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Meeting with Whitman Walker Clinic Person Living with HIV Committee 2/15/94

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WHITMAN·WALKER CLINIC INC

MAIN FACILITY
1407 S STREET, NW
WASHINGTON, DC 20009
202-797-3500
TTY 202-797-4449
FAX 202-797-3504

MAX ROBINSON CENTER
3920 S. CAPITOL STREET, SE
WASHINGTON, DC 20032
202-562-1160
TTY 202-562-1178
FAX 202-562-1240

NORTHERN VIRGINIA OFFICE
3426 WASHINGTON BOULEVARD
SUITE 102
ARLINGTON, VA 22201
703-358-9550
TTY 703-243-7243
FAX 703-358-9557

SUBURBAN MARYLAND OFFICE
7676 NEW HAMPSHIRE AVENUE
SUITE 111
HYATTSVILLE, MD 20783
301-439-0731
TTY 301-439-0733
FAX 301-439-2983

set-up for 1/27 @ 6:30
staff to go?...

January 10, 1994

Tucker Andrew
Bob 9

Ms. Kristine M. Gebbie, RN, MN
National AIDS Policy Coordinator
Office of National AIDS Policy
Executive Office of the President
Washington, DC 20500

Dear Ms. Gebbie:

Following our conversation at the recent World AIDS Day reception at the Old Executive Office Building, I am writing to invite you to meet with members of the Persons Living with HIV (PLHIV) Advisory Committee of the Whitman-Walker Clinic on Thursday, February 24, 1994 from 7:00 to 8:00 p.m. in the Austin Day Treatment and Care Center at Whitman-Walker Clinic, 1407 S Street, NW., in Washington, DC. We would be most interested in learning more about your plans and aspirations as our country's first AIDS "czar." We would also appreciate the opportunity to discuss with you our issues and concerns regarding increasing "empowerment" of HIV+ people.

The PLHIV Advisory Committee is composed of HIV+ individuals who are directly are served by Whitman-Walker Clinic, active as volunteers serving other PLHIVs, or employed by the Clinic. A number of our members serve on other Whitman-Walker Clinic operating and steering committees as well as its Board of Directors. The PLHIV Committee views itself as a networking vehicle for HIV+ "consumers" as well as a policy and planning voice for the needs and interests of HIV+ clients of Whitman-Walker. We believe that we bring certain experience and sensitivity to the decision-making process that is critical and essential on HIV/AIDS health care services and policies.

One of our Committee's main objectives is to promote increased empowerment of HIV+ individuals as a primary means for improving our health status, quality of life, and sense of community. Members of our Committee tend to reject a paternalistic model of HIV/AIDS care in favor of an empowering model of care. We know that long-term survivors of HIV disease are empowered people who are actively involved in decisions that affect their lives -- at the personal as well as the community level. We are striving very hard to create the space and means necessary so that all HIV+ individuals can gain this kind of power.

CELEBRATING 20 YEARS 1973 1993

We would be deeply honored to be able to share with you personally our ideas about empowerment. We would also welcome the unique opportunity to hear directly from you about the "State of the Union" with regards to research, education, and services for HIV disease, as well as about your ideas for ways in which HIV+ people can help your Office in its very important mission. I have suggested a time for our meeting above, which coincides with our regular monthly Committee meeting (fourth Thursday of the month). Please know, however, that we will make every effort to accommodate your busy schedule in order to arrange this special meeting with you.

I would be happy to discuss this matter further with your scheduler or other member of your staff. I can be reached at the U.S. Department of Justice, Office of Information and Privacy, 7238 Main Justice, Washington, DC 20530. My phone numbers are: (202) 616-5491 (work); (202) 462-4666 (home); (202) 514-1009 (fax).

On a personal note, it was a pleasure to be on the stage with you during the U.S. Department of Justice World AIDS Day Program, and to visit with you later that day at the reception at the Old Executive Office Building. I truly believe that your Office commands a powerful government force in the fight against AIDS, and I wish you continued success with your mission.

With best wishes for a Happy New Year,

Sincerely,

Jerry Roemer, Esq.
PLHIV Advisory Committee

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7979 NEW HAMPSHIRE AVENUE
SUITE 111
HYATTSVILLE, MD 20783
301-439-0731
TTY 301-439-0732
FAX 301-439-2933

February 1, 1994

Dear PLHIV Committee Colleagues:

This is just a quick note to inform you that our postponed meeting with Kristine Gebbie, National AIDS Policy Coordinator, has now been rescheduled. Ms. Gebbie has now agreed (again!) to meet with us at a special session on Tuesday, February 15 from 7:00 to 8:00 p.m., in the Group Room of the Elizabeth Taylor Medical Clinic, 1701 14th Street, NW. Although this is not our usual meeting time, this date was amenable to members who attended our meeting last week. I hope it will be convenient for many, if not all, of the rest of you, too. Ms. Gebbie will be accompanied by two of her staff – Paul Tran, who heads her Research Cluster, and Bob Jackson, who heads her Services Cluster.

As you will recall, the main theme of our meeting with Ms. Gebbie will be PLHIV empowerment. I would still appreciate hearing your suggestions on how to structure the meeting to make the most of this time. Please give me a call if you have any ideas. Please also try to arrive a few minutes early to the meeting in case we have to change rooms.

Just as a reminder, the next regular monthly meeting of our Committee will be on Thursday, February 24, 7:00-9:00 p.m. in the Austin Center Multipurpose Room of WWC's Main Facility, 1407 S Street, NW. The first hour will be our regular business meeting, including reports from various committees and subgroups. The second hour will focus on two separate issues which were proposed at our meeting last week. First, we will have a presentation by a medical professional/expert on the subject of tuberculosis and the HIV community. Second, we will invite someone from AIDS Action Council to meet with us to explain what they do with respect to policy development and lobbying on HIV/AIDS issues.

In case you haven't received a copy, enclosed are the final minutes of our November meeting with WWC Board President Bill Olwell. Minutes of our December meeting will be finalized next week.

I look forward to seeing you twice in February. Hope you are all well and staying warm. And, Happy Valentine's Day!

Yours,

Kris

Kris
(o) 202-473-1767 (h) 301-890-7171

CELEBRATING 15 YEARS

Enclosure

JEFFREY E.M. JOYNER
8302 49th Avenue
College Park, Maryland 20740
(301) 345-1789

BAR AFFILIATIONS:

- District of Columbia and Pennsylvania

EDUCATION:

UNIVERSITY OF NOTRE DAME, The Concannon Programme of International Law, London, England. Juris Doctorate, May 1989.

PRINCETON UNIVERSITY, A.B. Political Economics, June 1986.

ST. ALBANS SCHOOL, Diploma, June 1982.

THE GEORGE WASHINGTON UNIVERSITY SCHOOL OF MEDICINE, Master of International Public Health, May 1995.

HONORS:

University of Notre Dame Law School Scholarship Recipient; *Journal of Legislation* -- Development Editor and Book Review Editor; National Achievement Scholarship Recipient; Princeton Club of Washington Scholarship Recipient; Concourse Nationale de Francais (ranked ninth in nation).

EXPERIENCE:

Attorney-Advisor. Office of the Chief Counsel -- Export Enforcement and Litigation, U.S. Department of Commerce; Attorney Consultant/Compliance Specialist. Bureau of Export Administration, Department of Commerce, Washington, D.C. Represent the Office of Export Enforcement and the Office of Antiboycott Compliance in enforcement litigation matters before administrative review panels as well as in U.S. District Court. Advise these offices regarding the legal ramifications of actions taken prior to the formal referral of such enforcement cases to the Office of the Chief Counsel. Advise the Office of Antiboycott Compliance regarding current private sector international business practices, including questionable transactions structured to lie beyond the scope of the Export Administration Regulations. Counsel and assist both offices in developing methods of conducting effective investigations of transactions negotiated and finalized by United States entities abroad. Represent offices in settlement negotiations and in pre-hearing conferences. 1992 to present.

Attorney. Baker & McKenzie, Washington, D.C.
Advised clients regarding U.S. Export Control Regulations, Antiboycott Regulations (Commerce and Treasury), U.S. Customs matters and special sanctions maintained by the U.S. Government against specific countries. Advised clients on issues relating to questionable domestic and international business practices including those arising under the Federal Acquisition Regulations and the Foreign Corrupt Practices Act. Researched and drafted dispositive and procedural motions, and initial, response and reply briefs in civil litigation matters. Represented clients in pre-hearing/pre-trial conferences and in settlement negotiations before U.S. Government agencies and in U.S. District Court. 1990-1992.

Law Clerk. The Honorable Sylvia Bacon, District of Columbia Superior Court, Washington, D.C.
Drafted legal memoranda and decisions of orders regarding misdemeanor, civil, felony, and juvenile/neglect matters. Compiled and maintained judge's calendar. Performed extensive legal research and analysis. 1989-1990.

Legal Intern. United Nations Office of Legal Affairs - International Trade Law Branch (UNCITRAL), Vienna, Austria. Drafted memoranda regarding electronic international business transactions which served as Branch recommendations for the revitalization of inadequate and outdated regulations. Summer 1988.

Summer Associate. Baker & McKenzie, Washington, D.C.
Drafted numerous legal memoranda, petitions, client letters and sections of briefs in the areas of international trade and tax law. Performed extensive legal research and analysis. Summer 1987.

PUBLICATIONS:

"Electronic Documentary Transactions: Can the Existing Statutory Framework Govern this New Automating Medium?" 16 *Journal of Legislation* 1 (1989); "U.S. Customs Valuation of Imported Merchandise" in *Foreign Investment in the United States* (ed. Marc M. Levey, New York, J. Wiley Pub. Co., 1992).

REFERENCES AND WRITING SAMPLES AVAILABLE UPON REQUEST

Dr. Linda Markham
Fayetteville, Arkansas

a local doctor who has had patients with HIV for the last 10 years.

Mary Grace Sinnatt
(a former patient)

THE WHITE HOUSE

WASHINGTON

Health Care Reform and the HIV Epidemic
Top Ten Issues

For those infected with HIV, the assurance of comprehensive health insurance is an essential public health goal.

The Office of the National AIDS Policy Coordinator has provided advice on policy formulation during the development of the Health Security Act (HSA). These efforts were directed towards assuring adequate care and services for people with HIV/AIDS. As the Congress now debates the HSA, the Administration is making every effort to assure that modifications to the President's proposal maintain equity and sensitivity to the special needs of HIV-infected individuals.

Private insurance companies, like other businesses, seek to maximize profits by choosing only "acceptable" insurance risks. Under the HSA, universal coverage is guaranteed. Universal means everyone! What does Health Security mean to you?:

* **Universal coverage - HIV status or other health conditions do not prevent you from getting coverage.**
* **Community ratings prevent persons with HIV infection from being charged more for premiums.**
* **Prescription drugs will be covered.**
* **Ryan White CARE Act services will not be lost.**
* **Any form of discrimination is prohibited.**
* **Essential providers - specialists in treating HIV and AIDS will be available to all people who need them.**

Based on a series of focus groups with people with AIDS and HIV/AIDS service organizations, a list of "top ten" concerns for the HIV community were identified. Information regarding these concerns is attached for your review.

I hope this information will be helpful to you. If I can be of further assistance or provide any additional information, please contact me or Andrew E. Barrer, Ph.D. at (202) 632-1090. Thank you.

Kristine M. Gebbie, R.N., M.N.
National AIDS Policy Coordinator

Top Ten Issues

1. **Premium Financing and Risk Adjustment**

2. **Availability of and Assured Access to "Essential Providers"**

3. **Long-term and Home Care Coverage**

4. **Availability of Mental Health and Substance Abuse Services**

5. **Impact of the HSA on the Ryan White CARE Act**

6. **Medicaid and Medicare Funding and Program Transition Issues, especially as related to the Medicare and Medicaid programs**

7. **Confidentiality**

8. **Grievance Procedures**

9. **Effects of "State Options" on the HSA package of benefits**

10. **Funding for Public Health System Core Functions (e.g. Behavioral Research, Prevention Services, etc.)**

1. Premium Financing and Risk Adjustment

Issue: Will the risk adjustment mechanism prevent "redlining" for persons with HIV/AIDS or other life threatening illnesses?

Summary: Yes. Redlining, or any attempts to limit access to people with HIV or AIDS is clearly prohibited. The HSA provides mechanisms which require states to spread the financial risks associated with special communities by adjustments which would take into account such factors known to affect utilization of services, such as age, sex, health status and services to disadvantaged populations. The health plans have to meet specific rules on enrollment, community rating, information, and grievance procedures.

2. Availability of HIV Specialist, "Essential Providers"

Issue: Will HIV positive persons be able to continue using their local HIV medical specialist?

Summary: The Health Security Act establishes a special category of health care provider which is referred to as an "essential provider". Any health care provider or organization can make application to be certified as an essential provider. Within the HSA, a Ryan White grantee or subgrantee can be automatically certified as an essential provider. Each health plan must enter into a written agreement with each essential provider located within its service area.

3. Long-term Care and Home Health Care

Issue: Persons with HIV/AIDS often need home health care and long-term care services. Will the Health Security Act provide those needed services?

Summary: Home health care is included in the nationally guaranteed comprehensive benefits package. A new long-term care initiative will expand coverage of home and community-based care. This will make it possible for more elderly and disabled persons, including persons living with HIV/AIDS to live in their homes and communities while receiving long-term care. The Act will improve

Medicaid coverage for persons in nursing homes.

The HSA will improve the quality and reliability of private long-term care insurance and provide tax incentives for persons to buy it; and tax incentives to help individuals with disabilities work.

4. Availability of Mental Health and Substance Abuse Services

Issue: Mental health needs in the HIV/AIDS community tend to be greater than the average. What will HSA do to provide these services? Injecting drug users, at high risk of HIV infection and transmission, currently have inadequate treatment and preventive services available to them. Will adequate services be available to treat these individuals in order to ameliorate their additive disease and halt the epidemic?

Summary: A base level of mental health services will be provided to all persons through the Health Security Act. We know that viable mental health services are part of a good program of health care and especially beneficial to HIV infected persons.

In order to make a significant difference in the rate of new infections in the injecting drug use population and their sexual partners, the HSA will provide substance abuse treatment to everyone.

5. Health Care Reform and the Ryan White CARE Act

Issue: Will the financial restructuring of the health care system assure the delivery of health care services appropriate to the needs of vulnerable populations whose access problems go beyond lack of insurance?

Summary: The comprehensive benefits package provided by the HSA may not provide all essential services for persons with HIV/AIDS. Conversely, a variety of services currently provided by the CARE Act would be covered under the HSA benefits package. These would include primary care services, medications, assistance for health insurance coverage, home-based services, case management,

funds "freed up" by the provision of these services under HSA to subsidize the supplemental and client's share of insurance premiums, co-payments, deductibles, and expenditures that exceed spending caps.

The CARE Act is not a "band-aid" that can be discarded after health care reform. The Act will serve as a critical resource to sustain health care delivery systems and insure the continued delivery of essential and comprehensive health and support services to those infected with HIV.

6. Medicaid and Medicare Funding and Program Transition Issues

Issue: What impact will the HSA have on funding for the Medicaid and Medicare programs? What programs will be available during the transition from the old system to the one provided under the HSA?

Summary: Under the HSA adult Medicaid recipients who now receive cash supplements (currently 9 million beneficiaries) would be enrolled in the new system, but would not have to pay premiums. Further, they would be entitled to join a new state and federally-matched program providing wrap-around services similar to those now available under the Medicaid program. Children less than 18 years of age who are currently eligible or would be Medicaid recipients, with eligibility for wrap-around services (primarily based on poverty level), would be provided those services through a new federally funded (but state administered) program, ***regardless of their cash assistance status.***

The Medicare program will be preserved and strengthened under the HSA, which will add new coverage for prescription drugs and expanded coverage of home and community-based care.

7. Health Security Act (HSA) and Confidentiality Issues

Issue: What safeguards are envisioned for the handling of health information on HIV affected persons under the Health Security Act ?

Summary: The HSA addresses the issue of how information will be handled and what penalties will be imposed for misusing information. The HSA will provide guidance level information on creation of the oversight board, users and uses of information, privacy standards, enrollee rights, outright prohibitions, training of information handlers, and comprehensive health information privacy protection. The development of the Comprehensive Health Information Privacy Protection Act will be implemented within two years from the date of passage.

8. Grievance Procedures

Issue: How can individuals ensure that their health plan will provide the health benefits and services they require?

Summary: The HSA is intended to provide adequate health care coverage for all citizens and legal residents of the United States. The Act requires States to approve each health plan before it can engage in providing health care under the Act. The law prohibits exclusions because of pre-existing conditions or through "red-lining," the practice of excluding a particular group of individuals because of perceived high risk.

The Health Security Act includes a comprehensive grievance process for any person aggrieved by acts or practices which result in denial or delay of benefits or payments. Individuals must work within the individual plan's grievance process before going to adjudication through the Complaint Review Offices set up in each state. If there is a question as to an individual's eligibility for a plan, subsidies or cost sharing, the individual may go directly to court and all costs can be reimbursed if the court finds for the individual.

The complaint office must rule in under 30 days, although a 24 hour appeal is available in cases of emergency. Appeals must be processed within 60 days. There are means of appealing, with the national board being the ultimate administrative appeal.

9. "State Options"

Issue: What impact will "State Options" have on coverage under the HSA? What impact will it have on services, availability, and affordability?

Summary: Some states cover additional services under federally matched Medicaid programs. Under the HSA, a number of programs will become available at each state's option. To assure that there is not a loss of services to the person with AIDS, Ryan White will continue to act as the safety net to assure needed services reach all people in need. The expanded use of case management, will help follow individual needs and assure services are provided.

10. Public Health System Core Functions

Issue: What is the nature of the funding for research on behavior, health services and Core Functions of Public Health Programs?

Summary: The Health Security Act will provide funding for AIDS specific research and public health initiatives that will have to be provided under the authority of the Public Health System. Behavioral research into those behaviors that may cause or contribute to disease will be conducted by the National Institutes of Health. The Act will also provide funding for strengthening the public health core function of states, including those components related to diseases of public health significance. This support will allow communities to maintain strong programs to prevent the spread of HIV, tuberculosis, and other conditions of public health importance.