FOIA Number: 2018-0756-F

FOIA MARKER

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

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Kristine Gebbie

Subseries:

OA/ID Number: 8300

FolderID:

Folder Title:
[HIV in America: "Activating a New Paradigm for Care Giving"] [loose]

Stack:	Row:	Section:	Shelf:	Position:
S	66	5	1	3

Built upon our 1992 landmark needs assessment, *HIV in America: A Profile of the Challenges Facing Americans with HIV*, we believe that the process outlined in the enclosed presents a unique opportunity for the nation to take another significant step forward in caring for people with AIDS. Further, through our proposed coordination of public and private sector resources, we are presenting a new paradigm -- a paradigm that, if successful, offers promise in addressing other significant, complex social challenges such as drug abuse, poverty, and welfare reform.

Thank you, again, for your support. I look forward to hearing from you.

Warm personal regards,

William J. Freeman
Executive Director

Enclosures

HIV IN AMERICA: "ACTIVATING A NEW PARADIGM FOR CARE GIVING"

CONFIDENTIAL

DETERMINED TO BE AN
ADMINISTRATIVE MARKING

INITIALS: JGP DATE: 8/21/19

2018-0756-P

A Project of
The National Association of People with AIDS
Washington, D.C.

In Collaboration With
The National AIDS Policy Office
Executive Office of the President
Washington, D.C.

Request for Funding Submitted to
The Robert Wood Johnson Foundation
March 1994

TABLE OF CONTENTS

Appendices 21-37

Executive Summary

The National Association of People with AIDS (NAPWA) believes that America cares about AIDS, but caring is not enough. Although we have marshaled enormous resources for fighting this epidemic, many people with HIV and AIDS still do not receive adequate health care, early detection, or compassion. Every 8 minutes, another American becomes infected with HIV.

In its 1992 survey, *HIV in America: A Profile of the Challenges Facing Americans Living with HIV,* NAPWA documented that AIDS is financially devastating even for those who are employed; people with HIV/AIDS lack access to affordable health care; people with HIV/AIDS are in danger of losing their insurance coverage; violence is a fact of life for many with HIV/AIDS; people with HIV/AIDS routinely experience difficulties in qualifying for private and government programs; co-workers and health care providers discriminate against people with HIV/AIDS; and people with HIV/AIDS need a wide range of services.

Now, aiming to build upon its own landmark study, the reports of the National Commission on AIDS, and other expert findings, NAPWA is proposing an entirely new approach to addressing the care giving aspects of the AIDS epidemic. Through ***HIV in America: Activating a New Paradigm for Care Giving,*** NAPWA intends to seize the opportunity afforded by national debate over health care reform to create a dynamic and inclusive partnership among individuals living with HIV disease, community-based AIDS organizations, the health care and insurance industries, and the media, as well as significant decision makers from government, philanthropy, religious communities, and business and labor. Now, the nation is ready to move beyond patchwork solutions, beyond seeing AIDS as largely a financial crisis, beyond expecting government, alone, to solve this crisis, and beyond empty gestures. NAPWA aims to bring together people who are capable and willing to produce results!

The *Activating a New Paradigm for Care Giving* project will involve: recruiting fifty significant decision makers to participate in a public policy working group; identifying barriers that inhibit adequate support for people living with HIV/AIDS; and hosting a two-day conference to produce a concrete action plan. Most importantly, the *Activating a New Paradigm for Care Giving* project will facilitate aggressive implementation of strategic action!

The National Association of People with AIDS is the national voice of people with HIV and AIDS. NAPWA will work in collaboration with the National AIDS Policy Office, and will contract with Hill and Knowlton and Macro International, two of the nation's leading public relations firms, to assemble a team with the skills, experience, and motivation to succeed at implementing a coordinated and comprehensive plan to support the more than one million Americans living with HIV and AIDS. The total budget for ***HIV in America: Activating a New Paradigm for Care Giving*** is $495,765. A total of $44,000 has previously been raised, and we respectfully request that the Robert Wood Johnson Foundation fund the balance of $451,765.

THE CHALLENGE

America cares about AIDS, but our national response to this ever growing epidemic has been neither consistent nor sufficient. For too long, fear and denial have characterized our collective response to AIDS and the impact it has had on our society. This is understandable as confronting the HIV epidemic requires grappling with issues our society prefers to ignore--homosexuality, illicit drug use, promiscuity, adolescent sexual activity, to name just a few. AIDS has also irrevocably shattered the myth that America is one great melting pot or one society. Rather, America is a stew of cultures and communities. Fighting AIDS amid much social diversity has been at times highly divisive. Fighting AIDS, however, could help us realize the great potential that diversity brings to this nation.

Thirteen years into this epidemic, America's response to AIDS has been both remarkable and tragic. We now devote huge financial resources to researching HIV and looking for both new therapies and a cure. We also spend large amounts of money caring for people living with HIV and AIDS. For all that we have learned and for all of the positive things we have achieved, however, we have not done enough. For every American with HIV or AIDS who receives comprehensive high-quality health care, there are many others who receive only minimal care until they are in the late stages of their disease. For every American who receives early diagnosis of HIV infection and can thus benefit from prophylaxis and treatment, many others do not even learn of their HIV status until they actually have AIDS. For every American living with HIV who has the love and support of family, friends, and co-workers, many others face discrimination, violence and rejection. America does care about AIDS, but the challenge of AIDS demands more!

The goal of the National Association of People with AIDS (NAPWA) is to **stimulate comprehensive action**--to produce a public and private partnership that blends caring with results. NAPWA firmly believes that America wants to do what is right for its people living with HIV and AIDS. What is needed is a strategy for action that goes beyond simply spending money on AIDS, that goes beyond simply demanding that the government attend to this crisis, that goes beyond simply writing reports, and that goes beyond simply wearing red ribbons or making other well-intentioned, yet empty gestures. NAPWA aims to bring together the varied and numerous segments of our society to facilitate leadership that will enable us to meet the needs of people living with HIV and

AIDS today, and that will enlighten our actions as this epidemic continues in the future.

THE CRISIS

- After 13 years, 339,250 Americans have been diagnosed with AIDS, and 134,860 of them are still living.[1]

- An additional one and a half million Americans are believed to be infected with HIV.

- Through incremental therapies, earlier diagnosis, and improved care systems, AIDS has gone from being an acute condition to a chronic disease. AIDS, however, is not yet a well-managed or tolerable disease.

- While research for better therapies and a cure is critical, there is much that can be done now to improve the lives of people who are infected with HIV or who have AIDS.

- Better access to new therapies, improved services, and strengthened support systems for people with AIDS will not be realized until greater private-sector and governmental support can be generated.

- National health care reform is an incredible opportunity to greatly improve the lives of people with HIV and AIDS. Reform, however, also poses great danger for people affected by AIDS. A reformed health care system, alone, could never address all of the care and treatment needs of people living with HIV and AIDS.

- As the epidemic grows, the strains on several urban health care centers in communities where the prevalence of HIV infection is high indicate what lies ahead for the entire nation. Recent CDC data reveal a significant prevalence of HIV infection in 62 cities.

- Quality care and access to knowledgeable and sensitive health care providers varies dramatically for rural and urban populations; for rich and poor; for whites and people of color; for men and women; children, adolescents, & adults

[1]AIDS cases reported to CDC through 9/93

and among special populations such as prison inmates and the homeless.

- Fragmented public and private care programs often duplicate services and waste scarce resources.

- A strategic national plan coordinating public and private sector responsibilities remains to be developed and implemented.

- Despite the availability of free, confidential and anonymous HIV testing, the majority of people learn they are infected with HIV in emergency rooms when they are experiencing a *pneumocystis carinii pneumonia* infection, which is a highly preventable illness.

- National housing experts report that 15% of the homeless in the United States are HIV-infected.

- Seventy-five percent of long-term AIDS survivors receive their care in the private sector, whereas the proportion of people with HIV receiving care in the private sector continually decreases.

The Bottom Line

- Every 8 minutes, another American becomes infected with HIV. As public debate over contentious prevention and treatment issues stifles comprehensive and coordinated action, men, women, and children living with HIV and AIDS struggle in a health care system that is unable to meet their needs. There is much that we do not know about HIV and AIDS. We do know, however, how to solve many of the care-related aspects of the AIDS epidemic. What is needed is a broadly-based and determined public/private strategy. We need to activate a new paradigm for care giving!

BACKGROUND ON HIV IN AMERICA

In September 1992, The National Association of People with AIDS released its landmark assessment of the needs of Americans living with HIV disease. *HIV in America: A Profile of the Challenges Facing Americans Living with HIV* was compiled from the first national survey of over 1,800 Americans with HIV/AIDS. This seminal report outlined the formidable challenges faced by persons with HIV infection in the areas of access to health care, finance, violence, and discrimination. Key findings are summarized as follows:

AIDS is financially devastating, even for those who are employed.

- Over half of the NAPWA survey respondents reported significant difficulties in meeting their needs for basic necessities such as rent, food and medicines. One third of HIV-infected respondents live on less than $500 a month; another third reported monthly income of $500 to $1000. Many employable people with HIV/AIDS are forced to *stop working* in order to qualify for Medicaid as their only means of receiving care.

People with HIV/AIDS lack access to affordable health care.

- More than 36% of the survey respondents need assistance in obtaining health insurance and medicines, and 25% say they need assistance in accessing health care. These proportions are even greater among women and minorities. Whereas 29.9% of men need assistance obtaining health care, 35.1% of women need this assistance. Whereas 59.5% of whites need some form of financial assistance, 81.3% of African Americans need assistance. Additionally, over 32% of the fully employed need access to health insurance and medicine, and 16.7% need access to adequate health care. In addition, people with HIV/AIDS need choice in health care. Because of their experiences with discrimination in accessing health care, it is important that people with HIV/AIDS retain their ability to choose physicians who are capable of managing the complexity of HIV disease.

People with HIV/AIDS are in danger of losing their insurance coverage.

- In addition to the lack of financial resources, recent events have illustrated the fact that people with HIV/AIDS are in constant danger of losing their insurance or having benefits capped due to their condition. It is important that health care reform measures emphasize the need to strengthen ERISA and that strong supportive enforcement be established in the Americans with Disabilities Act to cover those employed by self-insured and small businesses. Our data shows that 28.5% of people with coverage are concerned about having their insurance canceled. Another 32.9% are concerned about not being able to pay future premiums, and 27.6% indicated that they may lose their insurance due to bills that exceed their cap.

Violence is a fact of life for many with HIV/AIDS.

- NAPWA found that reported verbal abuse and physical violence against HIV-infected survey respondents was a common experience. A high proportion of the respondents described themselves as victims of verbal and physical abuse, both in the home (12.3% of respondents) and in the community (21.4%). The proportion of women in the sample who reported experiencing abuse in the home is greater than that of men (17% versus 11.8%). Among women, HIV-positive Latinas experienced a greater incidence of domestic violence (25%) than African-Americans (18.7%) or whites (12.9%). Violence in the community was even higher among all three populations: Latina women (38%), African-American women (20.4%) and white women (18.5%). The traumatic psychological and social effects of verbal and physical violence pose a horrifying and as yet unaddressed health challenge among many living with HIV disease; the threat of such violence may also negatively affect our public health system's efforts to combat the disease through prevention and education programs, HIV antibody testing and care delivery.

People with HIV/AIDS routinely experience difficulties in qualifying for private and government programs.

- People with HIV/AIDS have great problems qualifying for various types of entitlements and benefits. Of greatest concern to our respondents is obtaining group health insurance; this concern reflects both the fact that much health insurance is employment-based and that drastic changes have occurred in health care coverage in the past ten to twenty years (such as pre-existing conditions limitations and exclusions, and in disease-based coverage limits). Substantial numbers (30% - 40%) of survey respondents with HIV/AIDS encountered obstacles in qualifying for group health insurance (42%), Medicaid (30.9%), and private disability insurance (23.7%) regardless of their race, gender, or sexual orientation.

Co-workers and health care providers discriminate against people with HIV/AIDS.

- Discrimination in the workplace was cited by 26% of our respondents, and an alarming percentage reported acts of discrimination when receiving health care services (36%). Health care discrimination is especially acute among African Americans (42.7%). Women are also more prone to be discriminated against than men, 43.9% to 35.5%, respectively. Almost a quarter of respondents characterized their experience by saying that "health care workers seem afraid because I have HIV." Furthermore, 16% experienced discrimination from providers who would not accept medical cards. NAPWA's findings about the prevalence of discrimination in health care settings are consistent with a study conducted by Dr. Martin F. Shapiro, et. al. as reported in the *Journal of the American Medical Association*, which found that 23% of American physicians surveyed, if given a choice, would prefer not to care for persons with AIDS.

People with HIV/AIDS need a wide range of services.

- It is important that any comprehensive measure include all inpatient and outpatient services critical to those with HIV infection and other chronic illnesses, including: diagnostics, long-term care, home health care, hospice care, therapeutic and pharmacological agents and services, rehabilitation, substance abuse and mental health counseling and related services, and preventive services including full gynecological services, as well as perinatal, obstetrical and well-baby services. While these broad services pose major challenges to all people with AIDS, it is important not to lose sight of the concerns of the distinct undeserved populations, such as the need of one-quarter of women for assistance with child care and unmet needs for substance abuse treatment.

THE VISION

As a continuation of the essential *HIV in America* project and to build upon numerous other studies including the reports of the National Commission on AIDS, NAPWA envisions a project that:

- outlines a national response to the care needs of the HIV community;
- brings together the numerous and diverse communities affected by AIDS;
- recommends essential roles for the public and private sectors;
- identifies concrete actions for local and national decision makers;
- **implements** specific programs and activities.

The *HIV in America* project proposes **a new way of doing business**. It is NAPWA's conviction that any meaningful response to the challenges of living with HIV must involve **a dynamic and inclusive partnership** among individuals living with HIV disease, community-based AIDS organizations, the health care and insurance industries, and the media, as well as significant decision makers from government, philanthropy, religious communities, and business and labor. The project will convene these diverse interests to review the original needs assessment and to develop workable responses concerning HIV in America.

Previously, two national AIDS commissions have been convened. While these commissions assembled valuable testimony and made specific recommendations, the Commission's work is frequently overlooked. Several worthy documents have also been produced that have examined the national response to the HIV epidemic, yet none have made a significant policy impact on care giving. The Centers for Disease Control and Prevention (CDC) and the Health Resource Services Administration (HRSA) continually face serious resource constraints as they address the overwhelming care and social service needs of people living with HIV/AIDS. Philanthropic interests, the religious community, and most recently the business community have also become more deeply involved in the national effort to provide an effective community response to AIDS. The absence of an overall strategy for implementing valuable ideas and coordinating roles and responsibilities has stymied attempts to produce substantive change.

With the call for reform, private insurance companies, physicians and other medical service providers are now addressing structural barriers to

comprehensive health care, including two issues of great importance: improved access to a continuum of services and the elimination of coverage due to caps or pre-existing conditions.

At this critical juncture, a coordinated public-private strategy is essential to take advantage of the opportunity created by the flux of ideas concerning the delivery of health care in this country. This nation must seize the moment to respond to the care needs created by the unique nature of this viral infection and its accompanying epidemic. **NAPWA does not propose to re-visit issues already studied. Rather, NAPWA aims to move the nation to the next step--achieving results.** The *Activating a New Paradigm for Care Giving* project includes the formation of a dynamic and inclusive Public Policy Working Group whose composition will reflect a partnership among government, health care providers and related caregivers, business, the religious community, philanthropy, and the media.

The Working Group will develop HIV/AIDS policy recommendations -- creating a new paradigm for comprehensive, long-term care that encompasses the physical, psychological, and financial aspects of the treatment of chronic illness. These recommendations will be published and disseminated nationally as *HIV in America: Activating a New Paradigm for Care Giving* -- a comprehensive, yet targeted document that will detail specific actions that must be implemented to deliver compassionate and quality health care to people living with HIV/AIDS.

NAPWA, in collaboration with the National AIDS Policy Office, will work with public and private decision makers including: labor leaders such as Lane Kurkland; television personalities like Barbara Walters and Peter Jennings; health care academic leaders like Jonathan Mann, M.D.; religious leaders such as the Reverend Billy Graham; business executives such as John Scully, Lee Iacocca, or Earl Graves; community advocates such as Antonia Novello, Bill Gray, Marian Wright Edelman, or Bill Cosby in order to implement strategies to meet the challenge of care giving for people with HIV/AIDS.

The Plan

OBJECTIVE

To produce a public and private partnership among key decision makers and implement a comprehensive plan for meeting the care giving needs of the more than one million Americans living with HIV and AIDS.

STRATEGIC OVERVIEW

To augment its other activities, NAPWA intends to achieve this objective through the creation of a highly visible "leadership" game plan for public and private action. NAPWA intends to convene a Public Policy Working Group of approximately fifty significant and highly visible leaders in their communities or professional fields. These would all be people with formidable esteem who are capable of influencing their constituents and communities. These leaders would also be persons who have demonstrated their willingness to look beyond accepted customs and established ideas to find novel solutions to persistent problems.

The collaborative role played by Kristine Gebbie, the National AIDS Policy Coordinator, is highly significant. By working with the National AIDS Policy Office, the *Activating a New Paradigm for Care Giving* project is assured of the attention and support of the Executive Office of the President, and indeed the United States government. Most importantly, working with the National AIDS Policy Coordinator will ensure that government is actively involved in identifying and implementing solutions, without dictating or dominating the process.

Following the initial working group selection process, NAPWA will produce brief issue statements and policy papers which will be sent to all Working Group Members as a way to focus the work while generating meaningful decisions.

NAPWA will conduct a two-day meeting of the Working Group in Washington to achieve consensus on necessary actions. NAPWA will then publish a finished report which will be a strategic plan for action. To create awareness --

and stimulate action -- at every level of American society, NAPWA will work aggressively to facilitate adoption of the report's recommendations.

AUDIENCES

Wouldn't there also be participants

The audiences are:

- Policymakers
- Government Officials
- News Media
- People with AIDS (PWAs)
- Health Care Providers
- Public Health Leaders
- Educators
- Community and Service Organizations
- Business and Union Leaders
- Insurers
- Gay and Lesbian Community
- Other AIDS advocacy organizations (e.g., treatment information providers)
- Charitable Foundations and Philanthropic Organizations
- Religious Leaders

TACTICAL OVERVIEW

Through organizing and convening the Public Policy Working Group, the following activities will support our objective:

- Contract with the public relations firms Hill and Knowlton and Macro International to utilize their expertise in recruiting significant decision makers, planning and organizing the conference, communicating our goals and objectives to the public at large and to selected audiences, and to facilitate communication with the news media.

$300,000 worth LOADED!

- Identify barriers that prevent target audiences from supporting people with HIV and AIDS, as well as identify opportunities to

We already know what these are folks.

enhance support efforts and promote problem solving and conflict resolution.

- Host a two-day conference with participants comprised of people who can impact public policy and public opinion, including interest groups that have not become fully involved in the struggle of people with AIDS.

- Produce a strategic plan outlining ways to improve the lives of Americans with HIV and AIDS.

- Disseminate this plan at all levels of American society.

- Enhance public and policymaker awareness of the needs of individuals with HIV and AIDS.

- Collaborate with public and private institutions and individuals to establish strong relationships between various communities and organizations.

PROJECT PHASES

We envision the project to involve three phases, as follows:

CONCEPTUALIZATION AND PLANNING, including conference design; logistics planning; establishment of participant criteria and identification; notification and confirmation of participants; initial communications with participants; development of pre-conference materials; pre-conference promotion and media work.

CONDUCTING THE MEETING, including professional facilitation; on-site management and logistics; research; materials development; and media communication.

PUBLISHING THE ACTION PLAN AND IMPLEMENTING ITS RECOMMENDATIONS, including development and publication of the final document; post-conference logistics and follow-up; conducting press briefings

and other media contacts, and generating interest in the strategic plan. **Success will only be achieved to the extent that the Working Group's recommendations are implemented.**

NAPWA will direct all phases of this project, but will utilize Hill and Knowlton and Macro International for their experience in:

CONCEPTUALIZATION AND PLANNING

- Constructing a dynamic meeting format and agenda to stimulate discussion and resolution.

- Developing one-page issue statements in the following eight targeted areas with particular attention directed to the challenges faced by communities of color:

  -- optimizing health care services delivery
  -- preventing discrimination and the threat of violence
  -- improving workplace sensitivity towards people with HIV
  -- encouraging strategic philanthropy
  -- enhancing the educational and informational roles of the media
  -- supporting the necessary role of religious institutions in defining common values
  -- generating public support for assisting the HIV homeless, intravenous drug users, and other vulnerable populations
  -- learning from the experience of HIV in the gay community

- Developing thought-provoking background materials to be sent to conference participants two weeks before the meeting.

- Determining meeting site and dates.

- Obtaining recommendations for potential participants of the Public Policy Working Group.

- Inviting selected participants and communicating with Public Policy Working Group Members.

- Assuring that logistical and background information is sent to participants 30 days before the meeting, including assignments to specific break-out sessions at the conference.

- Creating awareness of NAPWA and the conference among all targeted audiences.

- Assisting NAPWA in communicating with AIDS-related organizations, informing them of the conference, its mission and soliciting their involvement. Because these other organizations may be called on by the media for comments, special efforts will be made to keep these organizations apprised of the conference.

CONDUCTING THE MEETING

- Handling meeting registration, meal arrangements, and day-of-meeting logistics (such as transcription, name cards, easels, etc.).

- Arranging for the compilation of all meeting materials that are to be contained in the final report to the Nation.

- Preparing the news media to receive the conference's results and overall findings.

- Issuing press releases announcing the conference and its participants, as well as any key endorsements.

- Providing on-site coordination and management to assure productive sessions.

- Supervising the printing of the conference report and assuring its timely availability for widespread distribution.

- Developing ancillary materials that are needed to achieve the project's objectives.

PUBLISHING THE ACTION PLAN AND IMPLEMENTING ITS RECOMMENDATIONS

- Assisting NAPWA in drafting the final conference report.

- Media training NAPWA spokespersons and select participants to speak credibly about the report and NAPWA's mission.

- Preparing appropriate press materials, including conference report fact sheets, biographies of participants, a NAPWA profile, and other background information.

- Targeting feature news placements for NAPWA/participant spokespersons, as well as targeting print and broadcast media across the country, including national and regional outlets and consumer, trade and business media.

- Presenting the report and conference findings to the national media in Washington, D.C., which would include inviting select policymakers and advisors to attend the briefing, as well as key endorsers of the conference and report.

- Identifying editorial opportunities in which to reference the report and conference after the initial round of publicity.

Budget Summary

I. NAPWA PERSONNEL		$ 89,400
Executive Director ($75,000 x 25%)	$ 18,750	
Project Director (100% salary)	$ 40,000	
Policy Director ($55,000 x 15%)	$ 8,250	
Medical Director ($50,000 x 15%)	$ 7,500	
Total Salary	$ 74,500	
Taxes and Benefits (20% of total salary)	$ 14,900	
II. Travel, NAPWA		$ 15,000
Project-Related Travel (@$1,000/trip x 15 trips)	$ 15,000	
III. PROJECT MANAGEMENT*		$290,000
Consultant Fees	$233,000	
Expenses	$ 57,000	
IV. Conference, Other		$ 36,700
Presenter(s) (Fees and travel)	$ 10,000	
Participant Travel: Airfare Subsidy (15 airfare @ $700 each)	$ 10,500	

wow, full years salary

unbelievable

* See Summary & Detail in Appendix A

Hotel (50 participants x 2 nights x $120/night)	$ 12,000	
Meals ($35/lunch x 60 participants x 2 lunches)	$ 4,200	
V. TOTAL DIRECT EXPENSES		$431,100
VI. NAPWA INDIRECT (@15% of Total Direct)		$ 64,665
VI. TOTAL PROJECT COST:		**$495,765**

+ the Salaries bumps
$89,400
Travel
15 000

shown on p 18

Total to NAPWA

64665
89,400
15 000

$169,065

Request for Funding

As the premier national health care foundation, The Robert Wood Johnson Foundation was the first national philanthropic body to understand the significance of the HIV epidemic. While much has taken place since then, programs and recommendations still remain focused on specific sectors or populations without any attempts to coordinate overlapping and complimentary roles. Various publicly and privately sponsored programs have been recommended, but none have altered the devastating course of the HIV epidemic.

The significance of NAPWA's *HIV in America* project cannot be underestimated. While this project focuses on the health care needs of people living with HIV, the plight of this population illustrates major deficiencies in our health care system that affect all Americans who are now or could be living with a chronic illness. The paradigm for action embodied in the Working Group's strategic plan would provide a precedent for action against other debilitating diseases and future public health crises that will certainly arise.

Given the sobering realities, a well-designed and inclusive public-private partnership to respond to HIV in the United States is long overdue. We are seeking the assistance of the Robert Wood Johnson Foundation in convening this partnership -- of placing providers, consumers, and payers on the same side of the table. **Through *HIV in America: Activating a New Paradigm for Care Giving*, NAPWA seeks nothing less than the development of a new paradigm to address the effective long-term management of complex chronic illnesses such as HIV disease.** Collaboration between the National Association of People with AIDS, the National AIDS Policy Office, and the Robert Wood Johnson Foundation would support communities struggling to develop local solutions to the challenges of the AIDS epidemic, it would provide needed leadership in the area of HIV/AIDS policy, and it could significantly impact the course of the AIDS epidemic in the United States.

The National Association of People With AIDS (NAPWA) is a respected national voice for the needs and concerns of people impacted by HIV/AIDS. It carries out a broad range of informational, educational, and advocacy activities to make Americans more aware of the challenges of living with HIV/AIDS and to foster a richer quality of life for those infected with HIV.

The National AIDS Policy Office under the leadership of Kristine Gebbie is charged with the coordination of the public sector's response to HIV. This includes significant outreach to the private sector. The National AIDS Policy Office will serve as a crucial advocate and partner for *Activating a New Paradigm for Care Giving*.

Hill and Knowlton, Inc. is the nation's leading public relations/public affairs firm and Macro International, Inc. is one of the largest government contractors in the field of public health policy and program development. Both companies have worked extensively in developing and implementing programs involving people with HIV and AIDS.

NAPWA firmly believes that the timing is right for a turning point in caring for people with AIDS. We believe that America does know what is needed to meet this challenge, and the political will to implement a meaningful, compassionate response is now present. The combined skills of NAPWA, the National AIDS Policy Office, and Hill and Knowlton/Macro International offer an historic opportunity to take a giant step forward for those living with HIV in the United States.

The total production budget for the project is $495,765. To date, $44,000 has been raised against this total. We respectfully request that the Robert Wood Johnson Foundation fund the balance of $451,765.

Appendix - A

HILL AND KNOWLTON/MACRO INTERNATIONAL
(Summary of Project Management Expenses)

PHASE I, II, and III

BUDGET TOTALS

	Staff	OOP*	Total
Phase I	$105,000	$ 10,500	$115,500
Phase II	$ 47,500	$ 11,500	$ 59,000
Phase III	$ 80,500	$ 35,000	$115,500
Total Budget	**$233,000**	**$ 57,000**	**$290,000**

*OOP=Out of Pocket Expenses

Subject to further discussions about specific work assignments and responsibilities; Hill and Knowlton estimates a project management budget of $290,000

This total includes printing of 20,000 copies of the final report. We have been quoted a cost of $16,500 to the final report in a manner comparable to NAPWA's original needs assessment report.

Appendix - A

HILL AND KNOWLTON/MACRO INTERNATIONAL BUDGET DETAIL

(Detail of Project Management Expenses)

Phase I. CONCEPTUALIZATION AND PLANNING

	Staff	OOP
Conceptualization/Design/Research/ Materials/Development	$50,000	$ 5,500

- Audience and messages analysis
- Consultation with NAPWA leaders
- Consultation with other thought leaders
- Database research
- Program design and implementation
- Initial outreach for program endorsers
- Development of conference backgrounder
- Development of one-page issue statements (8 papers)
- Distribute materials to participants

	Staff	OOP
Participant Identification	$11,000	$ 1,000

- Establishing participant criteria
- Participant research and identification
- Invitation, notification, and follow-up
- Confirmation
- Letter to AIDS-related organizations
- Participant list and bios

	Staff	OOP
Logistics/Planning	$ 9,000	$ 1,000

- Site search/menu selection
- Coordination of AV equipment
- Security
- Development of signage
- Slides/overheads
- Introductory remarks
- Distribute logistics package to participants
- Name tag development

Pre-Conference Media Work	$15,000	$ 1,000

- Media list development
- Media contact to involve in project
- Media training

Pre-conference working group program to review papers and plans for conference	$12,000	$ 1,000
Guest speaker identification	$ 8,000	$ 1,000

SUMMARY OF PHASE I BUDGET

Staff	OOP	Total
$105,000	$10,500	$115,500

Phase II. *CONDUCTING THE MEETING*

	Staff	OOP
On-Site Management	$22,500	$ 9,500

- AV equipment (including review/rehearsal)
- Transcription services
- Refreshments
- Training and conference costs
- On-site management
- Coordination of food and lodging
- Manage break-out sessions
- Participant/audience registration
- On site assistance in plenary and break-out sessions by account team including providing at least 4 facilitators from among experienced H&K and Macro personnel

Research/Material Development/Media	$25,000	$ 2,000

- Write and distribute press release announcing conference
- Develop and distribute conference results press release
- Compilation of meeting materials to be contained in final report
- On-site media relations including interview coordination

SUMMARY OF PHASE II BUDGET

Staff	OOP	Total
$47,500	$11,500	$59,000

Phase III. PUBLISHING THE ACTION PLAN AND IMPLEMENTING ITS RECOMMENDATIONS

	Staff	OOP
	$18,000	$ 5,000

Press Conference

- Logistics
- Media Advisory
- Invite Media
- On-site Staffing
- Follow-up with media to ensure coverage

Press Kit	$ 6,500	$ 3,500

- Backgrounder on NAPWA
- Fact sheets on conference
- Profiles of participants
- Summary findings of conference

Media Relations	$15,000	$ 3,000

- Identification of opportunities
- On-going proactive effort

	Staff	OOP
Conference Report and Ongoing Counseling	$25,000	$20,500

- Final drafting and printing of conference report
- Post conference logistics
- Ongoing counsel.

Congressional briefings or hearings	$10,000	$ 1,500
White House presentation	$ 6,000	$ 1,500

SUMMARY OF PHASE III BUDGET

Staff	Total	OOP
$80,500	$35,000	$115,500

Appendix - B

THE TEAM COMMITMENT

HIV in America: Activating a New Paradigm for Care Giving is among the highest priorities of the National Association of People with AIDS. As such, it will be supervised and managed by the Executive Director's Office. A Special Assistant to the Executive Director will serve as the project manager, and will coordinate the contributions of the National AIDS Policy Office, Hill and Knowlton, Macro International, and all NAPWA staff to ensure the success of this endeavor. NAPWA staff will include William J. Freeman, Executive Director, A. Cornelius Baker, Director of Public Policy & Education, Alberto Avendaño, M.D., Director of Health and Treatment Issues, and Jeffrey S. Crowley, Special Assistant to the Executive Director. Biographic summaries are included in Appendix - C.

A suitable team from Hill and Knowlton and Macro International will be developed for the purposes of carrying out this project.

Individuals who are likely to be included on this project are:

Tom Latimer, Hill and Knowlton, Atlanta
Jim Jennings, Hill and Knowlton, Washington, D.C.
Steven Grossman, Hill and Knowlton, Washington, D.C.
Brian Hujdich, Hill and Knowlton, Washington, D.C.
Ellena Friedman, Hill and Knowlton, Washington, D.C.
A. Billy S. Jones, Macro International, Washington, D.C.
Martin Kotler, Macro International, Washington, D.C.

Appendix - C

William J. Freeman

Executive Director
National Association of People With AIDS

As Executive Director of NAPWA, William J. Freeman has contributed his extensive knowledge of organizational development and management to provide a cooperative link between people with HIV/AIDS and service providers and physicians. Mr. Freeman's previous work demonstrates successful nonprofit management, program development, marketing, fund raising and public relations on a national scale. As a result of Mr. Freeman's dedicated work with HIV organizations, he was named Best AIDS Fundraiser of the Year by the Manhattan AIDS Technical Assistance Roundtable in 1990.

Prior to his work with NAPWA, Mr. Freeman served as National Director of the HIV Program for the University Pharmacy Health Center of Washington/San Diego. As a senior executive, Mr. Freeman was responsible for design and implementation of a national marketing campaign for the purpose of introducing a national mail order prescription program to key physicians, service providers and people with HIV/AIDS in the 25 U.S. cities with the highest incidence of HIV infection.

Mr. Freeman also served as Executive Director of the AIDS Assistance Fund in San Diego from 1989 to 1990. Major accomplishments included stabilizing a nearly bankrupt organization while repositioning it from a poorly identified AIDS program to a respected, multi-cultural community-wide AIDS resource and successfully working with the Board of Directors to merge the organization with the other leading San Diego AIDS service organization. Mr. Freeman initiated new programs to meet needs of ever increasing caseload, he greatly increased contributed income, and he advocated for increased federal, state, and local public sector support through aggressive lobbying efforts. Mr. Freeman also successfully lobbied U.S. Congress for inclusion of San Diego as a

Title 1 AIDS disaster relief city resulting in $8-million each year for five years. Coordinated highly successful San Diego leg of "Heartstrings: The National Tour" garnering first major corporate support for HIV-related programs in San Diego Country. Mr. Freeman sponsored the first major conference on HIV and Drug Abuse for over one-hundred professional service providers. Mr. Freeman's work with the Assistance Fund won him special commendation from San Diego Mayor Maureen O'Connor in 1990.

From 1987 to 1989 Mr. Freeman was Director of Institutional Affairs for the National AIDS Network in Washington, DC, where he coordinated both public and private sector support for community-based HIV programs and services, monitored the organization's revenues, and functioned as a national spokesperson. As a result of a grant proposal coordinated by Mr. Freeman in 1988, the Ford Foundation established the National Community AIDS Partnership, an affiliated program which has provided more than $8 million to support AIDS service providers in nine cities since its inception.

Mr. Freeman was Director of Development for Boston University's School of Medicine from 1984 to 1987 where he managed a six-figure operational budget. He increased contributions by more than 300% for the School and its research programs, raising $9.3 million in the last year of his tenure.

Mr. Freeman holds a B.A. in Philosophy from St. John Vianney Seminary and an M.A. in Theology and Pastoral Counseling from St. Mary's Seminary and University of Baltimore. He has completed advanced studies in family therapy at the Kanter Family Institute, Harvard University.

Appendix - C

A. Cornelius Baker

Director of Public Policy and Education
National Association of People With AIDS

A. Cornelius Baker is Director of Public Policy and Education for NAPWA. He is responsible for identifying issues of concern to those with HIV and advocating policy changes that are responsive to their needs.

Mr. Baker brings previous experience with HIV policy issues from his work as Confidential Assistant to the Secretary of Health, National AIDS Program Office (NAPO), U.S. Department of Health and Human Services. An appointee of the Bush administration, Mr. Baker acted as External Liaison Officer. He was responsible for establishing and maintaining correspondence with state and local government agencies, non-public institutions and advocacy groups. In this position, Mr. Baker developed a broad awareness of both policy and technical issues regarding HIV/AIDS and the public health agenda.

Mr. Baker was previously staff assistant to the Deputy Assistant to the President, Office of Presidential Personnel at the White House. Before joining the administration, he was Administrative Assistant to former District of Columbia Council member Carol Schwartz.

As a volunteer community leader, Mr. Baker has been president of the Brother, Help Thyself Foundation of Washington/Baltimore since 1990, and a member of the AIDS Foundation Panel of Whitman-Walker Clinic in Washington since 1988. Additionally, he is a founder of Best Friends, a Washington, DC, AIDS service organization assisting African Americans Living with AIDS.

Mr. Baker is a native of central New York and received his undergraduate degree at Eisenhower College/Rochester Institute of Technology.

Appendix - C

Alberto Avendaño, M.D.

Director of Health and Treatment Issues
National Association of People With AIDS

Dr. Alberto Avendaño brings to his position a wide medical knowledge base and awareness of trends in HIV/AIDS policy in both the public and private sectors. Dr. Avendaño is the director of NAPWA's Treatment Development Partnership, an effort to ensure the development and approval of the most effective therapies for HIV/AIDS and related opportunistic infections. The program focuses on strengthening cooperation among the HIV/AIDS community, pharmaceutical and biotechnology companies and federal regulatory agencies. Dr. Avendaño is also the Senior Editor of NAPWA's bi-monthly treatment and research update, *Medical Alert*. He is NAPWA's general liaison for issues related to HIV/AIDS treatment.

Dr. Avendaño possesses a strong background in medicine, family practice, and treatment of HIV/AIDS and other sexually transmitted diseases. Prior to working with NAPWA, Dr. Avendaño was Training and Health Director at the Midwest Hispanic AIDS Coalition (MHAC) in Chicago. He has also served as the AIDS/STD Program Coordinator for the West Side Health Center of St. Paul, Minnesota, and Chair of the Community Advisory Board for the AIDS Clinical Trial Unit at the University of Minnesota in Minneapolis.

Dr. Avendaño has also participated in diverse HIV-related groups, including the AIDS Fraud Task Force in Chicago and the Clinical Training Advisory Council for the Midwest AIDS Training and Education Center; he was also a board member of the Chicago Community Programs for Clinical Research for AIDS. Dr. Avendaño is fluent in Spanish, and has written for both the bilingual MHAC newsletter and the Test Positive Aware Network magazine, *Positively Aware*.

In July, 1987, Dr. Avendaño received a University Degree as Physician and Surgeon from Pontificia Universidad Javeriana in Bogotá, Columbia. He also

participated in a short residency specific to HIV infection at the University of Minnesota in 1991, and is familiar with pediatric medicine and immunology.

Appendix - C

Jeffrey S. Crowley

Special Assistant to the Executive Director
National Association of People With AIDS

As the Special Assistant to the Executive Director at NAPWA, Jeffrey S. Crowley will be responsible for coordinating and supervising *HIV in America: Activating a New Paradigm for Care Giving*.

Mr. Crowley has worked with NAPWA as a policy intern since January 1994. Since his arrival, he has taken primary responsibility for following the debate over national health care reform, and analyzing various reform proposals for their impact upon people with HIV/AIDS. Mr. Crowley has also worked closely with Mr. Baker, NAPWA's Director of Public Policy and Education, to formulate and disseminate NAPWA's health care policy.

Mr. Crowley is presently a Master of Public Health degree candidate at the School of Hygiene and Public Health at the Johns Hopkins University. Mr. Crowley will complete all of his degree requirements in March 1994 and anticipates receiving his degree on May 26, 1994. Although Mr. Crowley has followed a broad public health curriculum at Johns Hopkins, he has taken several epidemiology courses and has concentrated his studies in the area of health policy.

From May 1991 until July 1993, Mr. Crowley was employed as a Chemist at the National Institute of Mental Health (NIMH). At NIMH, he studied tryptophan metabolism, and in particular, the neurotoxin quinolinic acid that has been etiologically linked to neuro-inflammatory diseases including the AIDS-dementia complex. Mr. Crowley was responsible for operating a gas chromatography/mass spectrometry assay system, for which he more than doubled the analytical capacity of the laboratory through the automation of sample processing and analysis. Mr. Crowley was also involved in several experimental studies, he conducted collaborative research with more than twenty laboratories

throughout the world, he coordinated sample collection and data collation, and he supervised summer students and interns. Mr. Crowley is a co-author of several publications.

From 1988 until 1991, Mr. Crowley served as a Peace Corps Volunteer in the southern African nation, Swaziland. Mr. Crowley's volunteer assignment was to teach biology, chemistry, physics, and geography, and to serve as the Science Department Head at Nsongweni High School. During this time, Mr. Crowley lived in a rural community approximately twenty miles from the South African border.

Mr. Crowley is originally from Grand Rapids, Michigan. In 1988, he received a Bachelor of Arts degree in chemistry from Kalamazoo College in Kalamazoo, Michigan. Mr. Crowley is also a member of the American Public Health Association.

Appendix - D

The National Association of People with AIDS

The National Association of People with AIDS (NAPWA) is dedicated to improving the lives of people with HIV/AIDS at home, in the community and in the workplace. Founded in 1983 by a coalition of people with AIDS, NAPWA serves as a national information resource and "voice" for the needs and concerns of all Americans infected and affected by HIV. NAPWA is particularly committed to ensuring that people with HIV/AIDS understand their treatment options and have access to quality health care.

Through its programs, NAPWA:

- provides HIV-infected individuals and their caregivers with information about treatment options, legal rights, and available resources for assistance;
- identifies the issues of critical importance to people with HIV infection and advocates for their needs at the national level while facilitating grassroots coalition-building; and
- co-sponsors an annual training conference that enables community-based organizations to develop HIV-related services and expertise in securing funding.

In an effort to prevent the spread of HIV disease, facilitate a richer quality of life for HIV-infected individuals and create a unified national response to the epidemic, NAPWA builds meaningful partnerships among people with HIV, service providers, business, government, philanthropy and the media.

In 1992, NAPWA released *HIV in America: A Profile of the Challenges Facing Americans Living with HIV*. This report, compiled from the first national survey assessing the needs of Americans with HIV/AIDS, documents the issues of access to health care, finance, discrimination and violence affecting those with HIV/AIDS. This landmark report has

provided a vital step in addressing the critical needs of Americans with HIV.

Appendix - E

HILL and KNOWLTON BACKGROUND

For 60 years, Hill and Knowlton has defined the cutting edge of the theory, practice, and technology of communications and related consulting, and has remained preeminent in its field. As a result, they are today the counsel of choice for more than one-quarter of the world's largest corporations and more than one-third of the Fortune 500 companies, as well as for hundreds of growing companies in industry, trade, and finance.

HIV Expertise. Hill and Knowlton's AIDS-related capabilities are outstanding. They have worked with a number of organizations to increase public awareness of AIDS-related issues, including how the AIDS virus is transmitted, prevention measures and availability of AIDS therapies. They are the only national counseling firm to have a formal HIV/AIDS specialty group within their health care practice.

For example, Hill and Knowlton worked with the Robert Wood Johnson Foundation to promote "The AIDS Quarterly," the first public television series on AIDS. A record number of calls were made to the national AIDS hotline the evening of the program premiere.

Public Affairs and Health Care Expertise. Public affairs and health care are Hill and Knowlton's two largest specialized communications practices. Their clients span the entire gamut of health care: pharmaceutical manufacturers, medical technology companies, health care providers, professional and trade associations, and biotechnology companies.

Media Relations Expertise. From creating mass news media exposure for new drug therapies to encouraging editorials on complex health care policy initiatives, Hill and Knowlton's results-orientation stems from careful communications strategy development and tactical planning and execution.

They have worked with science and medical writers/editors at all of the major health care and general media outlets across the country. Hill and

Knowlton staff members who are former news anchors and network correspondents train executives, scientists, and other spokespersons to handle every kind of media situation with confidence -- from talk shows to ambush interviews. They also provide training for effective speeches, testimony, and presentations.

Coalition-Building Expertise. Hill and Knowlton maintains strong relationships with a number of government and non-profit associations that can be leveraged to develop coalitions or cooperative programs.

Health Care Issues Expertise. Hill and Knowlton Health Care is especially qualified to assist clients in developing and implementing well-reasoned, strategically sound and, most of all, effective responses to complex problems involving health care issues and government. Working for a wide range of health care clients, Hill and Knowlton seeks to achieve our client's monitoring and public policy initiative objectives.

Appendix - E

MACRO INTERNATIONAL BACKGROUND

Macro International Inc. (Macro) is a diversified research and management consulting firm created in 1966 by professional management consultants interested in focusing their skills on timely management and policy issues. The company has earned a reputation for superior performance by providing critical information and analysis useful to government agencies in formulating policy debate and carrying out program assessment efforts. During the past 25 years, Macro has successfully completed more than 1,000 assignments for clients at many levels of government, as well as for clients in the private sector.

Macro has been committed to work in the AIDS field since 1984. Its first project was a resource manual of services for people with AIDS, the first such publication outside of New York and San Francisco, which became widely used throughout the country. Since that initial project, its consulting work has addressed the spectrum of critical functions related to HIV/AIDS prevention and service delivery, encompassing public health policy development, program planning and implementation, research and evaluation, and curriculum design and materials development.

Macro has conducted myriad policy and programmatic initiatives at the Federal, state, and local levels. It has provided strategic planning around AIDS issues for several Federal agencies, and has conducted numerous studies on such topics as pediatric AIDS, non-acute care services for people with HIV/AIDS, and HIV counseling for women and adolescents. It has developed briefing documents for policy makers, made site visits to hundreds of service delivery programs, facilitated meetings for decision makers and experts in the field, and conducted focus groups with affected populations. This range and experience uniquely position Macro to assume additional initiatives in the field of HIV/AIDS prevention and service delivery.