supportive therapy
case finding / early dx
maternal testing / reporting
"index of suspicion" incl. PCP prophylaxis
Ryan White / Housing / etc
health reform

3) preventing further infection
Partner notification
harm reduction - syringe exchange / drug Rx
clearer, focused mechanisms
local control of planning
prevention research

STATE OF NEW YORK
DEPARTMENT OF HEALTH

Corning Tower The Governor Nelson A. Rockefeller Empire State Plaza Albany, New York 12237

Mark R. Chassin, M.D., M.P.P., M.P.H.
Commissioner
Paula Wilson
Executive Deputy Commissioner

OFFICE OF PUBLIC HEALTH
Lloyd F. Novick, M.D., M.P.H.
Director
Diana Jones Ritter
Executive Deputy Director

October 29, 1993

Steve Lee
750 17th Street NW
Suite 1060
Washington, DC 20500

NOV 12 1993

Dear Mr. Lee:

We are honored that Kristine Gebbie has agreed to present at our fourth annual HIV/AIDS policy conference on Sunday, November 14, 1993. As requested, I have enclosed informational materials on this three day event.

Allow me to confirm with you that Ms. Gebbie will arrive in Albany on Sunday afternoon (arrival time to be determined). We will arrange to have someone from the AIDS Institute meet her flight and transport her to the conference site, the Omni Albany Hotel, approximately 15-minutes away. Participants will be seated for dinner at 6:00 PM, and we ask that Ms. Gebbie present at approximately 6:45 PM. This would leave ample time for Ms. Gebbie to be escorted to the airport for her return flight at 7:50 PM.

Please forward to me a biography or introduction for Ms. Gebbie and a list of any audio/visual equipment she will need. You are welcome to include an item in our registration packet or in our press release, if applicable.

I can be reached at (518) 473-8484 and my fax number is (518) 486-1317. Please contact me if I can be of further assistance. Thank you.

Sincerely,

Hope Goldhaber
Conference Coordinator
NYSDOH AIDS Institute