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**FolderID:**

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**Folder Title:**
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# NAPWA

**NATIONAL ASSOCIATION OF PEOPLE WITH AIDS**

**PHOTOCOPY PRESERVATION**

# NAPWA

**NATIONAL ASSOCIATION OF PEOPLE WITH AIDS**

*1413 K Street, NW • Washington, D.C. 20005*
*TEL: (202) 898-0414 • FAX: (202) 898-0435*

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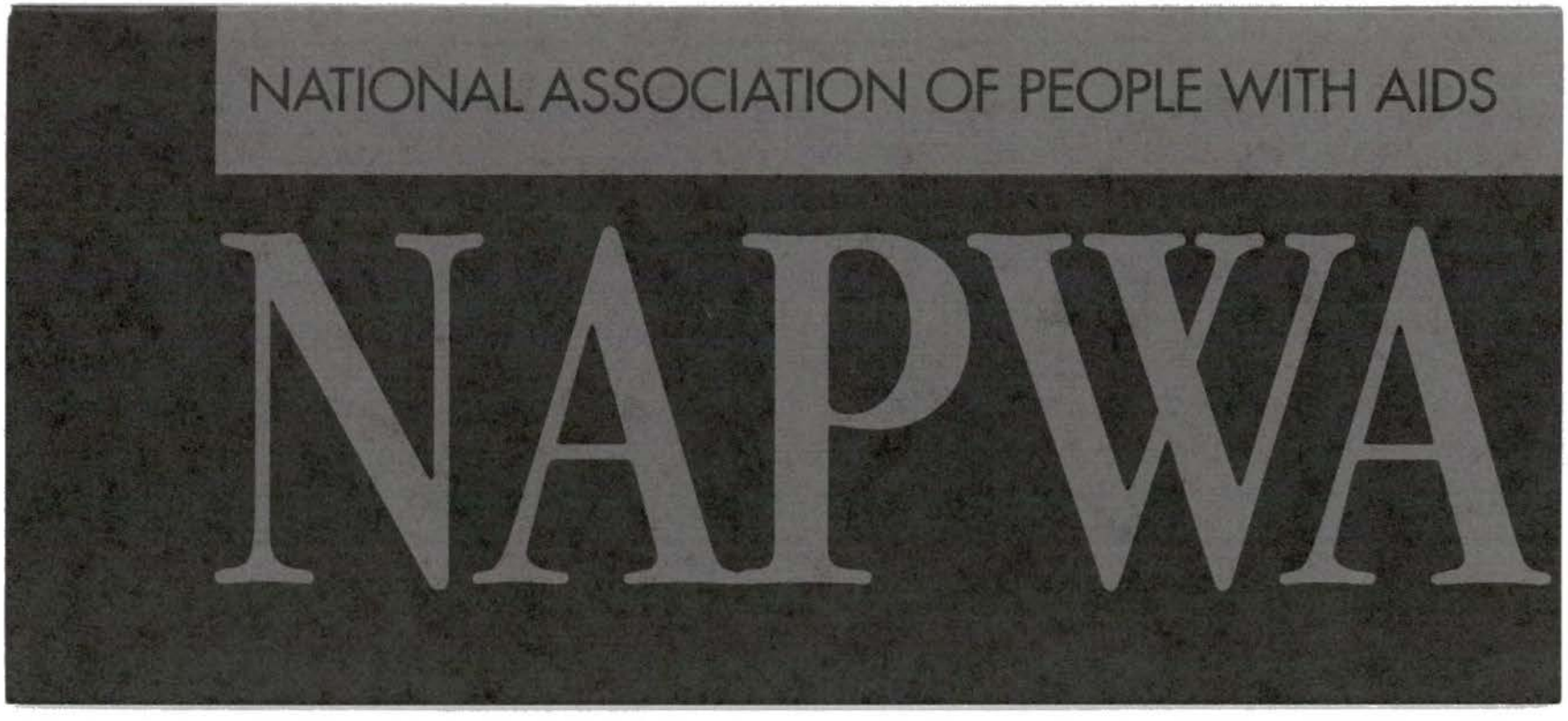
National Association of People with AIDS

8pgs


NATIONAL ASSOCIATION OF PEOPLE WITH AIDS
NAPWA

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MAY/JUNE 1993
VOL. 1, NO. 3

A PUBLICATION OF THE NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

SPONSORED BY:
T² MEDICAL, INC.

# ALERT MEDICAL

## GP160, POLITICS AND YOU

*BY ROBERT J. DARGA, M.D.*

For several years now, scientists have been speculating whether or not the immune response of people with HIV against the virus could be strengthened through vaccination and if this would provide the patients with any survival benefit. Several companies began developing synthetic copies of the outer envelope proteins of HIV, to be used as "Therapeutic Vaccines". These recombinant protein products, called rGP120 and rGP160, would be injected into HIV infected people; unlike traditional vaccines that protect against infection, therapeutic vaccines are intended to strengthen the immune response in people who already carry HIV.

Dr. Robert Redfield and his colleagues at the Walter Reed Army Institute of Research were early proponents of this approach and much of the supportive evidence for the benefit of therapeutic vaccination has come from their work. The National Institutes of Health (NIH) has been relatively late in getting into the therapeutic vaccine field. Their main interest has been in developing vaccines to protect HIV negatives from infection. Several years and unknown dollars have been spent establishing a network, here and abroad, to test preventative vaccines - long before a candidate vaccine has even approached development.

In 1992, Congress allocated $20 million to be spent by the military to continue their research into the leading therapeutic vaccine product Vaxsyn (rGP160), developed by MicroGeneSys. This really got the attention of the NIH, which objected to Congress deciding which treatments and products would be researched. Such decisions had traditionally been the role of the NIH (although the military medical research establishment has been independent of their grasp). The NIH wanted the study done according to their design: a special Blue Ribbon committee was called, the AIDS community was consulted, and a multi-arm, long term, multi-product study was designed.

Somewhere along the way, several principles of research design were lost. While the data behind rGP160, discussed below, showed that it is the leading candidate vaccine, there is still no proof or definitive study to show that therapeutic vaccines help patients survive HIV disease. The fastest way to obtain such proof is to conduct a single agent, placebo controlled phase III trial. The statistics in such a trial are straight-forward and the data can be accumulated to reach statistical significance more efficiently than in a multi-arm study. After the leading candidate has been proven effective, it becomes the standard; secondary products can then be compared against the standard, with no placebo arm required. These studies are usually complex and long term (like ACTG 0175), but everyone enrolled receives some treatment, not placebo. Ultimately this limits the number of patients who receive placebo and answers the question of which product is best. If no standard treatment is proven before large multi-product, multi-arm trials are initiated, then placebo controls for each arm are necessary.

**Continued on page 5, GP160**

## NEW AZT STUDY VIEWED WITH CAUTION, CONCERN

*BY NICK BARTOLOMEO*

A brief evaluation of the world's largest HIV drug treatment trials to date suggests that AZT provides no added advantage to those in the early stages of HIV infection. But U.S. health officials and pharmaceutical industry representatives caution that the preliminary nature of the results, mid-course changes in the study design, and other aspects of the trial indicate that this conclusion should be viewed with caution.

The findings, reported in the April 3 edition of the British medical journal *The Lancet*, stem from a joint United Kingdom-French study known as Concorde. Since 1988, Concorde resesearchers have been following approximately 1,750 persons who initially tested positive for the HIV antibody but were without symptoms. Each of the study participants were randomized to one of two study arms: AZT at 1,000 milligrams per day (877 persons were in this group), or to a placebo. The study design called for each of the 872 on the placebo to be placed on AZT as soon as they developed any of the opportunistic infections characteristic of clinically-defined AIDS.

In their initial analysis, the European researchers could find no statistically significant difference between the AZT and placebo groups in the time it took to develop clinical AIDS or in the time to death.

However, the AZT group did demonstrate an initial increase in CD4 (otherwise known as T-4) cell counts, as compared to the placebo group. This pattern has also been identified in other studies. Apparently, this CD4 cell rise translates into certain clinicial benefits, including lessened risk of dying or developing AIDS during the first 12 to 18 months of AZT use. However, the Concorde researchers found that these early clinical benefits were not sustainable. After three years of AZT use, Concorde researchers concluded, there was no statistical difference in either the risk of developing AIDS or the risk of death between those receiving the drug and those on the placebo.

The researchers also noted that certain side effects, including nausea and anemia, occured in a higher percentage of those taking AZT versus those taking placebo. Such side effect findings have been demonstrated in numerous AZT trials in the United States, principally when AZT dosages were above the 500 milligram per day levels that are standard here.

The full analysis of the Concorde results will not be released until later this year. However, study researchers have expressed confidence that these preliminary results accurately represented the

**Continued on page 2, AZT**

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MARCH/APRIL 1993
VOL. 1, NO.2

A PUBLICATION OF THE NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

SPONSORED BY:
T² MEDICAL, INC.

# ALERT MEDICAL

## BUILDING A BETTER MOUSE TRAP

*BY ROBERT DARGA, M.D.*

Many in the HIV community have lost faith in reverse transcriptase inhibitors such as AZT, DDI and DDC as the answer to controlling HIV infection. Even the recent repor of test tube success with the new triple combination therapy (See *On the Pulse . . .*) has doubters, given the toxicities. Other classes of antiviral drugs (TAT Inhibitors and Protease inhibitors) have bogged down in development and are years away at best. This has left many asking "Where are the new approaches?"

The biotechnology company IDEC of LaJolla, California has hope for its newly developed HIV therapeutic, Theravir® which is designed to strengthen the body's immune response against HIV. Their technique, which grew out of similar successful work in developing anti-cancer therapies, uses mouse antibodies (Murine Monoclonal anti-idiotype antibodies). A Phase I clinical trial using Theravir® was initiated last January; the preliminary, unblinded results of the first 24 patients are intriguing and hopeful.

A few basic facts about antibodies are required to really understand the theory behind this product:

1) Antibodies are complex proteins which are produced by the immune system in response to substances which are recognized as being foreign, called antigens.

2) The antibodies have an active end and an inactive end. The active end of the antibody fits around a portion of the antigen it is trying to eliminate. This active end, also called the idiotype, has a unique three dimensional relationship with the antigen - like a glove on a hand.

3) The inactive end of the antibody protein is the same for all antibodies produced within a particular species. Antibodies taken from a donor can be injected into a patient without being recognized as foreign proteins; because they are the same, no immune reaction occurs.

4) Antibodies from another species, with a different composition of their inactive ends, are recognized as foreign and a strong response is mounted to eliminate them. New antibodies are produced against the other species' antibodies. If mouse antibodies are injected into a human new anti+mouse antibodies are produced -- the HAMA response, Human Anti+Mouse Antibodies.

With that information as background, let's look at how these antibodies may work. In humans, the CD4 receptor appears on the ▶

## DNCB: COMMON PHOTOCHEMICAL ALLEGED TO DELAY HIV

*BY NICK BARTOLOMEO*

An inexpensive and readily-available chemical, used for years in color photography development, may be beneficial in fighting HIV infection in its early stages. DNCB, which is shorthand for the chemical dinitrochlorobenzene, has been in the arsenal of "underground" HIV treatments for at least six years. Diluted with a solvent and applied to the skin, the chemical has gained a large following of persons who believe it is effective in blocking certain workings of HIV. This belief is now supported by at least one DNCB study, the work of a San Francisco research team. Their results were presented last summer at the VIII International Conference on AIDS in Amsterdam.

### *STUDY REPORTS DELAY IN HIV PROGRESSION*

The researchers, headed by California Pacific Medical Center Immunotherapist Dr. Raphael Stricker, conducted a pilot study of 20 gay men who were HIV-infected but had not yet progressed to clinically-defined AIDS. Included in the study were persons who had either taken no antiretroviral therapy, or had been on stable doses of these therapies for six months or more. No other drugs besides the antiretrovirals AZT, ddI, and ddC were used by the patients prior to the study.

The goal of the researchers--determining if DNCB had any effect on HIV infection--was built on recently-discovered evidence about HIV and dendritic and Langerhans cells. These cells, which are present in skin and mucosal tissue, have been shown to act as a significant "reservoir" of infection for HIV. But most importantly, the dendritic and Langerhans cells have a direct effect on the immune system's ability to bring disease-causing organisms—including HIV as well as the microbes that cause HIV-related illnesses—to the cells that normally destroy them. This, many researchers believe, is primarily why HIV can so devastatingly cripple the immune systems of those infected with the virus.

DNCB is believed to act on the dendritic and Langerhans cells and, in essence, restore their immune system functions. Working from this premise, the researchers diluted DNCB with the solvent acetone to a wide range of concentrations and applied it to the skin of patients, eventually reducing the application of the chemical until it caused no adverse skin reactions.After continued application and up to 20 months of follow-up, the researchers noted several promising results. The 16 patients that completed the entire follow-up had only a slight decrease in CD4+ cell counts, from an average count of 347 prior to the study to 343 at the end of monitoring. Another crucial immune ▶

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Talking About AIDS

6pgs

NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

# TALKING ABOUT AIDS

# THE NATIONAL ASSOCIATION OF PEOPLE WITH AIDS (NAPWA)

## *1992-1993 Board of Directors*

### *Jack D. Markham, President*

Mr. Markham is a person living with AIDS and founder/President of the Positive Action Coalition of Kansas. He is a member of the Kansas HIV Ryan White, Title 2 Advisory Committee and primary speaker for AIDS risk reduction for Northeastern Kansas. He has been the recipient of the Toby Award recognizing outstanding volunteer activities in Topeka, Kansas. Mr. Markham served as an officer on the Board of Directors of the Topeka AIDS Project. He is currently the editor of the only Kansas statewide HIV/AIDS Newsletter and has been a guest writer for the "Lifetimes," a publication of Stadtlanders Pharmacy's Lifetime Program. His professional background is in sales and marketing.

### *Patricia Wetzel, M.D., Vice President*

Dr. Wetzel was infected with HIV by an accidental needle stick while treating an HIV-infected patient in 1991. Dr. Wetzel's specialty is family medicine, and she is a Medical Consultant with Caremark, Inc., and Attending Physician for the HIV unit of John Peter Smith County Hospital, Ft. Worth, Texas. Dr. Wetzel travels throughout the country speaking on HIV and occupational exposure issues. Dr. Wetzel and her husband, also a physician, live in Forth Worth.

### *Thomas Berg, Treasurer*

Mr. Berg lives in St. Paul, Minnesota and is the Senior Program Officer for The McKnight Foundation. Since 1986, Mr. Berg has been responsible for the funding of AIDS-related program initiatives in the State of Minnesota. He has 20 years experience in nonprofit management and philanthropy. Mr. Berg has served on the National Board of the Girls Clubs of America, the University Film Society, the United Way of Minneapolis and the Council on Foundations.

### *J. Kevin Wood, Secretary*

Mr. Wood is an African American living with HIV in San Diego, California, where he is a regionally recognized expert in higher education administration. He is very active in San Diego's community-based AIDS response where he has served as Chair of the Board of the AIDS Assistance Fund. He is Dean of Students, San Diego City College, and a Ph.D. candidate in Educational Leadership and Administration at the University of San Diego.

### *Marcy Chapin*

Ms. Chapin is Senior Foundation Officer at the AT&T Foundation in New York City with funding responsibilities for more than $12 million in grants annually. Ms. Chapin has been instrumental in marshalling AT&T national philanthropic response to HIV disease. She is a nationally recognized expert in nonprofit management and service delivery.

### *Bart Casimir*

Mr. Casimir is an African American living with AIDS. He is presently Health Educator for the San Francisco Department of Public Health where he conducts AIDS education sessions for high risk youth in continuation high schools and numerous out-of-school settings. Mr. Casimir has been Community Liaison for the Black Coalition on AIDS and was a consultant in AIDS Education and Training for the Multicultural Training Resource Center, both in San Francisco. His extensive community involvement includes serving as a member of NIH's AIDS Program Advisory Committee, and Chair, People with AIDS, San Francisco.

### *Kathleen Gerus*

Ms. Gerus is a wife and mother living with HIV in Detroit, Michigan. Her husband is a hemophiliac who was infected through using contaminated blood products. Ms. Gerus is co-founder of Detroit Area Women's Support Group, which focuses on hemophilia and HIV issues, and is co-chair of the Women's Advisory Committee of the National Hemophilia Foundation. She works part-time as an AIDS educator with Midwest AIDS Prevention Project. In 1992, Ms. Gerus was one of fourteen Americans honored by Congress as a recipient of the first *Pathfinders Awards* in recognition of leadership, achievement and commitment to the fight against HIV/AIDS.

### *Sam Matheny, M.D.*

Dr. Matheny is currently professor of medicine at the University of Southern California in Los Angeles, California. From 1986 - 1991, he was Chief of HIV Services for the Health Resources Services Administration in Rockville, Maryland. While at HRSA, Dr. Matheny designed and implemented the Federal Government's service programs for HIV disease.

### *Ruben Garcia*

Mr. Garcia is a person living with AIDS in San Antonio, Texas. He established the HIV testing program at the San Antonio AIDS Foundation, where he also served as a counselor, case manager and grants manager. Mr. Garcia is currently a member of the Board of Trustees at the Foundation and was recently elected Secretary of the Boxar County HIV/AIDS Consortium. In addition to his activities as a member of the Board of Directors for the San Antonio PWA Coalition, Mr. Garcia educates junior and senior high school students about HIV and AIDS through the San Antonio Wedge Program.

### *Robert McBride*

Mr. McBride is a person living with AIDS and is a benefits design analyst at the Gillette Company in Boston, Massachusetts. Mr. McBride was instrumental in the development of Gillette's corporate personnel AIDS programs. He is very active in the Catholic Church's AIDS program, and is a frequent AIDS educator with church-related audiences. He is a member of the New England Corporate AIDS Consortium, a member of the board of directors of both the Names Fund for AIDS Services and the Ecumenical Task Force on AIDS.

# WILLIAM J. FREEMAN

**Executive Director**
**National Association of People With AIDS**

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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. Mr. Freeman also served as Executive Director of the AIDS Assistance Fund in San Diego from 1989 to 1990, where he increased the visibility of the multicultural organization and worked to include San Diego as a Title I disaster relief city for Ryan White CARE funding. 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.

# A. CORNELIUS BAKER

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

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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.

# ROBERT J. DARGA, M.D.

**Director of Programs**
**The National Association of People With AIDS**

---

As the Director of Programs for NAPWA, Dr. Darga is responsible for designing and administering the organization's Information and Referral Services, National Speakers Bureau and NAPWA-Link, a computerized AIDS information bulletin board system.

Robert J. Darga, M.D. was Director of Education Programs for Lifelink, Inc., where he directed the development of the Peer Education Program, providing guidelines for implementation of the program, and was also responsible for production of quarterly financial reports and the database which tracks participants.

Dr. Darga has done many public speaking engagements about HIV/AIDS: He moderated a panel discussion "Update from the 7th International Conference on AIDS" and was interviewed about the issues surrounding HIV and health care workers for a BBC Television production entitled Heart of the Matter.

Dr. Darga was previously a marketing representative with Metropolitan Washington Blood Banks, Inc., of Silver Spring, Maryland, producing marketing materials for donor programs and connecting area physicians with blood bank services. He was Independent Medical Examiner for ASB Meditest of Arlington, VA, where he performed mobile screening examinations for employers and the insurance industry. Dr. Darga was an associate with a private Internal Medicine and Pediatric practice in Laurel, MD, from 1988-89.

In 1984 Dr. Darga received his Doctor of Medicine from the University of Michigan, where he was President of the Phi Chi Medical Society. He completed his post-graduate training at Loyola University Affiliated Hospitals, Stritch School of Medicine in 1988. He is certified by the American Board of Internal Medicine and is eligible for certification by the American Academy of Pediatrics.

# JAMES A. MCCLAIN

**Director of Institutional Affairs**
**National Association of People With AIDS**

---

As Director of Institutional Affairs, Mr. McClain is responsible for designing and implementing NAPWA's fund raising, membership, marketing and public relations. Mr. McClain has more than ten years of broad-based fund raising and management experience with international, national and regional education, cultural, medical, mental heath, research and religious nonprofits organizations.

Prior to joining NAPWA, Mr. McClain served as Vice President of The Sheridan Group, a Washington based fundraising consulting firm. He conducted numerous multi-million dollar capital and endowment campaigns, planning studies and provided strategic counsel for a diverse range of nonprofits including Meridian House International, University of Maryland College of Engineering, Allentown Art Museum, St. Luke's House, The American Council on Transplantation and Mount Vernon Ladies' Association.

Before joining The Sheridan Group, he created the development program at Suburban Hospital, Bethesda, Maryland, where he served as the first director of development after successfully directing a $2.6 million capital campaign.

Mr. McClain also served as Assistant Director of Annual Funds at The Catholic University of America for four years, where he was responsible for direct mail and phonathon campaigns which raised $1 million annually.

He has been a contributing writer for The Taft Group's *The Donor Developer* and *FRI Monthly Portfolio*, and a contributing author in Marketing Your Consulting and Professional Services ("Using Direct Mail," 1990).

Since 1989, Mr. McClain has served on the Board of Directors of Whitman-Walker Clinic, which is the primary provider of HIV/AIDS services in the Washington metropolitan area. Mr. McClain also serves as Chair of Whitman-Walker Clinic's Alcohol and Substance Abuse Services Program.

He received a Bachelor of Art degree from West Virginia Wesleyan College in 1973 and has completed graduate studies at The American University and The Catholic University of America.

# NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

## *Corporate and Foundation Donors*
*1991-1992*

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Accelerated Benefits of New York
Aetna Foundation, Inc.
American Foundation for AIDS Research (AmFAR)
American Life Resources Corporation
Arnold & Porter
Astra Pharmaceutical Products, Inc.
AT&T Foundation
Broadway Cares/Equity Fights AIDS
Burroughs Wellcome Corporation
Caremark, Inc.
Critical Care America
Design Industries Foundation for AIDS (DIFFA)
Fox Broadcasting Company
Home Intensive Care, Inc.
Kent Richard Hofmann Foundation, Inc.
Independence Life
Intracorp
John F. Kennedy Health Care Foundation, Inc.
Legacy Benefits Corporation
Levi Strauss Foundation
Lifetime Options, Inc.
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New York Life Foundation
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Public Welfare Foundation, Inc.
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NATIONAL ASSOCIATION OF PEOPLE WITH AIDS
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TEL (202) 898-0414 • FAX (202) 898-0435



NAPWA

PHOTOCOPY
PRESERVATION

Jan. 28th

Dear Kristine,

RWS has contacted us and wishes to proceed with fund. discussion regarding "Blueprint for Action". Thank you for all you did to help this along.

Warm regards,

Bob

NATIONAL AIDS POLICY OFFICE
OFFICE OF THE COORDINATOR

**ROUTING SLIP**

**DATE:** _____

**TO:** Bob Jackson

_____

**FROM:** ✓ **W. STEVE LEE**

_____

_____ For your information

✓ For your action _____

_____

✓ Review and comment by (date) 7/8

_____ Prepare reply for Coordinator's signature

_____ Reply directly and blind copy Coordinator

_____ **Circulate/**forward to: _____

_____ File

**COMMENTS:** Bob, make this a priority. The letters that need reply can follow. Thanks

SA

NAPWA

NATIONAL
ASSOCIATION
OF PEOPLE
WITH AIDS

*Via Courier*

March 1, 1994

Kristine Gebbie
National AIDS Policy Coordinator
750 17th Street, N.W.
Suite 1060
Washington, D.C. 20500

**Re: Robert Wood Johnson Foundation,**
***"Activating a New Paradigm for Care Giving"***

Dear Kristine,

As you are aware, The Robert Wood Johnson Foundation has given a significant "green light" to our request for support for our proposed action strategy. I am enclosing two copies of the revised draft proposal that we are preparing to send to RWJ. We are very interested in your comments.

It is very important to NAPWA and ultimately to our ability to secure RWJ funding that our proposed workplan meet with your approval. You will notice that this project is positioned as a collaboration with your office. **Would you please review the enclosed and let me know your thoughts on the proposal's vision and implementation strategy by Tuesday, March 8th?** We would like to incorporate your comments and recommendations into the final draft that will be sent to RWJ.

Our grant review meeting is scheduled for Wednesday, March 23rd in Princeton. We are very pleased that you will attend the meeting. Steve Schroeder will also attend.

We are planning a day-long meeting at Hill and Knowlton's Washington office in mid-March to prepare for the March 23rd grant interview. Your attendance, at least for part of the planning session, would be of great help as we prepare our presentation strategy. For obvious reasons, it is imperative that we are all "singing from the same hymnal". **Would you have someone from your staff contact me to see if we could schedule 60-90 minutes with you to prepare for the March 23rd meeting?** Naturally, we could meet in your office if that is more convenient.

*1413 K Street, N.W.,*
*Washington D.C. 20005*
*Phone: (202) 898-0414*
*FAX: (202) 898-0435*

[63] From: Bob Jackson 3/7/94 2:47PM (2984 bytes: 47 ln)
To: Kristine Gebbie, Andrew Barrer
cc: Timothy Fox, Carlos Velez, Arthur Lawrence, Steve Lee
Subject: NAPWA Proposal
---------- Message Contents ----------

At 1:15pm Today, I received a large packet from Steve with a note asking me to "make this a priority". and to review and comment by tomorrow. It had apparantly been received by courier last Monday 3/1/94.

The packet contained two copies of a proposal to spend almost 500,000 dollars to hold a two day meeting for 50 movers and shakers. $300,000 going to Hill and Knowlton, PR Firm. The description of the goals and objectives of this meeting overlap considerably with what might be expected from our new Advisory Committee.

I talked with ART, TIM, BOB M., ANDREW, and CARLOS. Only Carlos had any knowledge of this and all he knew was that Freeman had asked him last week to help get this to KG's attention. KG was out of town. Nobody on the staff has been involved in this proposal's development. Under those circumstances it seemed very strange that we were being touted as the major collaborator with NAPWA.

My scrutiny of the proposal is obviously superficial given the times involved but I am very uncomfortable having our name and credibility attach to this proposal--particularly with the Robert Wood Johnson people. RWJ is too valuable a resource for us to waste on puffery. All the background for this proposal seems to be based on the earlier NAPWA tome called "HIV in America: A Report by the National Association of People with AIDS". It was and remains a very weak document with lousy statistics, and conclusions which are not in any way supported by the data such as it was.

I will, of course, say no more that is negative and find some positive things to say if so directed but at the moment I am very uncomfortable about this. Before knowing that KG had any kind of investment in this, Carlos, Art and I all came to the same conclusions: That we were being put on the spot; there was inadequate time for a thorough review and response; and it was unlikely that such comments would result in any improvement in the proposal.

I believe that an honest expression of our feelings about the quality of this proposal would (and should) probably kill it with RWJ. There are much better uses for $500,000. It is, also, a not very subtle way to spend lots of RWJ money on indirect lobbying for Ryan White. I have some discomfort about our being involved in that aspect of it as well.

[78] From: Kristine Gebbie 3/7/94 6:55PM (1448 bytes: 18 ln)
To: Bob Jackson, Andrew Barrer
cc: Timothy Fox, Carlos Velez, Arthur Lawrence, Steve Lee
Subject: Re: NAPWA Proposal
---------- Message Contents ----------

I'm sorry that I did not get any information to others earlier--I think Buck was involved in some of the earlier discussion. This came up over several meetings with NAPWA. The involvement with us was their hearing our earliest conversations about wanting some approach which would assure regional/local input into the new National Advisory Committee. They had failed with their earlier proposal. I did talk with RWJ--the earlier proposal never got serious consideration, because it came in at a time when RWJ was pulling back a bit from HIV issues. They are now willing to reconsider some approach to community involvement, and our comments/relationship would be significant to the decision making process. I don't want to suddenly become a wet blanket, given that we have been encouraging so far. BUT we cannot put our names to something that we think won't work at all. Thus, our comments need to be constructive, in a positive direction, and should tie this in with our ideas for the Advisory Committee. I hope this helps.

Window: 1 - 24 Lines: 23 Edit: ↑ ↓ → Help: F1 End: ENTER

[1] From: Bob Jackson 3/8/94 11:48AM (3456 bytes: 53 ln)
To: Kristine Gebbie, Andrew Barrer
cc: Timothy Fox, Steve Lee, Terry Beswick, George Walter, Carlos Velez, Arthur Lawrence
Subject: NAPWA Proposal
Draft message
---------- Message Contents ----------

The Cluster Leads met this morning and discussed the NAPWA Proposal. Everyone is sensitive to the "wet blanket" concerns expressed in your memo, KG. We remain unanimously concerned and negative about participation of almost any sort in the NAPWA project.

I have carefully reread the proposal in light of your e-mail looking for anything that suggested it had any way of contributing to the local/regional input into the Advisory Committee. The Leads have all read it looking for ways we could be constructive and positive about any aspect of it. I reiterate, we were unanimous. Nothing in the current proposal qualifies--Only a major revision in both concept and content would be sufficient to get any support.

The proposal's title page shows us as a collaborator with NAPWA--almost a partner. Contained on page 12, third paragraph is the entire depiction of what our role will be. The role described is vague and limited. It certainly does not fit that of a collaborator. What it fits, of course, is someone whose title and personal credibility are being used in order to give credibility to someone else.

Collaboration is a word that carries the connotation of partnership--a buy in on concept, methods, and OUTCOMES. We do not want to be in that position since it is very likely that the recommendations will in some cases turn out to be in conflict with WHITE HOUSE and DHHS positions. All of us feel that our Office and its Boss need to be very careful about collaborating with anybody on anything since it could establish a precedent which could result in every HIV/AIDS related proposal--be it research, policy, service, prevention, etc.--ending up in our Office expecting support. Apparantly this is something which has been studiously avoided in the past and we believe should continue to be as a matter of policy.

Carefully worded but very clear proscriptions on any kind of free lance sharing of ideas or recommendations on health care reform, other than those which are specifically contained in or have been approved in advance by appropriate WH or Secretarial level staff, are surfacing. One of the agenda items on the NAPWA menu is health reform changes. We do not want to get in the position of appearing to be advocates of disparate points-of-view through our "collaboration."

If it is your desire to involve us as participants, consultants, co-sponsors, collaborators, etc. in any projects especially those which emanate from entities outside of government, we suggest that you insist upon active participation by a member of our staff in the

development of and the writing of any proposal. We also believe that you should insist upon at least 30 days of review time so that you can be in a position to get thorough review and research by your staff and, in the event that we have major problems with a project, that there will be time for the primary sponsor to redo their proposal.

The responsibility for the failure of this proposal to meet your expectations, for the short time frame, for the failure to invite someone from your staff to participate, for the weak and extravagent proposal are all clearly with NAPWA. If they are unable to get RWJ to spend $500,000 on this due to our non-collaboration, that too is their problem. It is also probably the right thing to have happen.

We are sorry that you have been put in this position but see no alternative but to recommend that you tell Freeman that he needs to take our Office out of the proposal.

NAPWA

**NATIONAL ASSOCIATION OF PEOPLE WITH AIDS**

# NAPWA Fact Sheet

NAPWA is dedicated to providing a national voice for the needs and concerns of all people impacted by HIV/AIDS and to fostering a richer quality of life for those infected with HIV. NAPWA provides effective strategies for preventing, coping with and treating HIV. Of major importance, NAPWA brings together people, organizations, business and government in order to build a responsive healthcare system for people with HIV/AIDS.

**NAPWA's programs include:**

- ***National Speakers Bureau***: a national network of speakers
- ***NAPWA-Link***: a computerized AIDS information bulletin board
- ***National Skills Building Conference***: the nation's largest annual training program for community-based AIDS organizations
- ***Information and Referral Service:*** answers requests from people and service providers for AIDS prevention and medical information and other information pertaining to HIV infection
- ***Publications***: *Living HIV*, a quarterly publication, and *the Medical Alerts*, bi-monthly HIV/AIDS treatment updates

**Why NAPWA makes a difference:**

- NAPWA is for *everyone* concerned with and affected by the AIDS epidemic
- NAPWA is a national coordinating leader for people, nonprofit organizations, business and government
- NAPWA is an accessible national resource that reaches rural communities and lessens the isolation of people with HIV infection
- NAPWA empowers HIV infected people to take charge of their lives
- NAPWA serves as a reasonable voice on public policy issues at the national level

*1413 K Street, N.W.,*
*Washington D.C. 20005*
*Phone: (202) 898-0414*
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## THE NATIONAL ASSOCIATION OF PEOPLE WITH AIDS (NAPWA)

*Selected Accomplishments 1992 -1993*

- NAPWA testified before the U.S. House of Representatives Ways & Means Subcommittee on Social Security and Human Resources for greater inclusion of people with HIV/AIDS under Social Security Disability determinations, emphasizing recognition of HIV manifestations specific to women.

- *HIV in America* was released nationally; the landmark report, compiled from the first national survey assessing the needs of American with HIV/AIDS, addresses the issues of health care, finance, discrimination and violence affecting those with HIV/AIDS.

- NAPWA was one of 16 national participants in AIDS Watch '92, the first such coordinated effort to advocate for increased federal AIDS prevention and treatment efforts.

- NAPWA testified before the Antiviral Drug Products Advisory Committee in favor of the approval of rifabutin to prevent Mycobacterium avium complex (MAC), a deadly bacterial opportunistic infection afflicting people with advanced AIDS; the treatment was later approved.

- Our Promise to Remember: the 1992 National Skills Building Conference, co-sponsored by NAPWA, the National Minority AIDS Council and the AIDS National Interfaith Network, draws over 1,100 individuals representing 578 community-based HIV/AIDS agencies in 189 cities and 46 states.

- NAPWA testified before the Food and Drug Administration on behalf of Orasure, an oral HIV antibody testing device that will improve the ability to conduct widespread field testing.

- NAPWA's *Medical Alert*, a bi-monthly treatment and therapy update, was launched in January, 1993; over 30,000 now receive the publication free-of-charge.

- NAPWA advocated for changes in Medigap eligibility for people with HIV and AIDS; these provisions were adopted by the state of Nebraska and are under review in many states.

- NAPWA spoke on behalf of a proposed IRS tax-free ruling on the sale of life insurance policies by people with AIDS ("viatical settlements"); the measure was later approved.

# NATIONAL SPEAKERS BUREAU

## The National Association of People with AIDS

*David, 20, stood before a group of about 40 teenaged students at Beth Al Temple in Alexandria, Virginia. David looked out over the group and asked a question. "How many of you know someone who has AIDS?" Suddenly the room was very quiet. Two people timidly raised their hands. "Those of you who don't have your hands raised can put them up now. My name is David and I have AIDS."*

As HIV disease becomes less a distant issue and more of a reality in our daily lives, the necessity of educating Americans about this epidemic has grown. The National Speakers Bureau of the National Association of People with AIDS (NAPWA) provides schools, corporations, community groups, and professional organizations with the most effective weapon in the fight against AIDS: the voice of experience. Statistics give an audience a superficial understanding of the impact of AIDS; speakers who live with HIV disease on a daily basis can translate the numbers into human experience. The benefits of using the National Speakers Bureau are two-fold:

- The prevention message is conveyed more effectively by a peer who has been infected or affected by HIV disease. Such a person can relate the threat of HIV infection to the audience and personalize the risks.

- The speaker promotes assistance rather than isolation of people with HIV infection; the testimony of a person who lives with HIV on a daily basis conquers the fear and misinformation that complicates the acceptance of people with HIV/AIDS.

The National Speakers Bureau is unique in its ability to provide organizations across the country with a speaker qualified to address their needs. NAPWA maintains a vast national network of speakers, remarkable for its geographic and demographic diversity.

Whether you are looking for a way to achieve a more enlightened workplace or a classroom that understands the risks of transmission, NAPWA has the resources to find a speaker tailored to the particular audience, medium and issues.

For more information about the National Speakers Bureau, please contact Regina Sackrider or Christina Lewis at the National Association of People with AIDS, (202) 898-0414.

**NAPWA ■ 1413 K Street, N.W. ■ Washington, D.C. ■ 20005**

# Speakers Bureau Log
# Fiscal Year 93

| Date | Speaker(s) | Sponsoring Organization | Topic | Audience |
|---|---|---|---|---|
| 10/5/92 | 1 | Maury Povich Show | AIDS Education | |
| 10/8/92 | 1 | National Episcopal AIDS Coalition Annual Conference | Church and AIDS | 100 |
| 10/8/92 | 2 | National Skills Building Conference | Women and AIDS | 100 |
| 10/10/92 | 1 | National Skills Building Conference | Women and AIDS | 1000 |
| 10/10/92 | 1 | Nightalk | AIDS Education | |
| 10/11/92 | 1 | National Skills Building Conference | AIDS in the Workplace | 50 |
| 10/12/92 | 1 | Washington Post | Surviving Partner | |
| 10/14/92 | 1 | Charlotte Observer | AIDS Education | |
| 10/16/92 | 1 | Howard University | African Americans and AIDS in the Media | 20 |
| 10/18-19/92 | 1 | Northhampton PTA Allentown, PA | AIDS Education | 300 |
| 10/21/92 | 1 | Oprah Winfrey | Healing by Alternative Medicines | |
| 10/24/92 | 1 | Asians and Friends | Coping with HIV | 75 |
| 10/26/92 | 1 | CNN Cable News | AIDS Education | |
| 10/27/92 | 3 | Oprah Winfrey | Magic Johnson | |
| 10/27/92 | 1 | Flaherty-Zonis and Associates | AIDS Education | 40 |
| 10/28/92 | 1 | GW University Nursing Education | AIDS and the Americans with Disabilities Act (ADA) | 65 |
| 10/28/92 | 1 | GW University | Social Politics of AIDS | 20 |
| 10/28/92 | 1 | Flaherty-Zonis and Associates | AIDS Education | 40 |
| 10/29/92 | 3 | USA Today | Magic Johnson's Effect on AIDS Awareness | |
| 10/29/92 | 1 | National Association of Viatical Settlement Companies | State of the Epidemic, HIV in America | 38 |
| 11/3/92 | 1 | CBS-Wyoming | AIDS Patients and Suicide | |

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| 11/5/92 | 1 | Bethesda Rotary | AIDS Awareness - Understanding the Impact | 20 |
| 11/6/92 | 4 | Tampa Tribune | Public Speaking and AIDS | |
| 11/7/92 | 3 | Service Employees International Union | AIDS Education | 150 |
| 11/10/92 | 1 | Fox Channel Five | Insurance Capping after an AIDS Diagnosis | |
| 11/10-11/92 | 1 | Wyoming AIDS Education Project | AIDS Education | 100 |
| 11/11/92 | 1 | Colgate University Ithaca, NY | AIDS Education | 300 |
| 11/12-14/92 | 3 | American Society of Consultant Pharmacists | AIDS Education | 300 |
| 11/16/92 | 1 | St. Mary's College of MD | Living with AIDS | 300 |
| 11/17/92 | 2 | Boston Globe | Women and AIDS | |
| 11/17/92 | 1 | Pikesville High School | AIDS Education | 1000 |
| 11/17/92 | 1 | St. Mary's College of MD | Dealing with Death and Dying | 50 |
| 11/17/92 | 1 | Private School Conference, Princeton, NJ | Social Implications of AIDS | 100 |
| 11/17/92 | 1 | St. Mary's College of MD | AIDS and Politics | 200 |
| 11/19/92 | 1 | Howard University | Social Implications of AIDS | 30 |
| 11/19/92 | 1 | Western Kentucky, Bowling Green | AIDS in the Workplace | 250 |
| 11/27/92 | 5 | Sally Jessy Raphael | Women and AIDS | |
| 11/19-21/92 | 2 | National Conference of State Legislatures, St. Louis, MO | AIDS Education | 300 |
| 11/30/92 | 1 | Pan American Health Association | AIDS Education | 200 |
| 11/30/92 | 1 | Center for Population Options, D.C. | Peer Education (teens) | 12 |
| 12/01/92 | 1 | Small Business Administration | AIDS Education | 150 |
| 12/01/92 | 1 | SUNY Purchase, NY | AIDS Education | 25 |
| 12/01/92 | 1 | Colonial Beach High School Colonial Beach, VA | Living with AIDS AIDS 101 | 225 |
| 12/01/92 | 1 | Rainbow Partners Waycross, GA | Community Commitment and AIDS | 100 |
| 12/01/92 | 3 | Union High School, Union Co., NJ | Q&A: Living with AIDS | 600 |
| 12/01/92 | 1 | Red Cross, Nobles County, MN | AIDS in the Workplace | 200 |
| 12/02/93 | 1 | U.S. Public Health Service | AIDS Education | 80 |

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| 12/02/92 | 1 | U.S. Public Health Service | AIDS Education | 300 |
| 12/04/92 | 1 | CNN | AIDS and Young People | |
| 12/07/92 | 1 | Syracuse University | AIDS Education | 500 |
| 12/07/92 | 3 | Asahi Shimbun Newspaper (Japan) | AIDS Education | |
| 12/08/92 | 4 | Night Talk Boston, MA | Women And AIDS | |
| 12/09/92 | 3 | U.S. News and World Report | AIDS in the Workplace | |
| 12/10/92 | 1 | Office Kei (Japanese TV) | Women and AIDS | |
| 12/15/92 | 3 | American Psychiatric Association Office of AIDS | Women and AIDS | |
| 12/30/92 | 1 | ABC/Good Morning America | New Definition of AIDS, CDC | |
| 12/31/92 | 1 | UPI Radio | New Definition of AIDS, CDC | |
| 1/1/93 | 2 | Fox Channel 5, Washington | New Definition of AIDS, CDC | |
| 1/1/93 | 1 | CNN | New Definition of AIDS, CDC | |
| 1/4/93 | 1 | Fox Morning News | New Definition of AIDS, CDC | |
| 1/4/93 | 2 | Channel 7, Washington | New Definition of AIDS, CDC | |
| 1/7-8/93 | 1 | HRSA | Women and AIDS | |
| 1/11/93 | 1 | Pacifica National News | Impact of AIDS on communities of color | |
| 1/13/93 | 1 | Lifeguide | New Treatments and Testing | |
| 1/14,15 93 | 1 | National Education Association | Teachers and AIDS | |
| 1/16/93 | 26 | Franklin Institute Science Musuem, Phil., PA | Traveling Exhibit, "Faces of AIDS" | |
| 1/17/93 | 1 | CBS Street Stories | Mothers and AIDS | |
| 1/19/93 | 1 | National Public Radio | Death Disclosure Issues | |
| 1/22,23 24/93 | 2 | Wyoming AIDS Education | Peer Education | 35 |
| 01/27/92 | 2 | Northfield, Mt. Herman, MA | Women and AIDS | 800 |
| 01/30/93 | 1 | Masa Dobashi, Japan | AIDS and the Workplace | |
| 02/01/93 | 1 | Lear's Magazine | Women and AIDS | |
| 02/02/93 | 3 | Northern Virginia Community College/Red Cross | Living with HIV | 250 |
| 02/02/93 | 1 | Columbia Elementary PTA, Fairfax, VA | Discussing AIDS with Children | 60 |

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| 02/02/93 | 1 | Masa Dobashi, Japan | Living with HIV | |
| 02/03-05/93 | 3 | HRSA/PHS | Barriers to Care for African Americans | |
| 2/04/93 | 1 | Nassau County PTA, NY | Youth and AIDS | 150 |
| 02/05/93 | 1 | Funders Concerned About AIDS, NY | Patient Prospective of Case Management | 80 |
| 02/05/93 | 3 | Family Counseling Services, FL | AIDS and Prisons | |
| 02/08/93 | 1 | New York Daily News | Arthur Ashe and AIDS | |
| 02/15/93 | 1 | Seaton Hill College, PA | AIDS Education | 400 |
| 02/16/93 | 1 | Good Housekeeping/CBS Morning Show | Teens and AIDS | |
| 02/16/93 | 1 | School of American Ballet, NY | Teenagers and AIDS | 50 |
| 02/16/93 | 1 | U.S. Department of Labor | Black Youth and AIDS | 350 |
| 02/17/93 | 1 | East Strausburg Univ., PA | Living with HIV | 250 |
| 02/18/93 | 1 | Franklin High School, MD | AIDS Education | 1200 |
| 02/22/93 | 1 | Patapsco High School, MD | AIDS and Teenagers | 1100 |
| 02/24/93 | 1 | Washington Elementary, San Leandro, CA | Discussing AIDS with Children | 50 |
| 02/25/93 | 1 | Flint Ridge Prep School, CA | Living with AIDS | 400 |
| 02/26/93 | 1 | Career Teen World Magazine | AIDS in the Workplace | EST 500,000 |
| 03/01/93 | 2 | Shippensburg Univ., PA | Peer Education | 500 |
| 03/04/93 | 1 | Lambda Horizons, VA Tech | Women & AIDS | 200 |
| 03/04/93 | 1 | Friends Select School, Phil.,PA | AIDS Drug Development | 15 |
| 03/08/93 | 2 | Japanese Media | Living with AIDS | |
| 03/09/93 | 1 | AFL-CIO, LA | AIDS in the Workplace | 800 |
| 03/09/93 | 2 | Jerry Springer Show | Women and AIDS | EST 1,600,000 Homes |
| 03/10/93 | 2 | Lifetime Television | Women and AIDS | EST 56,000,000 Homes |
| 03/10/93 | 1 | Kemmer High School, WY | Living with AIDS | 600 |
| 03/11/93 | 2 | Verona High School, NJ | Living with AIDS | 450 |
| 03/12/93 | 1 | Howard University | Traditional/Complementary Therapies | 150 |

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| 03/15/93 | 1 | Neavis Public High School, MN | Living with AIDS | 200 |
| 03/15/93 | 2 | Young D.C. Newspaper | Young People with AIDS | EST 200,000 |
| 03/16/93 | 1 | NW Iowa Technical College | AIDS Education Workshop | 600 |
| 03/18/93 | 3 | T.V. Asahi, Japan | Long Term AIDS Survivors | |
| 03/17/93 | 1 | Japanese Media | Living with HIV | |
| 03/22/93 | 1 | Baltimore County Schools | Living with AIDS | 800 |
| 03/22/93 | 1 | SUNY Binghamton, Students | Living with HIV | 300 |
| 03/22/93 | 1 | SUNY Binghamton, Medical School | Living with HIV | 300 |
| 03/23/93 | 1 | Japanese Media | Living with AIDS | |
| 03/24/93 | 1 | Japanese Media | Living with AIDS | |
| 03/24/93 | 1 | Georgetown University | Colleges and AIDS | 200 |
| 03/25/93 | 1 | West Potomac High School | Living with HIV | 500 |
| 03/25/93 | 5 | NBC News, New York | Children with AIDS | |
| 03/26/93 | 1 | Queen Anne County Health Dept. | Teens & AIDS | 300 |
| 03/27/93 | 1 | AFL-CIO, KY | Working Women and AIDS | 200 |
| 03/29/93 | 2 | Tampa Tribune | AIDS in the Workplace | EST 800,000 |
| 03/29/93 | 1 | Grambling State University | Living with HIV | 100 |
| 03/30/93 | 1 | American University | Young People and HIV | 100 |
| 03/31/93 | 1 | Rehabilitation Management Corp. Chicago, IL | Insurance and AIDS | 1000 |
| 04/01/93 | 1 | Catonsville Community College, MD | Living with AIDS | 175 |
| 04/02/93 | 4 | HERO, Baltimore | Living with HIV | 500 |
| 04/02/93 | 1 | ABC News | AZT Research | EST 10,000,000 |
| 04/02/93 | 2 | Fox News | AZT Research | EST 200,000 |
| 04/02/93 | 1 | Congressman Deutsch | HIV Prevention Bill | |
| 04/02/93 | 1 | National Association of Equal Opportunity in Higher Education | AIDS and African American Educators | 40 |
| 04/05/93 | 1 | Howard University | Living with HIV | 20 |

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| 04/07/93 | 1 | WNYC | Health Care Workers and HIV | EST 3,000,000 |
| 04/07/93 | 3 | U Magazine (U of Conn.) | AIDS and College Students | EST 6,000 |
| 04/08/93 | 5 | Hunter School of Film, NY | Women and AIDS | 200 |
| 04/13/93 | 1 | EDN Magazine, Boston | AIDS in the Workplace | EST 150,000 |
| 04/14/93 | 1 | AIDS Alert | Concorde Study, AZT Research | |
| 04/14/93 | 2 | Walt Whitman High School, MD | Living with HIV | 1300 |
| 04/15/93 | 3 | ABC World News Tonight | AIDS Treatment | EST 10,000,000 |
| 04/15/93 | 1 | Baltimore Public Schools | Teens with HIV | 1000 |
| 04/19/93 | 1 | George Washington University | Public Policy and AIDS | 35 |
| 04/19/93 | 1 | Northern Arizona University | Living with AIDS | 150 |
| 04/19/93 | 1 | Coconino Co. Public Schools (2) | Teens and HIV | 1200 |
| 04/20/93 | 1 | Coconino Co. Public Schools (2) | Teens and HIV | 2000 |
| 04/20/93 | 1 | Sheridan School | Discussing AIDS with Children | 200 |
| 04/20/93 | 1 | St. Mary's College, MD | Alternative Lifestyles | 300 |
| 04/21/93 | 1 | WGBH, Health Quarterly | AIDS and Health Issues | EST 3,000,000 |
| 04/22/93 | 1 | NEA Health Information Network, MI | Living with HIV/AIDS | 50 |
| 04/22/93 | 1 | Conference on AIDS, MD | Youth and HIV/AIDS | 110 |
| 04/23/93 | 1 | American Federation of Teachers | Living with HIV/AIDS | 100 |
| 04/24/93 | 1 | Michigan Health Conference | Peer Education | 100 |
| 04/24/93 | 1 | Georgetown University | Students and AIDS | 200 |
| 04/26/93 | 1 | Baltimore Public Schools | Living with AIDS | 800 |
| 04/27/93 | 1 | NEA Health Information Network, CA | Living with HIV/AIDS | 15 |
| 04/28/93 | 1 | University of Scranton, PA | Young People and HIV | 1300 |
| 04/29/93 | 1 | Fox Television | Sex and Teens | EST 200,000 |
| 04/30/93 | 1 | G.W. University, Baltimore | Positive alternatives to pregnency | 40 |
| 04/30/93 | 1 | G.W. University, CPO | Living with AIDS | 30 |

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| 05/02/93 | 1 | Montgomery Co. Public TV | Living with HIV | |
| 05/04/93 | 1 | Howard University | Living with HIV/AIDS | 25 |
| 05/03/93 | 1 | D.C. Channel 7, Washington Area Consortium on HIV Infection in Youth | Teens and AIDS | EST 300,000 |
| 05/05/93 | 2 | Sparrows Point High School, MD | Teens and AIDS | 515 |
| 05/05/93 | 1 | Lakewood Middle School, NJ | Living with HIV | 700 |
| 05/05/93 | 2 | American University | AIDS and Health Care | |
| 05/07/93 | 1 | Baltimore County Schools | Living with HIV | 800 |
| 05/07/93 | 1 | SEIU | Living with HIV | 200 |
| 05/07/93 | 2 | Westwood High School, CA | Living with HIV | 150 |
| 05/08/93 | 1 | Hood College News | Living with HIV/AIDS | |
| 05/10/93 | 1 | Japanese Media | Living with HIV/AIDS | |
| 05/10/93 | 2 | Prince Georges Co. | Working With HIV/AIDS | EST 30,000 |
| 05/11/93 | 1 | Red Cross, Crosslink | Women and HIV/AIDS | 5000 |
| 05/11/93 | 1 | Group Health Association | AIDS Education | 15 |
| 05/12/93 | 1 | Japenese Media | Living with HIV/AIDS | |
| 05/13/93 | 1 | Glamour Magazine | Safer Sex | EST 2,000,000 |
| 05/13/93 | 1 | Howard County Schools (MD) | Living with HIV/AIDS | |
| 05/14/93 | 1 | Japanese Media | Living with HIV/AIDS | |
| 05/17/93 | 3 | Prince Georges' County (MD) Conference on HIV | Women and AIDS | 80 |
| 05/21/93 | 2 | Chevy Chase/Bethesda High School (MD) | HIV/AIDS and Youth | 1200 |
| 05/23/93 | 6 | 10th Annual Candlelight Vigil | Living With AIDS | 150 |
| 05/25,26/93 | 1 | National Football League | HIV/AIDS Prevention Training | 100 |
| 06/01/93 | 2 | Traditional Accupuncture Institute | AIDS and Alternative Treaments | 30 |
| 06/03/93 | 1 | Japanese Media | Living with HIV/AIDS | |
| 06/05/93 | 2 | Westover Consultants | Teens and HIV/AIDS | 40 |
| 06/12/93 | 1 | Screening of "Silverlake Life", TX, Lesbian and Gay Media Project | Living with HIV/AIDS | 300 |
| 06/28-30/93 | 1 | NIH Conference | HIV/AIDS Issues | |

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| 08/19-21/93 | 1 | Delta Sigma Pi, Grand Chapter | Living with HIV/AIDS | |
| 09/03-04-05/93 | 1 | National Council for Bereaved Parents | Losing a child to AIDS | 500 |
| 12/01/93 | 2 | VA Hospital, Sepulvida, CA | Living with HIV/AIDS | 200 |

DEPARTMENT OF HEALTH AND HUMAN SERVICES

file -

Mr. Cornelius Baker
Director of Public Policy
National Association of People with AIDS
1413 K Street, NW
Washington, D.C. 20005

Dear Mr. Baker:

I am responding to your letter of August 3 addressed to Secretary Donna Shalala supporting the need to conduct a federally-sponsored national minority HIV conference.

The Office of Minority Health (OMH) and other Public Health Service (PHS) representatives met with various community groups to discuss details for conducting such a conference. The anticipated date and format including expected outcomes were some of the issues discussed. I wish to thank you, Ms. Whiterabbit, and Mr. Valverde for your efforts as co-chairs of that planning meeting. Community involvement is always an important component of any planning and decision-making process.

The PHS is currently reviewing the various recommendations regarding the conduct of a national minority HIV conference in FY 1994. As soon as a decision is made, the co-chairs of the planning group and each of the planning committee members will be informed immediately.

Please be assured that the HIV-related experiences of the minority community are a priority within PHS. Thank you for your continued concern and support. A copy of this letter is also being sent to Ms. Renee Whiterabbit and Mr. Tom Valverde.

Sincerely yours,

Claudia R. Baquet, M.D., M.P.H.
Deputy Assistant Secretary for
Minority Health

cc:
Ms. Renee Whiterabbit
Mr. Tom Valverde

PREPARED BY:OMH/DPC/MMURGUIA/mm/8-20-93/301-443-9923
PHS Tracer No.: T59465 OS#: 9306250077

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| OMH | MMURGUIA | 8/24/93 | | | | | | |
| OMH | D. Seplowin | 8/29/93 | | | | | | |

June 23, 1993

NAPWA

NATIONAL ASSOCIATION OF PEOPLE WITH AIDS

The Honorable Donna Shalala, Ph.D.
Secretary of Health & Human Services
U.S. Department of Health & Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Shalala:

As you are well aware, the AIDS epidemic continues to take its deadly toll upon thousands of American citizens. Increasingly, that destruction is being burdened more and more in racial minority communities. In many of our people, such as black women of childbearing age, Latino and black children, and particularly gay and bisexual men, this disease is the leading cause of death. And as the Centers for Disease Control and Prevention recently reported AIDS is now the leading cause of death for men between the ages of 25 and 44 in 60 American cities and of women in nine.

The undersigned are writing to you as co-chairs of a community panel convened by the Office of Minority Health, U.S. Public Health Service to plan the next National Minority AIDS Conference. This conference originally scheduled for September 1992 was to serve as a follow-up to two previous such conferences the last of which was held in 1989. However, due to inaction by the Office of the Assistant Secretary for Health and the Public Health Service (PHS) agencies, this conference has now been postponed to March/April 1994. Since the postponement was announced over two months ago, continued delays and inaction now threaten the possibility of the conference occuring within that timeframe. We believe that the performance of the PHS in regards to the planning process for this conference is in many ways indicative of its lack of forthright action on behalf of our communities.

While some may question the validity of spending time and limited resources on "another" conference, we believe that without an extensive exchange of information within our specific populations and with one another much effort will be lost in our battle against this disease. We are equally committed to convening our communities to engage in a meaningful dialogue with officials of your department on relevant policies and program initiatives in order to develop serious opportunities for ending the

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unacceptable lack of attention to our communities needs.

As representatives of the diverse ethnic and racial populations who are grappling daily with the impact of this disease in our communities and in our own lives it is of profound urgency that we move forward. It saddens us greatly that repeatedly we have not received adequate support from the Public Health Service in addressing this disease in our communities. While we are grateful, for the support of the Office of Minority Health and the Centers for Disease Control and Prevention, we remain concerned that each agency of the Public Health Service has in some way failed to respond to the serious challenge of the impact of HIV/AIDS in communities of color.

We are greatly encouraged by your comments to the National Minority AIDS Council's Congressional Dinner on April 22. We look forward to your bringing about a broader discussion of our concerns and of your commitment to addressing the issues of HIV/AIDS as it relates to communities of color. Moreover, we are hopeful that in writing to you that finally your staff will immediately undertake an assessment of the response to date of the Public Health Service to the issues that have been repeatedly brought to its attention by communities of color.

Sincerely yours,

A. Cornelius Baker

A. Cornelius Baker
Director of Public Policy

and on behalf of:

Renee Whiterabbit
AIDS Project Coordinator
Indian Health Board of Minneapolis

Tom Valverde
President
Hispanic AIDS Coalition of Greater Kansas City

DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Office of the Assistant Secretary
for Health
Washington DC 20201

William H. McBeath, M.D., M.P.H.
Executive Director
American Public Health Association
1015 Fifteenth Street, NW
Washington, D.C. 20005

Dear Dr. McBeath:

I am responding to your letter of August 3 addressed to Secretary Donna Shalala supporting the need to conduct a federally-sponsored national minority HIV conference.

The Office of Minority Health (OMH) and other Public Health Service (PHS) representatives met with various community groups to discuss details for conducting such a conference. Anticipated date and format including expected outcomes were some of the issues discussed. I wish to thank you and the American Public Health Association for your efforts at that meeting. Community involvement is always an important component of any planning and decisionmaking process.

The PHS is currently reviewing the various recommendations regarding the conduct of a national minority HIV conference in FY 1994. As soon as a decision is made, your organization--in addition to the other community groups involved--will be informed immediately.

Please be assured that the HIV-related experiences of the minority community are a priority within PHS. Thank you for your continued concern and support.

Sincerely yours,

Philip R. Lee, M.D.
Assistant Secretary for Health

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William H. McBeath, MD, MPH
*Executive Director*

August 3, 1993

The Honorable Donna Shalala, Ph.D.
Secretary of Health and Human Services
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Dear Secretary Shalala:

As you are well aware, the AIDS epidemic is the leading public health crisis of this decade. Increasingly, the burden of the AIDS epidemic is being borne by communities of color in the US. Because the AIDS epidemic has been so devastating to minority communities, the American Public Health Association (APHA) was pleased to be asked to serve on the community advisory panel for a federally-sponsored National Minority AIDS Conference. We believe the conference can provide a national forum for skills building, information exchange, as well as an opportunity to shape the national agenda.

This conference originally scheduled for September 1992, was to serve as a follow-up to two previous conferences, the last which was held in 1989. We were truly sorry to hear that the conference was postponed until Spring of 1994. APHA is becoming increasingly concerned about the fate of this meeting as there is not much time to get it organized. It is imperative that the Office of Minority Health be given adequate support from the Department to move forward with this important and much needed conference.

We look forward to working with the Department of Health and Human Services on this endeavor.

Very truly yours,

William H. McBeath, MD, MPH
Executive Director