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Folder Title:

Correspondence - SLT - Incoming - 6/99 [2]

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Withdrawal/Redaction Sheet

Clinton Library

DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. resume	re: Jay Drosin [Personally Identifiable Information] [partial] (1 page)	06/01/1999	b(6)
002. resume	re: Jay Drosin [Personally Identifiable Information] [partial] [Duplicate of 001] (1 page)	06/01/1999	b(6)

COLLECTION:

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National AIDS Policy Office

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2018-0764-F

jm2095

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
- P2 Relating to the appointment to Federal office [(a)(2) of the PRA]
- P3 Release would violate a Federal statute [(a)(3) of the PRA]
- P4 Release would disclose trade secrets or confidential commercial or financial information [(a)(4) of the PRA]
- P5 Release would disclose confidential advice between the President and his advisors, or between such advisors [(a)(5) of the PRA]
- P6 Release would constitute a clearly unwarranted invasion of personal privacy [(a)(6) of the PRA]

C. Closed in accordance with restrictions contained in donor's deed of gift.

PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

Freedom of Information Act - [5 U.S.C. 552(b)]

- b(1) National security classified information [(b)(1) of the FOIA]
- b(2) Release would disclose internal personnel rules and practices of an agency [(b)(2) of the FOIA]
- b(3) Release would violate a Federal statute [(b)(3) of the FOIA]
- b(4) Release would disclose trade secrets or confidential or financial information [(b)(4) of the FOIA]
- b(6) Release would constitute a clearly unwarranted invasion of personal privacy [(b)(6) of the FOIA]
- b(7) Release would disclose information compiled for law enforcement purposes [(b)(7) of the FOIA]
- b(8) Release would disclose information concerning the regulation of financial institutions [(b)(8) of the FOIA]
- b(9) Release would disclose geological or geophysical information concerning wells [(b)(9) of the FOIA]

Drug Abuse Trends in Detroit/Wayne County

AIDS

Through July 1, 1998, a cumulative total of 9,581 AIDS cases, including pediatric cases, has been identified in Michigan. The injecting drug use (IDU) risk group continues to account for 30 percent of the total cases: 24 percent are sole IDUs, and six percent are IDUs who have engaged in male-to-male sex. Of the 359 cases identified during the first half of 1998, 21 percent were sole IDUs, and another three percent were in the dual risk group. Half of all cumulative AIDS cases among females are due to injecting drug use.

Statewide human immunodeficiency virus (HIV)-positive prevalence rate continues to be estimated at 2,210–3,105 IDUs and 510–690 IDUs who also engage in male-to-male sex; total HIV prevalence is estimated at 8,500–11,500 persons.

Only four of 83 counties in Michigan have no reported AIDS cases yet. Cases from Detroit/Wayne County account for 57 percent of cumulative cases statewide. Some 59 percent of cumulative AIDS patients have died.

HIV/AIDS is increasing especially among uneducated and unemployed persons in Michigan: 81 percent of HIV+ men and 57 percent of HIV+ women do not have a high school education. Four of every ten African American women and 57 percent of white women with HIV/AIDS were infected by heterosexual contact. New AIDS cases in 1997 show increases in women and young people between 20-29 years of age.

Over 40% of new infections
in Detroit are IDU related.

Black & white photo
of Sandy - send it
hard copy on PIF

Please draft letter - one is included - but we need to make it more 'White House-y' aka. more general about their commitment, less specific to what the program does. Use previous letters of rec. as a guide.

ASAP/
By end of this week?

=== COVER PAGE ===

TO: _____

FAX: 12024562438

FROM: C-HAG

FAX: 313-872-5546

TEL: 313-872-2424

COMMENT: CONFIDENTIAL

Fax

Name: Sarah
Organization: Office of National AIDS Policy
Fax: 202-456-2438
Phone: 202-456-2437
From: Harry L. Simpson
Date: June 17, 1999
Subject: CHAG Newsletter Article
Pages: Five (5), including this one

Sarah,

Thanks for agreeing to help out with this. Please contact me at (313) 872-2424, or by pager at (313) 328-8233 if you require additional information or clarification. The finished article can be sent via e-mail to: Harry1081@aol.com.

Thanks again.

A Message from
Sandra Thurman

I would like to take this opportunity to congratulate Community Health Awareness Group on the *Taking it to the Streets* program. The Centers for Disease Control and Prevention (CDC) has recognized this program as one of nine selected nationwide for the 1999 Characteristics of Reputationally Strong Programs project. This project promotes programs that are highly regarded by professional peers in the field and have strong reputations for preventing HIV in their communities.

Taking it to the Streets is a program that involves collaboration between CHAG and other Detroit service agencies to allow prevention education, behavioral interventions and all of the necessary prevention tools to get to those individuals who need it most. And just as the name implies, the program does this by reaching those at highest risk where they are at.

I have always been a strong advocate of using the best science available for prevention. Taking it to the streets incorporates well researched behavioral interventions that target injection drug users (IDUs) in Detroit. Preventing new HIV infections within the IDU population is very important to stopping the HIV epidemic.

The Michigan Department of Community Health reported in July that ____ % of the estimated HIV infections in the state are directly the result of injection drug use. If you add to that the number of their sex partners who became infected as well as the number of infants born to mothers who are IDUs, ____ % of the estimated HIV in Michigan is the result of injection drug use.

By combining harm reduction activities through the Life Points needle exchange program, health education, and HIV risk reduction counseling and testing with access to substance abuse treatment and other health services through collaboration with other agencies, CHAG's *Taking it to the Streets* provides a continuum of prevention strategies targeting substance users in Detroit's African American community.

This summer the CDC staff visited Detroit to see first hand how CHAG does this job so well. The CDC will now share this with other organizations developing HIV prevention programs for African American populations.

May 07 99 11:04a

CDC NRC

415 777 8601

p. 2



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

Date: March 24, 1999**To: Harry L. Simpson, Executive Director
Community Health Awareness Group****From: Behavioral Intervention Research Branch
Division of HIV/AIDS Prevention - Intervention Research & Support
Centers for Disease Control and Prevention****Re: Takin to the Streets has been selected for C-RSP 1999**

Congratulations! Takin It to the Streets is one of nine programs selected by CDC for the 1999 Characteristics of Reputationally Strong Programs (C-RSP) project. Thank you for responding to our request for materials and making it possible for your program to be selected.

The C-RSP project promotes programs that are highly regarded by their peers and have strong reputations for preventing HIV in their communities. The 1999 round of C-RSP will produce case studies that describe the characteristics of programs that show promise for preventing HIV infection in African American populations. The aim is to identify the characteristics shared by these programs that make a difference in HIV prevention and to share this information with other organizations that are seeking to design or further develop HIV prevention programs for African American populations.

Now that you have been selected the next step is for C-RSP staff to visit your project to observe your program in action and to interview program staff and participants. We want to emphasize that the purpose of this visit is not to evaluate your program. Rather it will provide an opportunity for us to learn first hand how you do your job so well. If you are still interested in participating in C-RSP, we would like to talk to you about when we can make this site visit. We will be contacting you in a few days to discuss this.

Again, Congratulations. It is clear that your hard work in the HIV prevention community is noticed by others. If you have any questions, please contact Sara McLanahan at (415) 777-8599.

Sincerely,

Ellen Sogolow, Ph.D.
Behavioral Intervention Research Branch
Division of HIV/AIDS Prevention - Intervention Research & Support
Centers for Disease Control and Prevention

Agatha Eke, Ph.D.
Behavioral Intervention Research Branch
Division of HIV/AIDS Prevention - Intervention Research & Support
Centers for Disease Control and Prevention

Sara McLanahan, MLS
Project Coordinator
Aspen Systems Corp.

May 07 99 11:04a

CDC MAC

415 777 8601

p.3



DEPARTMENT OF HEALTH & HUMAN SERVICES

Public Health Service

Centers for Disease Control
and Prevention (CDC)
Atlanta GA 30333

May 7, 1999

Harry Simpson
Executive Director
Community Health Awareness Group

Dear Mr. Simpson

Thank you for consenting to allow us to visit your organization to explore what factors contribute to making your HIV prevention program the success that it is. Your organization is one of nine programs that have been selected nationally for 1999 as a part of CDC's Reputationally Strong CBO Project. The goal of this project is to identify CBOs that have strong reputations for providing effective HIV interventions and then determine what works and why it works.

Just so there is no misunderstanding, we want to make it clear that our project is not related to any funding decision on the part of CDC: The information we gather will not be used to determine whether you do or do not receive CDC funding. We also want to make it clear that we do not have funds to pay fees for those who agree to participate in interviews.

When we visit you we will come with the intent of trying to understand what you are doing, who you are doing it for, and how you are doing it. As you are aware, our information gathering process will take the major part of two days. The two days that you suggested for the visit are May 17 and 18. Please accept this letter as confirmation that we have scheduled our travel plans for those dates. We expect to arrive at your office at about 9 A.M. on May 17 and hope to work until late afternoon. We hope to start working again on May 18 by 9 A.M. and again work until late afternoon. On both days we will be taking lunch around noon.

During the time that we are at your office, we hope to carry out detailed interviews related to your program. Ideally, we will interview the Program Director, key line staff, managers, volunteers, an evaluator, program clients and/or members of your target population, and people from outside the organization who are knowledgeable about your program. Below you will find a proposed schedule for our activity for May 17 and 18:

Day One

1. Interview with program director focusing on program development history, background and other basic information. (1.5-2 hours)
2. Interview with small group of key line staff/managers and volunteers focusing on the details of how program activities work. (2-3 hours)
3. Interview with program director and key line staff/managers focusing on staffing and organization as well as training and technical assistance issues. (1.5-2 hours)

May 07 99 11:04a

CDC NAC

415 777 8601

p.4

Harry Simpson
Day Two

1. Interview with program evaluator focusing on evaluation issues. (1-1.5 hours)
2. Mini-group interview with program clients and/or target audience members. (1-1.5 hours)
3. Individual interviews with small number of local HIV prevention leaders, one-half of whom actively and formally collaborate with the program in some way and one half who do not. These may be off-site and conducted by telephone, as necessary. (1-1.5 hours)
4. Interview with program director and key line staff/managers focusing on dissemination/replication issues as well as sponsoring organization issues. (1.5-2 hours)

Sometime During The Two Days:

1. Observation of program activities or promotional and outreach efforts. (As much time as possible, depending on the nature of activities and how they are scheduled.)

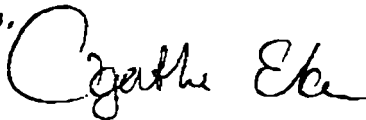
We would like to ask for your assistance in helping to coordinate our proposed schedule. If any of the people indicated in the above activities are unavailable for interview during the time we are in Detroit, we would like to schedule phone interviews at a later time.

Please know that your generous offer to allow us to come for a visit is much appreciated and your willingness to share what you have learned will be of great help to others.

If you have any questions or comments related to our visit, call Agatha Eke (404-639-1906) or Ted Duncan (404-639-5253).

We look forward to seeing you on May 17 and 18.

Sincerely yours,



Agatha Eke, PhD
Behavioral Scientist
Behavioral Intervention Research Branch
Division of HIV/AIDS Prevention/IRS/E-37
Centers for Disease Control and Prevention
Prevention/E-58
Atlanta, GA 30333
Phone: 404-639-1906
Fax: 404-639-1950
E-mail: aee2@cdc.gov

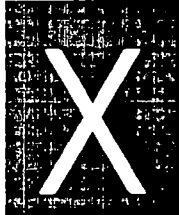
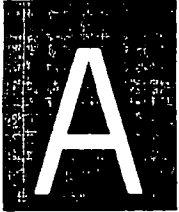
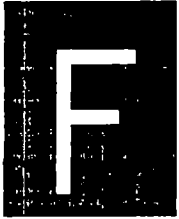
Ted Duncan, PhD
Behavioral Scientist
Community Assistance, Planning
and National Partnership Branch
Division of HIV/AIDS
Centers for Disease Control and
Prevention
Atlanta, GA 30333
Phone: 404-639-5253
Fax: 404-639-5258
E-mail: tfd11@cdc.gov

~~XXXXXXXXXX~~

TO: WHITE HOUSE OFFICE OF AIDS POLICY 2/6/99
ATTN: MS. SARAH THURMAN, DIRECTOR
FROM: ANGIE HENDRICKSON, WISCONSIN MOM
715-256-9748

I WAS SERIOUSLY INJURED 2 WKS
AGO TODAY PHONE CONTACT IS COSTLY
AT SLIM TIMES. PLEASE HELP ME
UNDERSTAND JUST EXACTLY WHAT
IT IS I'VE STUMBLERD INTO START-
ING WITH: WHO ARE THESE (C.O.T.T.
(COMMITTEE OF TEN THOUSAND) GUYS
AND WHAT HAVE THEY BEEN UP TO?
PLEASE TELL ME ABOUT
THE E.L.F. PROGRAM. I'M A
NICE PERSON WISHING DESPERATELY
TO SERVE A HIGHER PURPOSE. I
HATE THIS "DARKNESS" I NEED MY
LIFE TO BE DIFFERENT. PLEASE
HELP ME UNDERSTAND... GOD'S
BLESSINGS AND MY PRAYERS.

PEACE & HEALTH
-ANGIE HENDRICKSON
-ACTION= LIFE



A·D·A·P

Working Group

The AIDS Drug Assistance Program Future Funding Working Group

1775 "T" Street NW
Washington, D.C. 20009

Phone: (202) 588-1775
Fax: (202) 588-8868
e-MAIL Weaids@ix.netcom.com

To : Sandra Thurman
Company : Office of AIDS Policy Coordinator
Subject : Save the date
Pages : 2

From : William E. Arnold
Company : TII CANN
Date : 6/15/99
Fax Number : 202-588-8868

**SAVE THE DATE NOTICE FOR CONGRESSIONAL ADAP
(AIDS Drug Assistance Program) Briefing. FYI.**

Bill Arnold, The ADAP Working Group

— **SAVE THE DATE** —
Tuesday, June 22, 1998

**MEMBERS OF CONGRESS AND STATE HEALTH EXPERTS DISCUSS SUCCESS,
CHALLENGES OF AIDS DRUG ASSISTANCE PROGRAMS (ADAP)**

-- Predicted \$90.2M Federal Shortfall Threatens Life-Saving Program --

WHAT: Congressional Briefing sponsored by The ADAP Working Group

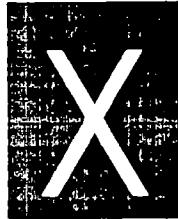
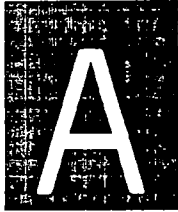
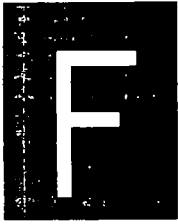
WHO: The Honorable Mark Foley (R-FL), U.S. House of Representatives
The Honorable Donna Christian-Christensen (D-VI), U.S. House of Representatives
Richard Moore, MD, Associate Professor, Division of Infectious Diseases, The Johns Hopkins University School of Medicine
Lanny Cross, Director, HIV Uninsured Care Program, New York State Department of Health
Joseph May, ADAP Program Manager, Florida Department of Health
Winnie Pressley, ADAP Client, Washington D.C.

WHY: **ADAPs serve as a lifeline** for thousands of people with HIV disease. The program provides life-extending AIDS medications to underinsured and uninsured Americans who otherwise cannot afford them. A projected \$90.2M increase in federal funding is needed in FY2000 to ensure all those who use the program will have access to treatments that meet the federal standard of care guidelines.

WHEN: Tuesday, June 22, 1998
Noon - 1:30 pm ET
Lunch will be served

WHERE: B-338 Rayburn House Office Building
Independence Ave. & South Capitol St. SW Washington, DC

CONTACT: For Press information: Kristina Becker, InterScience (202) 467-3909
For Administration staff and Congress (members & staff) for official invitation and RSVP instructions: Bill Arnold, The ADAP Working Group.
Phone: (202) 588-1775 Fax: (202) 588-8868



TII CANN

The Title II Community AIDS National Network, Inc.

1775 "T" Street NW
Washington, D.C. 20009

Phone: (202) 588-1775
Fax: (202) 588-8868
e-MAIL Weaids@ix.netcom.com

To : Sandra Thurman
Company : Office of AIDS Policy Coordinator
Subject : Tulsa Mayor letter
Pages : 3

From : William E. Arnold
Company : TII CANN
Date : 6/9/99
Fax Number : 202-588-8868

CC letter vfrom Tulsa Mayor fyi and files. *Bill Arnold, T8II8C*A*N*N
--

06/09/99

Congressman Tom Coburn
511 Cannon House Office Building
Washington DC 20515

Dear Congressman Coburn:

It is my understanding that you have requested an audit of HIV/AIDS programs from the US General Accounting Office.

While we share your concern that any federal funds should be spent wisely, in our community a consortium of providers working through Tulsa C.A.R.E.S. has created a model for delivery of services which has been emulated nation-wide. In Tulsa, no CARE funds are spent on housing, although a recent survey of people living with AIDS in our community showed that 41% needed housing.

The executive director of Tulsa C.A.R.E.S. manages sixteen employees and a \$1,000,000 budget. Of her annual salary of \$45,000, the Ryan White CARE Act funds \$9,000 for program oversight.

The Ryan White CARE Act will provide \$333,390 to Tulsa C.A. R. E. S in FY 1999 for programs. Services are provided to 541 unduplicated clients in prescription assistance, medical transportation, nutritional supplements and home health care for \$334,508. About \$150,000 was raised last year in contributions and a further \$1,000,000 is received from pharmaceutical companies in prescription assistance. The federal dollars are used to leverage private contributions.

Accessing medical care through an emergency room is estimated to be fourteen times more expensive than prevention and support services.

Since the number of infections is still rising steadily, and the fastest growing group of newly infected people is women, the Tulsa community is sponsoring a Women and AIDS

Congressman Tom Coburn
06/09/99
page 2

Conference in Tulsa on June 14. This event has no federal support but as part of an awareness that prevention and education are critical to control the epidemic.

We encourage you, or a member of your staff to attend the conference. Information about the conference may be obtained through Janis Nicklas at the Community Service Council in Tulsa. We encourage your support for the Ryan White CARE Act and the critical services it funds in the Tulsa area.

If you have any questions, please do not hesitate to contact this office.

Sincerely,

M. Susan Savage
Mayor

MSS/hk

Family AIDS Network, Inc.

MARY FISHER, FOUNDER

1601 N. Kent Street, Ste. 1003
Arlington, VA 22209
703 / 243-8276
703 / 243-8377 fax

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Marnie Martin Fletcher, *Secretary*
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Rodney Beck
Illinois

Stacey Beck
Illinois

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California

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Administrative Center

678 Front Street NW
Grand Rapids, MI 49504
616 / 451-2361
616 / 451-9180 fax

www.familyaidsnet.org

June 11, 1999

The Honorable Sandy Thurman
Director of National AIDS Policy
Executive Office of the President
736 Jackson Place, NW
Washington, DC 20503

Dear Sandy:

I can't imagine bringing this wonderful week to a close without sending you a note of thanks. Certainly, the highlight of the week was the marvelous tribute to Mary last Monday night. And it was the combination of your beautiful words at the dinner, the power of the show, and the purpose of the evening that made it so wonderful. Thank you so much!

When we began planning the event, I hoped that you might be willing to join us. You have brought such commitment to the fight against AIDS. And you do it in such a gracious (Rob would say "southern") way. You were the perfect person to speak on behalf of the National AIDS Community, thank-you.

On behalf of Mary, the Board and staff of the Family AIDS Network, and all of those touched by Monday evening's powerful moments, thank-you. Please know that our hearts and souls are filled with admiration, appreciation, and respect for who you are and all that you do.

Sincerely,



Steve Gunderson
Managing Trustee



AIDS Policy Center
For Children, Youth & Families

June 11, 1999

Sandy Thurman
Director
Office of National AIDS Policy
736 Jackson Place, NW
Washington, DC 20503

Dear Ms. Thurman:

On behalf of AIDS Policy Center for Children, Youth & Families and the participants in the Voices '99 conference, I would like to thank you for speaking at the event we held at the Capitol Triangle on May 25, 1999. We appreciate the time you took out of your full agenda to show your support and to help us dedicate Xavier Cortada's mural to people living with HIV and AIDS.

The gathering of numerous national leaders for this event was an important step in calling attention to the impact of HIV/AIDS on children, youth, women and families, particularly those who are people of color. Your presence at the event helped to sound the call that increased resources are needed to fight the HIV/AIDS epidemic at home and abroad.

Once again, thank you for lending your support to AIDS Policy Center and to the Voices '99 conference. We look forward to continuing our work with you in the future.

Sincerely,

David C. Harvey
Executive Director

Thanks Sandy!

*Looking forward to our
meets on August White
with Dorothy Mann.*



Marsha Johnson Evans
National Executive Director

June 28, 1999

Ms. Sandra L. Thurman
Director
Office of National AIDS Policy
The White House
Washington, DC 20501

Dear Ms. Thurman:

I am pleased to forward you a copy of Girl Scouting's latest publication, ***AIDS Awareness Update 1999***. As I mentioned during our meeting several weeks ago, we are very interested in educating not only our adult volunteers, but also our Girl Scouts about HIV and AIDS. I hope you will agree that this publication is a useful tool to accomplish that.

Please do not hesitate to contact me if you would like additional copies, or further information about what Girl Scouts are doing in support of HIV/AIDS prevention and awareness.

Sincerely,

8

Enclosure

Healthcare International Management Company
1825 Eye Street, NW - Suite 400
Washington, DC 20006
Telephone: 202.857-3290 Fax: 202.857-5220

facsimile transmittal

To: Ben Johnson Fax: 456-2577

From: Charles Stephenson Date: _____

Re: Ron's ltr to Pres. Clinton Pages: 3 incl. this cover

CC: _____

☒ Urgent ☐ For Review ☐ Please Comment ☐ Please Reply ☐ Please Recycle

Note:

Send TO
Sandra Thurman
aids office



May 25, 1999

President William Clinton
The White House
Washington, D.C. 20500

via fax: 202-456-2604

Dear Mr. President:

I write this letter to request a meeting with you to discuss the global threat of HIV/AIDS and the AIDS Marshall Plan for Africa (AMPFA). I have become very active in the effort to provide treatment and care to HIV/AIDS victims throughout the world. I now chair the Constituency for Africa (CFA), and serve on the board of directors for AIDS Action.

As you know, since my retirement from Congress I have been very active in seeking solutions and answers to combat the growing pandemic of HIV/AIDS. I have tried repeatedly to meet and share information with members of your Administration regarding the worsening situation caused by HIV/AIDS in Africa. Needless to say, I am both frustrated and surprised by the lack of follow through and access to key members of your Administration.

I am certain that you are aware of the problems caused by the global spread of HIV/AIDS and how its exponential growth threatens the security of the world. According to UNAIDS, there are currently 7.8 million orphans on the continent of Africa because of HIV/AIDS. That number could expand to 40 million by 2010. Additionally, 11.5 million people have died in sub-Saharan Africa, and 22.5 million will die in the next decade if measures are not developed to slow the spread of the virus.

The above statistics only begin to give you an idea of the extent of the problem caused by HIV/AIDS throughout the developing world. Since October of last year, I have met with several ministers of health from various African countries regarding the problems and solutions for the HIV pandemic. I have shared with them my intention to bring this matter to the attention of the American government. As a result, I have met with the Congressional Black Caucus (CBC) and they have endorsed the concept of the AMPFA. The CBC has tasked Congresswoman Barbara Lee to draft and introduce legislation that will embody the concept of AMPFA.

President William Clinton

May 25, 1999

Page 2

You should also know that there is considerable interest in the AMPFA in Africa and throughout the world. I am certain that our discussion is vital and that you will agree that we are pursuing a solution that is worthy of your support. Ms. Sandra Thurman, Director of National AIDS Policy, is familiar with the AMPFA and has provided me with valuable insight and information

Mr. President, the problems caused by HIV/AIDS throughout the world deserves and need the attention of America. We cannot be witnesses to a situation that will kill more people than all world wars combined and will cause severe devastation to the human family. We have a responsibility to prevent another holocaust and therefore, I seek your prompt attention and reply to my request for a meeting.

Please call me directly or contact Charles Stephenson or Ann Brown, of my staff, at 202-857-3290 to arrange for a meeting at your earliest convenience.

Sincerely,

A handwritten signature in dark ink, appearing to read "Ronald V. Dellums", with a long, sweeping horizontal stroke extending to the right.

Ronald V. Dellums

Chair

Mo'sha
Magic Johnson

Hispanic / African
American

of someone

called, said we really
couldn't help...

**POSITIVE EDUCATION, INC.****FAX COVER SHEET**

From: **Joseph L. Lennox-Smith**
Positive Education, Inc.
3008 Malijo Ave.
Tampa, FL 33629
(813)831-4159
Fax (813)839-3190

TO: Office of Arts Policy Phone: _____

Attn: Sandy Thurmon Fax: 202-456-~~444~~2439

Message: Conference information

T.A.S.K.


T.A.S.K.
Positive Education Inc.
The AIDS Survival Kit

Joseph L. Lennox-Smith, Executive Director
3008 Malijo AV.
Tampa, FL 33629-7055

E-mail: WWW.pos-ed.org or JLenzsmitty@aol.com
Phone (813) 831-4159 Fax (813) 839-3190

"With knowledge comes hope"

06/05/99

Sandy Thurman, Director
Presidents Office of HIV/AIDS Policy

Subject: Speaker(s) for upcoming conference.

Dear Sandy,

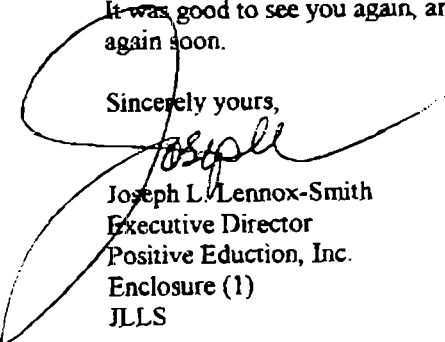
Per my conversation with Cheryl on June 3rd, I am sending you some information on the up coming conference I spoke to you about during AIDS Watch at the reception. This conference will have a focus on prevention issues for adolescents and developing peer educators to work in their communities and schools. It will also focus on continuing education for adults and teachers who work with adolescents such as: Health teachers, Aids Resource teachers and volunteer speakers. The participam area will be the Caribbean basin and Border States. We will have translators for non-Spanish speaking presenters.

We are just putting the agenda together and need to get our speakers lined up, particularly the Key Note speakers. What we are looking for are individuals that will be a draw for young people and have a commitment to preventing the spread of HIV. We are also looking for a speaker for the adults as well. Our budget is not the largest, so we hope to find someone reasonable, but will consider all. We have not completed our mail out information packet as of yet, but attached you will find a copy of the save the date flyer that has been handed out.

I am on the road again until next week. I will follow up with you next week. Listed above is my fax and telephone line should you need them.

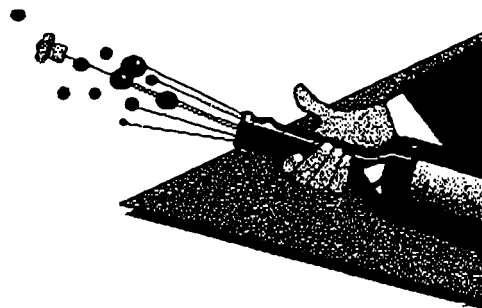
It was good to see you again, and I thank you again for your kindness and hospitality. Hope to see you again soon.

Sincerely yours,


Joseph L. Lennox-Smith
Executive Director
Positive Education, Inc.
Enclosure (1)
JLLS

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6/18 - spoke to
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Referred her to
Melissa Sheppard
@ CDC.

FAX COVER PAGE

Date: 5-13-99

To: Sandra Thurman

Company: The White House

Fax Phone: 202-456-2439

From: Bookie Shonuga/Director of programs

Message: Ref. To our meeting in Ghana about HIV/AIDS
epidemic in Africa

GLOBAL MEDIA PRODUCTIONS INC.

June 16, 1999

Sandra Thurman
Director/Office of National AIDS Policy
The White House

Dear Ms. Thurman:

It was a pleasure meeting you in Ghana at the African/American Summit V when Judy Adou introduced us. As per your suggestion, I am following up with this letter to you concerning the HIV/AIDS epidemic in Africa and how we can collaborate to develop effective hands-on training videos and materials which focus on prevention, transmission, and disease progression. Working together we can develop culturally sensitive materials to disseminate throughout Africa, which recognize cultural, tribal and religious differences taking into account customs, mores and beliefs. My staff and I understand the social and cultural dynamics of African society. The alarming rate at which HIV/AIDS is destroying Africa is devastating. We must do more to educate our brothers and sisters about how to protect themselves from this epidemic.

As you are aware, our company just returned from visits to Ghana, Nigeria and South Africa where we met with several television and radio stations to discuss the dissemination of one of our programs, "Between Sisters". "Between Sisters" is an educational program designed to empower young women growing up in Africa on issues surrounding mind, body and soul. We provide information on health issues such as birth control methods, PMS problems, breast cancer, sex education, sex abuse, incest, STDS etc. as well as educational and entrepreneurial opportunities.

But, after meeting with several television and radio executives it became abundantly clear that the stations were interested in airing the program "Between Sisters" but did not have the funds or resources to pay for the materials out right. Therefore, I am looking for resources to produce the videos here in the United States to disseminate throughout Africa free of charge to the television and radio stations as public service educational materials. But I need you assistance? Can you direct me to where resources are available to cover my production and dissemination costs? Are there resources available through your agency that could be used for such a project? How could we collaborate?

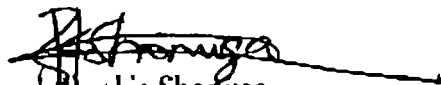
One of the things that I noted while in Africa was that some of the materials that are currently being disseminated do not speak to the average African in ways that they can understand. Based on the research we have done as a company of African and African American women we know the strategies that can be used to eradicate the spread of HIV/AIDS in the African communities. We surveyed several African women groups about the HIV/AIDS materials that are currently being used and we determined that some of the material is ineffective because it is too sexually explicit, western, culturally insensitive, and sophisticated for the average African to understand.

I would like to speak with you at length about this project and ways that our company can create educational materials (audio, video and print) that can modify and change sexual behavior patterns, which are not offensive to the African culture.

Let's get together in the next week or so either here in New York or Washington D.C. to discuss this further. I welcome an opportunity to sit down with you and discuss this project in more detail. Please call me at (718) 437-7617 or (917) 523-8144 or e-mail [Afm60sec @aol.com](mailto:Afm60sec@aol.com) that we can schedule an opportunity to meet.

I look forward to hearing from you in the near future and am pleased that we had an opportunity to meet in Ghana. Best of luck with your ambitious undertaking.

Sincerely,

A handwritten signature in black ink, appearing to read 'Bookie Shonuga', with a long horizontal line extending to the right.

Bookie Shonuga
Director of Programs

Facts:

Why the methods of controlling HIV epidemic in the western society do not work in Africa.

Social structure and cultural traditions

Polygamy in Africa is unique, multiple partnership is the norm of the society even for married couples

Religious factors, Muslim states, men are allowed to marry more than one wife

Men are more aggressive successfully in Africa

Sex is not openly discussed

Economic factor, cannot afford to buy condoms

Inaccessibility to information

STD/immune system lowered because of other diseases, malnutrition, cholera, and typhoid

Solutions

Staffs of professionals understand the social and cultural dynamics of African society

Create communication (audio, video and print) educational materials and video programs that can modify and change sexual behavior patterns, which are not offensive to the African culture

Based on the research that we have done as a company of African and African American women we know the strategies that can be used to eradicate the spread of HIV/AIDS in the African communities.

Office of HIV/AIDS Policy

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



Deliver To: _____

Todd / Sandy / Michael

Fax: () _____

Phone: () _____

From: Deborah von Zinkernagel
Deputy Director for Policy
Phone: (202) 690-5560
Fax: (202) 690-6584
E-mail: (202) DvonZinkernagel@osophs.dhhs.gov

Date: ____/____/____

This fax contains 9 page(s) plus cover

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

Comments: _____

Special Article

THE RELATION BETWEEN FUNDING BY THE NATIONAL INSTITUTES OF HEALTH AND THE BURDEN OF DISEASE

CARY P. GROSS, M.D., GERARD F. ANDERSON, PH.D., AND NEIL R. POWE, M.D., M.P.H., M.B.A.

ABSTRACT

Background The Institute of Medicine has proposed that the amount of disease-specific research funding provided by the National Institutes of Health (NIH) be systematically and consistently compared with the burden of disease for society.

Methods We performed a cross-sectional study comparing estimates of disease-specific funding in 1996 with data on six measures of the burden of disease. The measures were total mortality, years of life lost, and number of hospital days in 1994 and incidence, prevalence, and disability-adjusted life-years (one disability-adjusted life-year is defined as the loss of one year of healthy life to disease) in 1990. With the use of these measures as explanatory variables in a regression analysis, predicted funding was calculated and compared with actual funding.

Results There was no relation between the amount of NIH funding and the incidence, prevalence, or number of hospital days attributed to each condition or disease ($P=0.82$, $P=0.23$, and $P=0.21$, respectively). The numbers of deaths ($r=0.40$, $P=0.03$) and years of life lost ($r=0.42$, $P=0.02$) were weakly associated with funding, whereas the number of disability-adjusted life-years was strongly predictive of funding ($r=0.62$, $P<0.001$). When the latter three measures were used to predict expected funding, the conclusions about the appropriateness of funding for some diseases varied according to the measure used. However, the acquired immunodeficiency syndrome, breast cancer, diabetes mellitus, and dementia all received relatively generous funding, regardless of which measure was used as the basis for calculating support. Research on chronic obstructive pulmonary disease, perinatal conditions, and peptic ulcer was relatively underfunded.

Conclusions The amount of NIH funding for research on a disease is associated with the burden of the disease; however, different measures of the burden of disease may yield different conclusions about the appropriateness of disease-specific funding levels. (N Engl J Med 1999;340:1881-7).

©1999, Massachusetts Medical Society.

THE research programs of the National Institutes of Health (NIH) have been remarkably successful over the past 50 years. NIH-funded scientists have made substantial progress in understanding the basic mechanisms of disease and have vastly improved the preventive, diagnostic, and therapeutic options available.¹ However, the NIH is able to fund less than 30 percent of extramural grant applications; this fact has led scientists, patients, and other advocates of biomedical research to question how research funds are allocated to research on various diseases.²⁻⁶

The NIH working group on the setting of priorities has listed five major criteria for the allocation of research funds: public health needs, the scientific quality of research, the probability of success, the maintenance of a diverse portfolio, and the maintenance of an adequate scientific infrastructure.⁷ An Institute of Medicine panel recently embraced these criteria as an appropriate framework for funding.⁸ However, the panel also concluded that the NIH does not adequately describe how public health need is assessed, and it recommended that "in setting priorities, the NIH should strengthen its analysis and use of health data, such as burdens and costs of diseases."⁹

We performed this study to determine whether the amount of funding the NIH allocates to research on particular diseases is associated with commonly available measures of the burden of disease.

METHODS

Study Design

This was a cross-sectional study relating different measures of the burden of disease to the magnitude of NIH research funding. Diseases that were included in our study were those for which estimates of NIH funding, definitions from the *International Clas-*

From the Robert Wood Johnson Clinical Scholars Program, Johns Hopkins University School of Medicine, Baltimore (C.P.G., G.F.A., N.R.P.); and the Department of Health Policy and Management (G.F.A., N.R.P.), the Welch Center for Prevention, Epidemiology, and Clinical Research (N.R.P.), and the Department of Epidemiology (N.R.P.), Johns Hopkins University School of Hygiene and Public Health, Baltimore. Address reprint requests to Dr. Gross at the Primary Care Center, Yale University School of Medicine, 333 Cedar St., P.O. Box 208025, New Haven, CT 06520-8025, or at cgross@welchlink.welch.jhu.edu.

THE RELATION BETWEEN FUNDING BY THE NATIONAL INSTITUTES OF HEALTH AND THE BURDEN OF DISEASE

more prevalence, incidence, and mortality and developed a new composite measure for assessing health status.¹

Composite Measures

It is a widely held belief that increases in both the length and the quality of life are important.¹⁹ Therefore, measures were developed that took into account the notion that the value of a year of life spent in perfect health is greater than the value of a year spent in less than perfect health.^{19,22} The problem is how to ascertain the appropriate balance between the duration and the quality of life by converting time spent in various states of health to their "healthy-year equivalents."²³ Disability-adjusted life-years is the composite measure developed by the authors of the Global Burden of Disease Study; it incorporates the social values placed on various aspects of physical, mental, and social function.^{17,24} These social values were derived from a formal exercise involving health workers from throughout the world.²⁴ The results of this analysis were subsequently validated by nine additional exercises with other participants that used the same protocol.²⁵ One disability-adjusted life-year is defined as one year of healthy life that has been lost because of either disability or death.¹⁷

Sources of Data and Construction of Variables

Estimates of disease-specific research funding for all awards and contracts in fiscal year 1996 were obtained from an NIH report compiled in response to a request from the House Committee on Appropriations.¹⁶ Constructing annual budgets for the NIH is a complex process that begins approximately two years before each fiscal year.¹⁷ We wanted to examine the relation between NIH allocations and the burden of disease at the time funding decisions were made. Hence, we compared 1996 NIH funding with measures of the burden of disease in 1994, when possible.

The number of deaths attributed to each disease in 1994 was obtained from the National Center for Health Statistics.¹⁴ Data from the National Hospital Discharge Survey were used to estimate the number of hospital days attributed to each disease in 1994.²⁶ For disability-adjusted life-years, incidence, and prevalence in 1990, we used the estimates from the Global Burden of Disease Study for what is referred to as "established market economies," which includes western Europe, the United States, Canada, Japan, Australia, and New Zealand.²⁸ Specific estimates of disability-adjusted life-years are not yet available for the United States.

Statistical Analysis

The dependent variable was NIH funding for research on specific medical conditions, and the independent variables were measures of the burden of disease. Correlations between funding and measures of the burden of disease were assessed with Spearman's rho test. Because the data were not normally distributed, we also performed logarithmic transformations and used the Shapiro-Wilk W statistic to confirm reasonable normality of the log-transformed data. We performed simple linear regression analyses with funding as the dependent variable and a measure of the burden of disease as the independent variable. For each measure that had a statistically significant association with funding, we used the regression-derived estimates to predict the expected NIH funding for each disease. We then compared the expected funding with the actual funding.

RESULTS

Disease-Specific Funding

Estimates of NIH funding and measures of the burden of disease were available for 29 diseases. Funding for fiscal year 1996 and the various measures of the burden of these diseases are shown in Table 1. Total NIH research funding in 1996 was \$11.9 billion, of which approximately \$4.9 billion was for the diseases included in our analysis. Estimates of incidence and prevalence were not available for 4 of the 29 conditions (injuries, dental and oral disorders, sexually transmitted diseases, and perinatal conditions). Funding varied markedly, ranging from \$6 million for peptic ulcer to \$1.4 billion for the acquired immunodeficiency syndrome (AIDS).

Measures of the Burden of Disease

Measures of the Burden of Disease

The relation between each of the measures of the burden of disease and the amount of NIH funding, as determined by simple linear regression of the log-transformed data, is shown in Table 2. Neither the incidence nor the prevalence of disease was predictive of the amount of NIH funding ($P=0.82$ and $P=0.23$, respectively). The number of hospital days was also not predictive of NIH funding ($P=0.21$), suggesting that the consumption of resources for specific illnesses may not be a major factor in the allocation of NIH funds.

Mortality

Ischemic heart disease, stroke, and lung cancer were, respectively, the first, second, and third leading causes of death in the United States in 1994. There was a positive association between total mortality from disease and the amount of funding ($r=0.40$, $P=0.03$). Although the ranking of diseases according to mortality was somewhat different from that according to years of life lost (Table 1), the direction and magnitude of the association between each of these two variables and the amount of NIH funding were similar.

Disability-Adjusted Life-Years

The relation between NIH funding and disability-adjusted life-years was significant ($r=0.62$, $P<0.001$).

TABLE 2. ASSOCIATION OF MEASURES OF THE BURDEN OF DISEASE WITH AMOUNT OF RESEARCH FUNDING BY THE NIH *

MEASURE (YEAR ASSESSED)	UNITS	CORRELATION COEFFICIENT (r)	P VALUE
Incidence (1990)	No. of new cases per year	-0.05	0.82
Prevalence (1990)	No. of existing cases	0.25	0.23
Hospital days (1994)	Days in acute care hospitals	0.24	0.21
Mortality (1994)	Deaths per year	0.40	0.03
Years of life lost (1994)	Years	0.42	0.02
Disability-adjusted life- years (1990)†	Years	0.62	<0.001

*Research funding was measured in dollars, with logarithmic transformation of data. Estimates were available for all measures of the burden of disease for 25 diseases. For an additional four diseases, estimates were available of all measures except incidence and prevalence.

†One disability-adjusted life-year is defined as the loss of one year of healthy life to disease.

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TABLE 1. NIH RESEARCH FUNDS AND MEASURES OF DISEASE BURDEN FOR 29 CONDITIONS

CONDITION OR DISEASE	NIH RESEARCH FUNDS thousands of dollars (% of total)	MEASURE OF DISEASE BURDEN*					
		INCIDENCE	PREVALENCE	HOSPITAL DAYS	MORTALITY	YEARS OF LIFE LOST	DISABILITY ADJUSTED LIFE-YEAR†
				thousands (rank)			
AIDS	1,410,925 (28.7)	138 (20)	1,303 (17)	329 (20)	42 (10)	979 (4)	1267 (15)
Breast cancer	381,880 (7.8)	523 (12)	2,262 (18)	525 (18)	44 (9)	426 (8)	1421 (14)
Dementia	304,411 (6.2)	959 (9)	7,082 (8)	841 (16)	34 (12)	90 (14)	2866 (7)
Diabetes mellitus	298,920 (6.1)	2,308 (6)	37,850 (1)	3,181 (8)	57 (8)	407 (7)	3357 (8)
Ischemic heart disease	269,100 (5.5)	2,216 (7)	8,976 (6)	11,815 (2)	481 (1)	2973 (2)	8376 (1)
Alcohol abuse	256,600 (5.2)	11,085 (3)	18,092 (2)	2,563 (9)	7 (18)	98 (15)	4690 (5)
Injuries	198,700 (4.0)			15,218 (1)	149 (4)	3109 (1)	8608 (2)
Dental and oral disorders	187,100 (3.8)			158 (25)	0.1 (28)	0.9 (28)	870 (18)
Cirrhosis	169,800 (3.4)	168 (17)	1,238 (18)	869 (15)	31 (13)	380 (11)	1584 (13)
Depression	143,800 (2.9)	20,622 (2)	12,785 (4)	8,409 (4)	8 (17)	23 (24)	8493 (3)
Lung cancer	127,796 (2.6)	430 (16)	874 (19)	1,536 (12)	140 (3)	1158 (3)	2987 (6)
Stroke	120,280 (2.4)	1,282 (8)	9,467 (5)	6,450 (5)	153 (2)	746 (5)	6977 (4)
Schizophrenia	111,479 (2.3)	162 (18)	7,164 (7)	4,129 (6)	0.4 (26)	2 (27)	2249 (10)
Colorectal cancer	105,525 (2.1)	499 (14)	1,926 (15)	1,600 (11)	58 (7)	391 (10)	1626 (12)
Sexually transmitted disease	102,593 (2.1)			69 (29)	0.3 (27)	28 (26)	404 (22)
Prostate cancer	92,661 (1.9)	452 (15)	2,020 (14)	585 (17)	35 (11)	153 (13)	574 (19)
Multiple sclerosis	82,800 (1.7)	16 (24)	461 (21)	149 (26)	2 (23)	28 (21)	236 (25)
Asthma	81,600 (1.7)	3,504 (5)	15,919 (3)	1,820 (10)	5 (20)	65 (16)	1236 (17)
Parkinson's disease	77,158 (1.6)	136 (21)	1,849 (16)	162 (24)	10 (16)	36 (19)	447 (21)
Tuberculosis	64,125 (1.3)	155 (19)	39 (25)	163 (23)	2 (24)	15 (25)	118 (18)
Chronic obstructive pul- monary disease	62,400 (1.3)	670 (11)	4,271 (11)	3,537 (7)	96 (5)	518 (6)	2284 (9)
Pneumonia	61,900 (1.3)	9,257 (4)	178 (23)	8,625 (3)	81 (6)	363 (12)	1303 (16)
Cervical cancer	60,180 (1.2)	4 (25)	164 (24)	94 (28)	5 (21)	63 (17)	192 (26)
Epilepsy	55,100 (1.1)	504 (13)	4,511 (10)	483 (19)	1 (25)	25 (22)	505 (20)
Ovarian cancer	42,168 (0.8)	74 (23)	247 (22)	325 (21)	14 (15)	48 (18)	375 (23)
Perinatal conditions	26,400 (0.5)			1,882 (14)	14 (14)	473 (7)	1767 (11)
Uterine cancer	13,956 (0.3)	133 (22)	599 (20)	199 (22)	3 (22)	33 (23)	185 (27)
Otitis media	9,100 (0.2)	40,424 (1)	3,110 (12)	100 (27)	0.04 (29)	0.7 (29)	8 (24)
Peptic ulcer	6,000 (0.1)	944 (10)	5,005 (9)	1,440 (13)	6 (19)	35 (20)	239 (24)

* Estimates of incidence and prevalence were obtained from the Global Burden of Disease Study and apply to established market economies in 1990. All other estimates are specific to the United States for 1994.

† One disability-adjusted life-year is defined as the loss of one year of healthy life to disease.

ification of Diseases, 9th Revision, Clinical Modification (ICD-9-CM), and potential measures of the burden of disease were available.^{12,13}

Measures of the Burden of Disease

Number of People Affected

Two of the more frequently cited measures of the burden of disease are the total number of people with a disease (prevalence) and the frequency of new cases (incidence).

Use of Resources and Cost

Several methods have been proposed for estimating the financial burden imposed by various diseases on the health care system.¹⁴ As a proxy for financial burden, we estimated the number of hospital days attributed to each disease as the principal diagnosis.

Mortality

The most readily available and frequently cited measure for assessing the burden of disease is total mortality.¹⁴ For each death, the underlying cause is determined on the basis of conditions reported in the death certificate with the use of an algorithm described in the ICD-9-CM.¹⁵ Because statistics on total mortality do not take age into account, another measure has been developed, called years of life lost, which is calculated by subtracting a person's age at death from his or her life expectancy in the absence of a given disease.¹⁶ We calculated years of life lost using the methods described in the Global Burden of Disease Study.¹⁷

The Global Burden of Disease Study was a five-year effort sponsored in part by the World Bank and the World Health Organization.¹⁸ The goal was to develop a comprehensive and objective set of estimates of current patterns of morbidity and mortality due to disease and injury for all regions of the world. The investigators used a systematic and exhaustive approach to esti-

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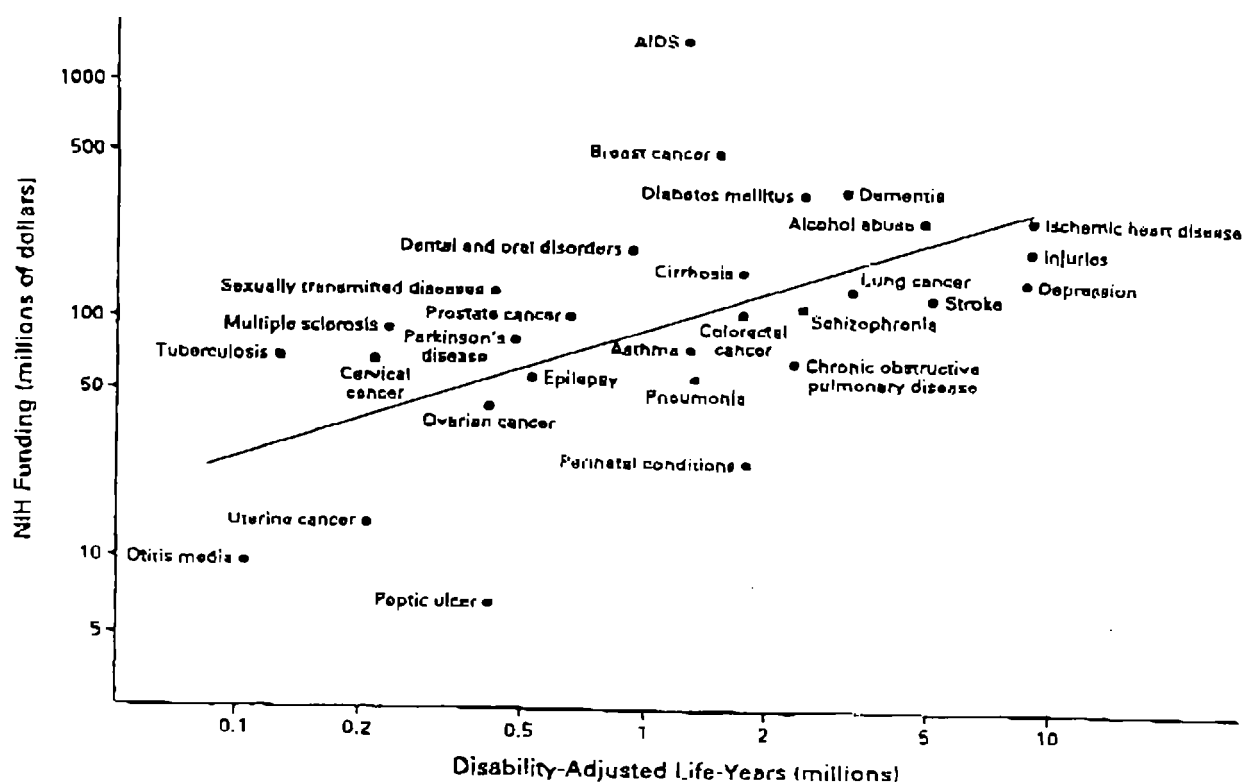


Figure 1. Relation between NIH Disease-Specific Research Funding in 1996 and Disability-Adjusted Life-Years for 29 Conditions in 1990.

The axes are drawn to logarithmic scale. The line represents funding predicted on the basis of a linear regression with disability-adjusted life-years as the explanatory variable. One disability-adjusted life-year is defined as the loss of one year of healthy life to disease.

The amount of predicted and actual NIH funding as a function of disability-adjusted life-years is shown in Figure 1. The line represents the amount of funding that would be predicted if the number of disability-adjusted life-years were the sole criterion for funding.

Differences between Actual and Predicted Funding

The difference between actual and predicted funding for each disease, with mortality, disability-adjusted life-years, and years of life lost used as explanatory variables, is shown in Table 3 (negative values indicate that the disease received less funding than predicted). Research in the areas of chronic obstructive pulmonary disease, perinatal conditions, and peptic ulcer was underfunded according to all three measures. On the other hand, AIDS, breast cancer, dementia, and diabetes mellitus all received more than the predicted amount of research funding, regardless of which measure of the burden of disease was used. However, for some diseases, the conclusions about the appropriateness of funding differ depending on which measure is chosen. For example, if the num-

ber of disability-adjusted life-years is used as the sole funding criterion, then ischemic heart disease, schizophrenia, and depression received less funding than predicted. If mortality-based measures (total mortality or years of life lost) are used as funding criteria, these diseases received more funding than predicted.

Sensitivity Analysis

Because the discrepancy between actual and predicted funding was far higher for AIDS than for any other disease, we repeated the analyses after excluding AIDS. There was no significant change in the relation of actual to predicted funding with any of the measures of burden of disease (data not shown).

DISCUSSION

Although it is arguable whether the burden of disease should assume priority in NIH funding decisions, the NIH's allocation process has been criticized as being arbitrary and insensitive to the burden of disease.^{2,3,10} However, only a few diseases have been analyzed, and often only one measure of the burden of disease has been assessed. Our analysis re-

THE RELATION BETWEEN FUNDING BY THE NATIONAL INSTITUTES OF HEALTH AND THE BURDEN OF DISEASE

vealed a significant relation between NIH research funding and measures of the burden of disease. Disability-adjusted life-years, a measure that takes into account the age of those affected, the degree of disability, and the number of deaths, was most strongly associated with the amount of funding. The number of years of life lost was not substantially more predictive of funding than total mortality. This result suggests that all deaths are treated as having equal importance, regardless of the age at death.

However, the prevalence of a disease, its incidence, and the number of hospital days attributed to a disease were not associated with the amount of funding. The lack of association of prevalence and incidence with funding may be due to the fact that these measures do not take into account the severity of illness. These measures assign a higher burden to mild but widespread diseases such as otitis media than to severe but less common diseases, such as breast cancer.

Our data demonstrate how policy makers could be misled by using a single measure of the burden of disease, because the ranking of diseases according to their burden varies with the different measures used. Comparison of actual and predicted funding based on mortality, years of life lost, and disability-adjusted life-years led to similar conclusions (i.e., that actual funding was above or below predicted funding) for 21 of the 29 diseases. As a result, advocates interested in promoting research on particular diseases could select measures that best support their cause.

The burden of disease is only one of the five criteria used by the NIH to set priorities; all should be considered when research funds are allocated.⁷ Scientific opportunity is a particularly important factor to consider, because recent discoveries may make some areas of research more "ripe" for success. However, external pressure can also influence funding priorities. It was partially in response to such pressure that the Institute of Medicine panel recommended that the NIH explicitly compare the burden of disease and the amount of research funding.⁸

Policy makers are faced with two main problems when choosing among alternative measures of the burden of disease. The first is the availability and quality of the data. For many measures, there is no central repository of data, and advocacy groups can select or emphasize data derived by a variety of methods.⁹ The second, and far more important, problem is the social values incorporated into various measures. Some may argue that all lives are equal in importance and that total mortality should therefore be used to guide allocation decisions.^{10,31} Others may contend that the equitable distribution of resources requires attention to any incremental improvement in health status. For this purpose, disability-adjusted life-years may be a more appropriate measure.^{19,24} The relations among different measures

TABLE 3. DIFFERENCE BETWEEN ACTUAL AND PREDICTED FUNDING BY THE NIH, ACCORDING TO THE MEASURE USED TO PREDICT FUNDING.*

CONDITION OR DISEASE	MORTALITY	DISABILITY-ADJUSTED LIFE-YEARS†	YEARS OF LIFE LOST
millions of dollars			
Chronic obstructive pulmonary disease	-83	-79	-76
Parasitic conditions	-81	-97	109
Peptic ulcer	-79	-36	-72
Pneumonia	-79	-41	-66
Uterine cancer	-61	-23	-58
Ovarian cancer	-57	-12	-41
Stroke	-39	-95	-29
Lung cancer	-31	-36	-36
Prostate cancer	-27	25	-14
Colorectal cancer	-27	-13	-25
Otitis media	-23	-15	-25
Cervical cancer	-21	22	-28
Parkinson's disease	-17	18	-1
Epilepsy	-9	-8	-17
Asthma	-2	-20	-7
Tuberculosis	-2	35	1
Multiple sclerosis	14	41	9
Cirrhosis	53	53	40
Depression	53	-140	72
Injuries	54	-89	-4
Sexually transmitted diseases	56	46	57
Schizophrenia	61	-29	68
Ischemic heart disease	70	-24	68
Dental and oral disorders	149	102	152
Diabetes mellitus	167	155	168
Alcohol abuse	170	48	160
Dependents	185	144	207
Breast cancer	257	272	249
AIDS	1,287	1,307	1,251

*Negative numbers indicate that research on a condition was underfunded in relation to the burden of disease, and positive numbers that it was overfunded.

†One disability-adjusted life-year is defined as the loss of one year of healthy life to disease.

should also be considered by policy makers, because some measures may be negatively correlated.³² For example, improved treatment of a disease could decrease mortality due to the disease but increase its prevalence by increasing the number of survivors.

Substitutes for NIH funding also need to be considered. For instance, private industry now funds nearly twice as much biomedical research as does the NIH.³³ Research on pneumonia may receive relatively low funding from the NIH because the pharmaceutical industry is keenly interested in developing new antibiotics. Although research performed by industry may be distinct from NIH-funded research in a number of ways, it is important for policy

The New England Journal of Medicine

makers to consider these substantial efforts when allocating funds. Trends in NIH-funded research should also be considered, since diseases that have been underfunded in earlier years may deserve additional funding.

Our study has several limitations. First, the serendipitous nature of science must be considered; investigations in one area frequently yield fruitful results in another. Research done by a virologist, for example, may produce information that is immediately and directly beneficial in cancer research. Hence, it may be overly simplistic to link funding to specific diseases. However, awareness of this factor does not preclude the need for rational methods to assign priorities and continue goal-directed initiatives.

Second, all measures of the burden of disease in our analysis are imperfect, since reporting errors, improper coding, and the use of proxy measures contribute to potential bias. For example, the death certificate is not always a reliable record of the cause of death. Improved diagnostic techniques may lead to increased recognition and diagnosis of some diseases. In addition, data may not accurately reflect the true burden of each disease, because many diseases contribute to the morbidity caused by other diseases.

Third, it was not possible to analyze all diseases, since we were constrained by the availability of data. However, the diseases in our study represented a substantial proportion of the total burden of disease. For instance, the sum of the mortality attributed to the 29 diseases and conditions we studied represents 63 percent of all deaths reported in 1994. Similarly, the sum of the disability-adjusted life-years for these 29 diseases represents 62 percent of the total estimate.

Fourth, our conclusions are based on estimates of disability-adjusted life-years for industrialized countries. The United States has a higher incidence of AIDS than most other countries in this group. However, even when we tripled the estimated number of disability-adjusted life-years attributed to AIDS, our results did not change substantially.

Finally, some funds may be assigned to more than one disease. For instance, a grant to investigate heart disease in patients with diabetes would be included in both categories.⁷ There may be disagreement about how some research expenditures are assigned to particular diseases.

Despite past criticisms, the allocation of research funds to specific diseases by the NIH is not arbitrary in relation to the burden of disease. The number of disability-adjusted life-years is strongly associated with funding levels. However, conclusions about the degree of matching between NIH funding and the burden of disease are extremely sensitive to the measure used, and assessments of the appropriateness of funding levels should be interpreted with great caution.

Supported by the Robert Wood Johnson Clinical Scholars Program.

We are indebted to Dr. Anna Reisman for her thoughtful comments.

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THE RELATION BETWEEN FUNDING BY THE NATIONAL INSTITUTES OF HEALTH AND THE BURDEN OF DISEASE

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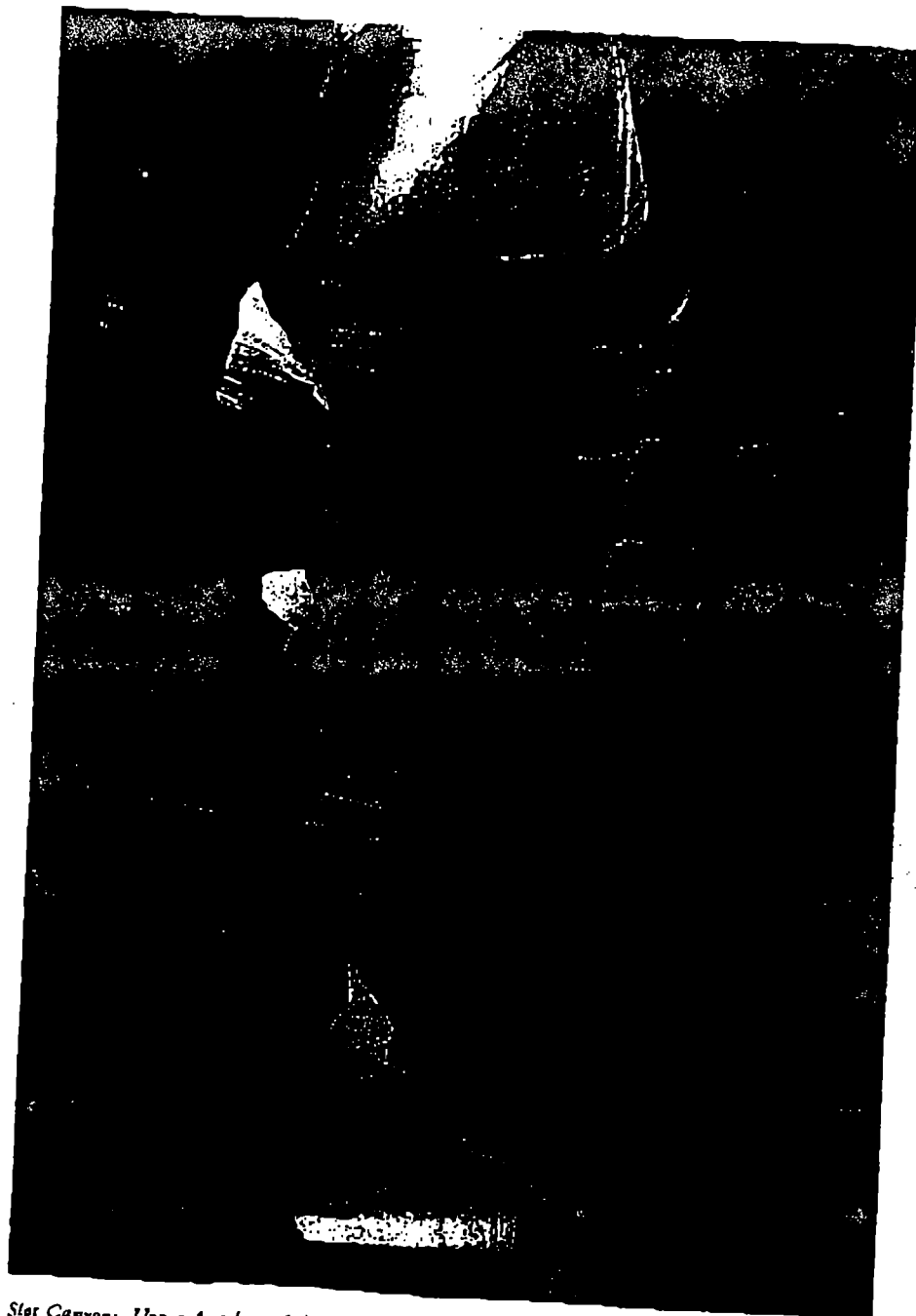
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Volume 340 Number 24 - 1887

EVALUATING THE BURDEN OF DISEASE AND SPENDING THE RESEARCH DOLLARS OF THE NATIONAL INSTITUTES OF HEALTH

THE appropriations process has been kind to the National Institutes of Health (NIH) during the past few years, for several reasons. The public and its representatives in government applaud our goal of making discoveries that ameliorate or eliminate diseases; our record of accomplishment is strong; and everyone's hopes are high. Thus, it is not surprising that fiscal growth at the NIH (especially the 15 percent increase received last year, bringing the annual budget to \$15.6 billion) has been accompanied by an intensified interest in the distribution of NIH funds — in particular, in the amounts devoted to each of the hundreds of diseases on which research is funded — and in the process by which these amounts are determined. Reflecting these issues, many advocacy groups have argued for changes in the actual distribution; several congressional committees have held hearings on the topic^{1,2}; numerous commentaries have appeared in the scientific and lay press; the NIH has published an explanatory guide to the process³; and in response to a congressional request, the Institute of Medicine has issued a report on the setting of priorities at the NIH.⁴

Many factors must be considered in the allocation of funds from the NIH budget — public health needs, scientific opportunities, the quality of research proposals, and the maintenance of staffing and infrastructure among them. Advocacy groups have tended, understandably, to focus their attention on alleged inequities between the toll of a specific disease and spending for research on that disease. These claims are of great concern to the NIH, because they threaten to undermine the agency's credibility, and to Congress, because they challenge its oversight in a politically sensitive arena. This aspect of NIH spending has, in addition, been highlighted by the recent Institute of Medicine report, which suggested that the NIH needs to evaluate the burden of disease more carefully and explain more fully to the public how that burden squares with spending patterns.

A report in this issue of the *Journal* by Gross et al.⁵ informs this debate in several ways. It illustrates how different measures of the burden of disease, such as prevalence, incidence, mortality, and economic costs, can dramatically alter conclusions. It demonstrates that a comprehensive and arguably more reliable measure of disease burden — disability-adjusted life-years, defined as the number of years of healthy life lost to a disease — correlates quite well with dollars spent on that disease. And it describes the complex relation between the burden of disease and NIH spending in ways that could calm what has

often been a fractious debate among disease-oriented constituencies. Although the results of this report are welcome news at the NIH, the study also affords an opportunity to reemphasize inherent methodologic difficulties in such analyses and to stress the importance of the factors, other than the multifaceted burden of disease, that must be considered in the planning process and in decisions about spending.

For many years, the NIH has closely monitored the cost and degree of suffering associated with various illnesses. Indeed, we are responsible for generating substantial amounts of such data through epidemiologic and other research. We support studies of the methods used to estimate the burden of disease; and we regularly report to Congress on these issues.⁶ Although current measures are admittedly imperfect and their results often divergent, the article by Gross et al. strengthens the credibility of our claim that there is a reasonable correspondence between the burden of disease and spending patterns. But it is important to emphasize that there is not an absolute correspondence. Thus, although the correlation of spending with disability-adjusted life-years passes the statistical tests applied by the authors, inspection of their Figure 1 reveals differences by a factor of as much as 10 in the dollar amounts assigned to research on diseases with similar numbers of disability-adjusted life-years.

Some of this variation can be attributed to the limitations inherent in the calculation of disability-adjusted life-years. But several other factors also contribute to these differences. For instance, the method of coding research dollars, while consistent from year to year for a specific disorder, may differ from one disease to another; thus, numbers may be relatively high when they include disease-related, as well as disease-specific, activities (as when studies of opportunistic infections or T-cell biology are counted as part of the budget for research on the human immunodeficiency virus [HIV] and AIDS). In addition, the planning of disease-oriented research by the NIH is influenced by complementary activities in other agencies, such as the Department of Veterans Affairs, the Centers for Disease Control and Prevention, or the Department of Defense, and — especially — in the pharmaceutical and biotechnology industries, where basic knowledge is often transformed into disease-specific applications in the form of drugs or other therapies. Such considerations may, for example, favor the expenditure of NIH dollars on relatively rare diseases, with low values for the burden of disease, as measured in terms of disability-adjusted life-years, for which there is little incentive for research and development in the private sector.

Policy makers at the NIH must also consider the prospects for reducing the burden of disease through research, not just attempt to equate spending with the current burden; this helps to explain the relative

ly high level of spending on HIV and AIDS that is noted by Gross et al., since AIDS is a new and increasingly prevalent infectious disease worldwide against which our extensive knowledge of retroviruses and the immune system can be effectively used. Our efforts to plan disease-oriented research activities are also influenced by projections of future patterns of disease and the effects of demographic changes (such as aging) and personal habits (such as tobacco use), as described recently in *The Global Burden of Disease*.⁸

At the same time, it is important to recognize that much of the planning of NIH-sponsored research is centered on broad scientific themes (such as genome projects, development of instrumentation, training in clinical research, or developments in basic science), without reference to the many specific diseases that might be addressed through these efforts. The disease-specific spending patterns that later result from such research are influenced by the success of individual applicants for NIH grants, the nature of their interests, and the specific knowledge generated by the non-disease-related projects, as well as by subsequent disease-oriented planning.

Finally, the NIH remains sensitive to an important aspect of the recent Institute of Medicine report. Despite the extraordinary breadth of our interactions with the public — a level of involvement unusual for any government agency — some advocacy groups remain dissatisfied. We have responded by swiftly implementing two important recommendations of the report — the designation of an NIH office of public liaison and similar offices in each institute and center and the establishment of a Direc-

tor's Council of Public Representatives.⁹ Through these new initiatives and other, more traditional mechanisms, the NIH hopes to enhance the public discussion of many important issues, including those raised by Gross et al. in this issue of the *Journal*.

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National Organizations Responding to AIDS (NORA)

Fax Memorandum

To: NORA Coalition Members

From: Jeannette Sebes, NORA Coordinator
AIDS Action

Date: June 30, 1999

Re: Sign-on letter

Attached is a letter regarding **The Early Treatment For HIV Act**. Due to AIDS Actions move and the loss of e-mail capacity for a week we have decided to re-send the sign-on. Please sign-on again, even if you did during the first round. Please *e-mail* your sign-on request to:

nora@aidsaction.org

include your organization's name as you would like it to appear on the letter, your name and your contact information. Please respond by **Wednesday, July 14th**.

Please also note the change of address for AIDS Action. As of May 31st AIDS Action's (as well as NORA's) new address will be:

**1906 Sunderland Place, NW
Washington, DC 20036**

P: 202-530-8030

F: 202-530-8031

Extensions remain the same.

Also, please note that the Ryan White Reauthorization Work Group meetings are now being held **EVERY** Wednesday at HRC from 2-4pm.

Thank you.

June 30, 1999

(to all members of Congress except sponsors):

Dear:

On behalf of the National Organizations Responding to AIDS (NORA), we are writing to urge that you support The Early Treatment for HIV Act (S. 902/H.R. 1591). This bill would give states the option to expand Medicaid coverage for low-income individuals living with asymptomatic HIV disease - making it possible for these individuals to receive primary health care and effective drug therapies before they progress to full-blown AIDS. NORA is a coalition of over 175 health, labor, religious and professional advocacy groups that represent a broad consensus on HIV and AIDS-related issues policy and funding levels.

Co-Chairs

Terje Anderson
NATIONAL ASSOCIATION OF
PEOPLE WITH AIDS

Rose Gonzalez
AMERICAN NURSES
ASSOCIATION

Executive Committee

Dave Cavanaugh
COMMITTEE OF TEN
THOUSAND

David Harvey
AIDS POLICY CENTER FOR
CHILDREN, YOUTH AND
FAMILIES

Jeff Jacobs
AIDS ACTION

Seth Kilbourn
HUMAN RIGHTS CAMPAIGN

Miguelina Maldonado
NATIONAL MINORITY AIDS
COUNCIL

Matthew McClain
CAEAR COALITION

Jane Silver
AMERICAN FOUNDATION
FOR AIDS RESEARCH

This legislation would provide access to care that is consistent with the Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents issued by the Department of Health and Human Services (HHS) recommending the use of antiretroviral therapy early in the course of HIV infection, before the manifestation of symptoms. Since Medicaid eligibility requirements are incompatible with these clinical guidelines, this measure will take important steps to bring as many people as possible under the HHS guidelines.

As AIDS patients become sicker, their Medicaid covered treatment costs double. According to a 1997 study published in the *Journal of Acquired Immune Deficiency Syndrome*, average monthly costs to Medicaid of treating patients increase more than two-fold as a patient's CD4 count declines. A 1999 study of patients from the Johns Hopkins HIV Service also showed a significant decrease in Medicaid payments for patients using combination antiviral therapy. Access to early antiretroviral therapy could save the expensive use of federal Medicaid resources by keeping individuals healthier.

We believe that both the health benefits and cost-effectiveness of early intervention, such as would be provided through early treatment, is in the best interest of the government and its people. Therefore, we urge you to support this Medicaid expansion to low-income people with HIV.

Sincerely,

To: Sandy / Todd

Fr: Deborah

ORIGINAL CONTRIBUTION

Variations in the Care of HIV-Infected Adults in the United States

Results From the HIV Cost and Services Utilization Study

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THE US HEALTH CARE SYSTEM IS going through many changes that raise concerns about adequacy of care, including new constraints on public programs¹ and changes in the insurance options available to the privately insured.^{2,3} Ascertaining the impact of the emerging organization of services on those most likely to benefit from care is important but difficult. Neither national surveys of households or medical providers nor most studies of specific diseases provide sufficient information. The former studies do not include enough patients with specific conditions of interest to analyze issues of particular concern in the care of those conditions and do not collect enough disease-specific information.⁴ The latter studies usually cannot be broadly generalized, either because they are local or use some form of purposive sampling to assemble a nonrepresentative cohort. Consequently, evidence of disparities in care at 1 or a few institutions may challenge assumptions about ad-

Context Studies of selected populations suggest that not all persons infected with human immunodeficiency virus (HIV) receive adequate care.

Objective To examine variations in the care received by a national sample representative of the adult US population infected with HIV.

Design Cohort study that consisted of 3 interviews from January 1996 to January 1998 conducted by the HIV Cost and Services Utilization Consortium.

Patients and Setting Multistage probability sample of 2864 respondents (68% of those targeted for sampling), who represent the 231 400 persons at least 18 years old, with known HIV infection receiving medical care in the 48 contiguous United States in early 1996 in facilities other than emergency departments, the military, or prisons. The first follow-up consisted of 2466 respondents and the second had 2267 (65% of all surviving sampled subjects).

Main Outcome Measures Service utilization (<2 ambulatory visits, at least 1 emergency department visit that did not lead to hospitalization, at least 1 hospitalization) and medication utilization (receipt of antiretroviral therapy and prophylaxis against *Pneumocystis carinii* pneumonia).

Results Inadequate HIV care was commonly reported at the time of interviews conducted from early 1996 to early 1997 but declined to varying degrees by late 1997. Twenty-three percent of patients initially and 15% of patients subsequently had emergency department visits that did not lead to hospitalization, 30% initially and 26% subsequently of those who had CD4 cell counts below $0.20 \times 10^9/L$ did not receive *P. carinii* pneumonia prophylaxis, and 41% initially and 15% subsequently of those who had CD4 cell counts below $0.50 \times 10^9/L$ did not receive antiretroviral therapy (protease inhibitor or nonnucleoside reverse transcriptase inhibitor). Inferior patterns of care were seen for many of these measures in blacks and Latinos compared with whites, the uninsured and Medicaid-insured compared with the privately insured, women compared with men, and other risk and/or exposure groups compared with men who had sex with men even after CD4 cell count adjustment. With multivariate adjustment, many differences remained statistically significant. Even by early 1998, fewer blacks, women, and uninsured and Medicaid-insured persons had started taking antiretroviral medication (CD4 cell count adjusted *P* values <.001 to <.005).

Conclusions Access to care improved from 1996 to 1998 but remained suboptimal. Blacks, Latinos, women, the uninsured, and Medicaid-insured all had less desirable patterns of care. Strategies to ensure optimal care for patients with HIV requires identifying the causes of deficiency and addressing these important shortcomings in care.

JAMA. 1999;281:2305-2315

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equacy of care to certain sectors of the population, but nationally representative data are needed to determine if broader attention is merited.

We conducted a comprehensive study of health care for a national probability sample of US adults with 1 important chronic disease, human immu-

nodeficiency virus (HIV) infection.⁶ Adequate treatment for this disease is important because of the clear benefit

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VARIATIONS IN CARE OF HIV-INFECTED ADULTS

of therapy and because HIV-infected persons are a paradigmatic example of patients who need complex treatment.⁷ Studies with limited or uncertain generalizability have raised concerns about the possibility of inequities in realized access or receipt of needed HIV care.⁸⁻¹² In this article, we examine variations in the care received by a national sample representative of the adult HIV-infected population receiving regular medical care in the 48 contiguous United States from early 1996 to early 1998.¹³

METHODS

Sample Design

The HIV Cost and Services Utilization Study (HCSUS) used multistage national probability sampling to select the study cohort.^{6,13} The reference population was persons at least 18 years old with known HIV infection who made at least 1 visit for regular care in the contiguous United States to other than a military, prison, or emergency department (ED) facility between January 5 and February 29, 1996, except for 1 city where sampling began and ended 2 months later.

In the first stage of sampling, we randomly selected 28 metropolitan statistical areas and 24 clusters of rural counties that together contained nearly 70% of all acquired immunodeficiency syndrome (AIDS) cases in the United States.^{14,15} In the second stage, we randomly selected 58 institutional or individual physicians known to care for patients with HIV infection (known providers) in urban areas and 28 in rural areas, who had been identified by local physicians or public health officials. Using data from the American Medical Association Master File, we randomly sampled approximately 4000 physicians in relevant specialties among whom 87 physicians (other providers) in urban areas and 23 in rural areas had confirmed in a screening survey that they cared for eligible patients.

In the first stage, we set sampling rates proportionate to caseload based on data obtained from the Centers for

Disease Control and Prevention and local health departments. In the second stage, sampling rates were proportionate to caseload reported by the providers. In the third stage, we set sampling rates to equalize probabilities within subgroups while increasing the overall sampling rate for women and members of private staff-model health maintenance organizations (HMOs).⁶ In the third stage of sampling, subjects were randomly selected with the appropriate predetermined probability from anonymous lists of those who received outpatient or inpatient care from participating providers during January and February 1996. We removed duplicate patient codes from the patient lists and adjusted for the fact that a patient might see more than 1 provider using multiplicity weights as described below.

After the replacement of a single urban provider with an equivalent one in the same community, we obtained agreement to participate from 100% of known urban providers and 79% in rural areas, 70% of other urban providers and 83% in rural areas, and 84% of selected patients. The baseline coverage rate, or the ratio of the population directly represented to the population that would have been represented if we had complete cooperation at all stages, was 68% for long-form interviews and 87% for long, short, and proxy interviews and forms completed by providers when no interview was possible (nonresponse forms). The short-form and proxy interviews were administered when subjects were too ill or otherwise unable to complete the full interview themselves. Nonresponse data included vital status, date of death if applicable, sex, age, race or ethnicity, insurance status, risk-exposure group, lowest and most recent CD4 cell counts, date of CD4 cell count, any AIDS-defining illness, and any inpatient stays in the last 6 months.

Data Collection

We performed 3 rounds of interviews: baseline, first follow-up, and second follow-up. Respondents who did not com-

plete a long-form interview in the previous survey wave were not approached for the subsequent wave. Centrally trained personnel from the National Opinion Research Center, Chicago, Ill, used computer-assisted personal interviewing to conduct in-person interviews.¹⁶ We approached anonymously selected subjects for interview only after providers or their agents obtained permission. The institutional review board of RAND, Santa Monica, Calif, and, if available, a local review board reviewed all forms and materials.

In the analyses described below, our baseline sample consisted of 2864 long-form respondents interviewed between January 1996 and April 1997 (71% of all sampled subjects). The first follow-up sample consisted of 2466 respondents interviewed between December 1996 and July 1997 (69% of all surviving sampled subjects); the second follow-up sample consisted of 2267 respondents interviewed between August 1997 and January 1998 (65% of all surviving sampled subjects).

Using all available data, we constructed a baseline analytic weight for each respondent to adjust the sample to represent the entire reference population, not just the proportion directly represented by the sample. Each weight, which can be interpreted as the number of persons represented by that respondent, is the product of a sampling weight, which adjusts for differential sampling probabilities; a multiplicity weight, which adjusts for patients who could have entered the sample through visits to multiple providers; and a nonresponse weight, which adjusts for differences in rates of cooperation.^{6,17,18} The sum of the baseline weights is an estimate of the size of the target population represented by HCSUS. The first follow-up weight is the product of the baseline analytic weight and an attrition weight, which accounts for the attrition of baseline respondents who were not successfully interviewed at first follow-up; the second follow-up weight takes into account attrition of first follow-up respondents not successfully in-

interviewed at second follow-up. Respondents who died prior to a wave are not considered eligible for that wave.

The analyses presented herein are based primarily on 3 cycles of 90-minute long-form interviews. At each wave, we asked all subjects about use of medical services and HIV medications during the preceding interval (6 months at baseline or since the last interview). We also inquired about their clinical status including their latest and lowest CD4 cell counts. We asked respondents who did not recall the exact value of their CD4 cell counts to provide a range.

We imputed missing values for essential covariates using a standard "hot-deck" strategy¹⁹ with further details given by Duan et al.¹⁷ Briefly, for each variable being imputed, we classified all respondents into imputation classes based on observed values for other variables. Then, for each respondent missing a value for the variable being imputed, we randomly selected a donor value from those respondents not missing a value in the same imputation class. At baseline, we had to impute 4.9% of CD4 cell count values, less than 4% for income, less than 2% for insurance status, 1.4% of values for ambulatory visits, and less than 0.5% of missing values in other essential variables. The follow-up data had comparable amounts of missing values, which were imputed using the same approach as at baseline.

Information on the use of protease inhibitors (PIs) and nonnucleoside reverse transcriptase inhibitors (NNRTIs) was obtained from baseline, first follow-up, and second follow-up interviews. To obtain comprehensive information on their use through January 1998, an additional, brief interview was completed with most subjects in early 1998. We asked respondents for the date on which they began use. Thus, for any particular month, we could determine the proportion who had used the medications by that month. We imputed the date of probable first use for the 10% of respondents who had not used these medications at baseline and did not complete a follow-up interview.¹⁷

Conceptual Model and Measures of Utilization

Our model of utilization or access to needed HIV care assumes that a need for care exists and that a less-than-optimal pattern of care is reflected in infrequent office visits among persons known to have HIV disease, in the use of EDs when there is no need for hospitalization, in increased hospitalizations, and in failure to take appropriate anti-HIV medications.

We constructed 3 measures of service and 3 measures of pharmaceutical utilization to gain insight into the adequacy of the access to needed care. The measures of service utilization included having, in the 6 months prior to the interview: (1) fewer than 2 ambulatory visits, (2) at least 1 ED visit that did not lead to a hospitalization, and (3) at least 1 hospitalization. Two visits were selected as an initial threshold for adequate care because 1 visit every 3 months is about the upper limit of an acceptable interval for monitoring disease events and response to treatment in most patients. While some hospitalizations are probably inevitable as HIV disease progresses, higher hospitalization rates clearly result from failure to receive indicated outpatient therapy. Ambulatory care that is sufficiently frequent, high in continuity, and adequate in quality should prevent some complications and decrease the rate of hospitalization, even in the advanced stages of the disease. Persons with good continuity of ambulatory care should, likewise, be better able to avoid using the ED in nonemergent situations.

The measures of medication utilization included having taken: (1) prophylaxis against *Pneumocystis carinii* pneumonia (PCP) in the 6 months preceding the interview for those subjects whose lowest CD4 cell count was less than $0.20 \times 10^9/L$, the accepted threshold for this treatment; (2) at least 1 antiretroviral medication at any time prior to the baseline interview or second follow-up interview, among subjects with a CD4 cell count of less than $0.50 \times 10^9/L$ (TABLE 1, TABLE 2, and TABLE 3); and (3) either PI or NNRTI

therapy by a specified date (December 1996 for the initial analyses presented in Table 1 and Table 3, and January 1998 for the analyses presented in Table 2), also among subjects with CD4 cell counts of less than $0.50 \times 10^9/L$. We asked about lifetime use of medications in these last 2 categories because of the possibility that subjects might have discontinued therapy prior to the time covered by the interview. We conducted additional analyses of these 2 variables that included all subjects irrespective of CD4 cell count. We constructed the variable indicating use of newer antiretroviral therapies from baseline, first follow-up, and second follow-up interview data as previously noted.¹⁷ To gain insight into the stability of differences in the use of these medications across population subgroups, we also examined patterns of dissemination of these therapies from January 1996 to January 1998, thereby encompassing a period during which there was growing awareness and wide publicity of the effectiveness of these treatments.²⁰

Statistical Methods

For the baseline sample and using the baseline long-form data, we estimated the weighted proportions and odds ratios for the utilization measures across categories defined by lowest CD4 cell count (Table 1). For each measure of utilization, we then adjusted for possible confounding via weighted logistic regression. We adjusted all SEs and statistical tests to compensate for the complex sampling design and differential weighting using linearization methods available in the SUDAAN (Research Triangle Institute, Research Triangle Park, NC) and Stata software packages (Stata Corp, College Station, Tex).²¹

We estimated 2 main effects models with different covariates to determine which covariates were most important in explaining differences among subgroups in the access measures. Model A includes CD4 cell count; model B adds age, sex, race or ethnicity, exposure group, insurance coverage,

VARIATIONS IN CARE OF HIV-INFECTED ADULTS

Table 1. Variations in Measures Related to Health Care Utilization at Baseline*

Characteristics	Sample Size	Weighted to Population	Weighted, %	Percentage (SE)					
				<2 Office or Outpatient Visits in 6 mo	≥1 Emergency Department Visit Without Associated Hospitalization in 6 mo†	≥1 Hospitalization in 6 mo	Did Not Receive PI or NNRTI Therapy by December 31, 1996 (CD4 <0.50 × 10 ⁶ /L)	Never Received Antiretroviral Therapy (CD4 <0.50 × 10 ⁶ /L)	Did Not Receive PCP Prophylaxis in the Last 6 mo (CD4 <0.20 × 10 ⁶ /L)
All subjects	2864	231 400	100	15 (1.4)	23 (1.4)	19 (1.4)	41 (2.2)	8 (0.8)	30 (1.9)
CD4 cell count, × 10 ⁶ /L									
≥0.50	253	22 000	9	18 (3.6)†	25 (3.2)†	9 (1.6)†‡	...	...	...
0.20-0.499	1096	86 700	37	17 (2.3)†‡	22 (1.9)†‡	12 (1.3)†‡	59 (3.5)†‡	13 (1.3)†‡	...
0.05-0.199	854	68 200	29	15 (1.4)†	22 (1.2)†	17 (1.3)†‡	33 (2.7)†‡	5 (1.0)†	37 (2.0)†‡
0.00-0.049	661	54 600	24	12 (1.5)†	26 (2.5)†	38 (2.8)†	24 (2.6)†	4 (0.8)†	20 (2.3)†
Age, y									
18-34	987	79 100	34	14 (1.8)	25 (1.9)†‡§	21 (1.8)§	45 (2.3)	10 (1.1)†	31 (3.6)†§
35-49	1591	125 900	54	16 (1.5)	21 (1.3)†§	18 (1.3)§	39 (2.9)	7 (1.0)†	27 (1.9)†‡§
≥50	286	26 400	11	14 (2.4)	19 (2.8)†§	21 (3.4)§	41 (4.1)	7 (1.8)†	38 (3.8)†§
Sex									
women	847	52 200	23	15 (1.9)	32 (1.9)†‡§	22 (1.7)†‡§	51 (2.7)†‡§	9 (1.3)	35 (3.2)†‡§
Men	2017	179 200	77	15 (1.4)	21 (1.5)†§	18 (1.6)†§	39 (2.6)†§	8 (0.9)	28 (1.8)†§
Race and ethnicity									
Black	959	75 800	33	18 (2.6)†‡§	30 (2.2)†‡§	23 (2.0)†‡§	56 (2.1)†‡§	11 (1.2)†	38 (2.9)†‡§
Latino	415	34 200	15	23 (2.8)†‡§	26 (2.6)†‡§	17 (2.3)†§	44 (3.5)†‡§	7 (2.0)	36 (4.4)†‡§
Other	91	7400	3	12 (4.5)†§	25 (4.1)†‡§	19 (4.4)†§	32 (6.3)†§	7 (3.2)	33 (6.9)†§
White	1399	114 000	49	11 (1.2)†§	18 (1.9)†§	18 (1.7)†§	32 (2.9)†§	7 (0.9)	23 (2.5)†§
Exposure									
Injection drug use	696	55 800	24	15 (1.7)	30 (1.4)†‡§	25 (2.0)†‡§	42 (3.0)†§	9 (1.4)	33 (2.8)†‡§
Heterosexual sex	578	42 600	18	18 (2.9)†	27 (2.8)†‡§	20 (2.6)†§	51 (2.9)†‡§	8 (1.1)	41 (6.1)†‡§
Other	287	20 500	9	21 (3.9)†	22 (3.3)†§	24 (2.8)†‡§	45 (3.7)†§	8 (1.5)	33 (4.9)†‡§
Male sex with males	1303	112 400	49	13 (1.5)	19 (1.7)†§	16 (1.7)†§	37 (3.1)†§	8 (0.8)	24 (1.5)†§
Insurance									
None	597	45 700	20	21 (2.5)†‡§	22 (2.0)†‡§	11 (1.6)†§	54 (2.9)†‡§	13 (1.6)†‡§	43 (3.8)†‡§
Medicaid	858	67 600	29	16 (2.1)†§	32 (1.7)†‡§	25 (2.1)†‡§	47 (2.9)†‡§	9 (1.2)†‡§	36 (2.9)†‡§
Medicare	544	44 300	19	13 (2.1)†§	28 (3.1)†§	28 (2.3)†‡§	38 (3.0)†‡§	7 (1.1)†‡§	22 (1.9)†§
Private health maintenance organization	474	35 500	15	13 (1.9)†§	15 (2.0)†§	12 (1.5)†§	34 (3.5)†§	5 (1.5)†§	19 (3.2)†§
Private	391	38 200	17	12 (2.2)†§	13 (2.0)†§	14 (3.2)†§	28 (4.2)†§	4 (1.3)†§	27 (2.9)†§
Education, y									
<12	723	57 700	25	19 (2.6)	31 (2.3)†‡§	23 (3.2)†‡§	49 (3.4)†‡§	8 (1.3)	41 (3.1)†‡§
12	805	63 500	27	14 (2.1)	25 (1.4)†‡§	20 (1.8)†‡§	46 (3.1)†‡§	10 (1.6)†	32 (3.5)†‡§
13-15	810	65 600	28	14 (1.8)	21 (2.1)†‡§	19 (1.9)†‡§	39 (2.0)†‡§	8 (1.5)	25 (2.7)†§
≥16	526	44 600	19	14 (1.9)	14 (2.0)†§	13 (2.3)†§	29 (3.8)†§	5 (1.3)	20 (2.1)†§
Region									
Midwest	332	25 700	11	10 (3.7)	30 (3.4)†§	23 (6.4)†§	38 (1.5)†	8 (2.4)	18 (4.3)†‡§
South	916	82 900	36	18 (3.6)	21 (1.1)†‡§	18 (2.1)†‡§	49 (4.2)†	8 (1.2)	35 (2.9)†§
West	909	65 700	28	14 (1.1)	18 (1.8)†‡§	14 (2.0)†‡§	34 (3.6)†	8 (1.7)	21 (2.5)†‡§
Northeast	707	57 100	25	16 (2.7)	30 (3.6)†§	26 (2.0)†§	40 (5.0)†	8 (1.8)	36 (2.8)†§

*PI indicates protease inhibitor; NNRTI, nonnucleoside reverse transcriptase inhibitor; PCP, *Pneumocystis carinii* pneumonia; and ellipses, not applicable. The withhold group for comparisons are CD4 cell count of 0.00 to 0.049 × 10⁶/L; aged at least 50 years; male sex and white race; exposed through homosexual encounter; had private insurance, have at least a bachelor's degree; and live in the Northeast region.

†Denotes a significant overall difference between subgroups in this category ($P < .05$) before adjustment for CD4 cell count.

‡Denotes a significantly different effect from the withhold group for this variable ($P < .05$) before adjustment for CD4 cell count.

§Denotes a significant overall difference between subgroups in this category ($P < .05$) after adjustment for CD4 cell count.

||Denotes a significantly different effect from the withhold group for this variable ($P < .05$) after adjustment for CD4 cell count.

VARIATIONS IN CARE OF HIV-INFECTED ADULTS

education, and region to model A. (Results are shown as statistical significance in Table 1 and Table 2 both with

and without adjustment for CD4 cell count [model A]. Table 3 presents the results of the model B analyses.)

To assess the sensitivity of findings to model specifications, we also conducted a number of exploratory analy-

Table 2. Variations in Measures Related to Health Care Utilization at Second Follow-Up*

Characteristics	Weighted, %	Percentage (SE)				
		<2 Office or Outpatient Visits in Last 6 mo	≥1 Emergency Department Visit Without Associated Hospitalization in 6 mo	≥1 Hospitalization in 6 mo	Did Not Receive PI or NNRTI Therapy by January 31, 1998 (CD4 <0.50 × 10 ⁶ /L)	Did Not Receive PCP Prophylaxis in the Last 6 mo (CD4 <0.20 × 10 ⁶ /L)
All subjects		16 (1.9)	16 (1.1)	14 (1.2)	15 (1.3)	26 (1.7)
CD4 cell count, × 10 ⁶ /L						
≥0.50	10	22 (3.5)†‡	15 (3.0)	8 (1.9)†‡		
0.20-0.499	40	20 (2.4)†‡	15 (1.7)	10 (1.5)†‡	25 (2.7)†‡	4 (0.8)†‡
0.05-0.199	30	11 (2.2)†	17 (2.1)	16 (1.5)†‡	8 (0.9)†‡	2 (0.5)†‡
0.0-0.049	20	14 (2.6)†	16 (2.0)	24 (2.5)†	5 (0.8)†	0 (0.2)†
Age, y						
18-34	34	18 (2.1)	19 (2.1)†§	15 (1.8)	17 (1.8)	4 (0.8)†‡
35-49	55	16 (2.1)	14 (1.2)†§	13 (1.1)‡	14 (1.6)	2 (0.4)†
≥50	11	14 (2.2)	11 (1.7)†§	20 (4.1)	13 (2.5)	1 (0.7)†
Sex						
Women	23	14 (1.6)§	23 (2.0)†‡§	19 (2.0)†‡§	22 (1.4)†‡§	3 (0.7)
Men	77	17 (2.2)§	14 (1.0)†§	13 (1.2)†§	13 (1.6)†§	2 (0.5)
Race and ethnicity						
Black	32	15 (2.6)†§	17 (1.6)	19 (1.6)†‡§	20 (2.7)†‡	3 (1.0)
Latino	15	27 (3.5)†‡§	17 (1.8)	11 (1.6)†§	16 (2.5)†	2 (1.1)
Other	3	15 (3.9)†§	12 (4.3)	19 (5.5)†§	10 (3.4)†	4 (2.5)
White	49	14 (2.1)†§	15 (1.4)	12 (1.7)†§	12 (1.5)†	2 (0.6)
Exposure						
Injection drug use	24	18 (1.8)	20 (1.7)†‡§	20 (2.2)†‡§	19 (2.1)†‡§	3 (0.7)
Heterosexual sex	19	17 (2.4)	18 (1.3)†‡§	12 (1.4)†§	18 (2.5)†‡§	2 (0.6)
Other	8	14 (2.9)	15 (3.0)†§	16 (3.6)†§	15 (2.0)†§	2 (1.7)
Male sex with males	49	16 (2.5)	13 (1.1)†§	12 (1.7)†§	13 (1.5)†§	2 (0.7)
Insurance						
None	20	25 (4.2)†§	16 (2.4)†‡§	13 (1.9)†§	21 (3.2)†‡§	4 (1.3)
Medicaid	29	14 (2.1)†§	21 (2.3)†‡§	18 (1.8)†‡§	19 (2.4)†‡§	3 (0.7)
Medicare	18	13 (2.0)†§	18 (2.3)†‡§	19 (1.8)†‡§	13 (2.1)†§	2 (0.6)
Private health maintenance organization	16	15 (2.2)†§	10 (1.6)†§	8 (1.1)†§	10 (2.0)†§	2 (1.4)
Private	17	15 (3.4)†§	10 (1.5)†§	10 (1.7)†§	9 (1.7)†§	1 (0.7)
Education, y						
<12	25	19 (2.8)	19 (1.6)†‡§	18 (1.9)	19 (2.8)†‡§	3 (0.6)
12	28	17 (2.6)	20 (2.0)†‡§	15 (2.0)	15 (2.6)†‡§	3 (1.0)
13-15	28	15 (2.1)	13 (1.4)†‡§	13 (1.6)	16 (1.6)†‡§	3 (0.9)‡
≥16	20	14 (3.2)	9 (1.6)†§	12 (2.5)	9 (1.6)†§	1 (0.5)
Region						
Midwest	10	12 (1.8)	22 (6.3)†§	22 (3.3)†§	13 (1.4)	1 (0.3)†‡§
South	36	21 (5.6)	14 (1.7)†‡§	13 (1.5)†‡§	19 (3.7)	3 (0.7)†§
West	29	12 (1.5)‡	12 (1.5)†‡§	8 (1.1)†‡§	13 (1.7)	3 (0.8)†§
Northeast	25	16 (2.1)	19 (1.0)†§	21 (2.0)†§	14 (2.0)	2 (0.8)†§

*PI indicates protease inhibitor; NNRTI, nonnucleoside reverse transcriptase inhibitor; PCP, *Pneumocystis carinii* pneumonia; and ellipses, not applicable. The withhold groups are the same as in Table 1. Data are weighted to the represented population. The N and weighted N for the second follow-up are 2287 and 213 500, respectively.

†Significant overall difference between subgroups in this category ($P < .05$) before adjustment for CD4 cell count.

‡Significantly different effect from the withhold group for this variable ($P < .05$) before adjustment for CD4 cell count.

§Significant overall difference between subgroups in this category ($P < .05$) after adjustment for CD4 cell count.

||Significantly different effect from the withhold group for this variable ($P < .05$) after adjustment for CD4 cell count.

VARIATIONS IN CARE OF HIV-INFECTED ADULTS

ses. In addition to the main analysis of 2 or more ambulatory visits in the preceding 6 months, we examined variations in receipt of 3 or more and 4 or more visits. The pattern of variations in disparities were very similar with

these other measures. We stratified the highly associated sex and risk variables in a single, 7-category variable for alternative analyses (male injection drug users, female injection drug users, men having sex with men, male heterosexu-

als, female heterosexuals, male other, or female other, with the hierarchy among women being injection drug users, heterosexuals, and others), again with little or no impact on the analyses. We examined variation in the rate

Table 3. Multivariate Odds Ratios of Measures of Utilization at Initial Interview*

Characteristics	Odds Ratio (95% CI)					
	<2 Office or Outpatient Visits in 6 mo	≥1 Emergency Department Visit Without Associated Hospitalization in 6 mo	≥1 Hospitalization in 6 mo	Did Not Receive PI or NNRTI Therapy by December 31, 1996 (CD4 <0.50 × 10 ⁹ /L)	Never Received Antiretroviral Therapy (CD4 <0.50 × 10 ⁹ /L)	Did Not Receive PCP Prophylaxis in the Last 6 mo (CD4 <0.50 × 10 ⁹ /L)
CD4 cell count, ×10 ⁹ /L						
≥0.50	1.50 (0.85-2.64)	0.86 (0.55-1.33)	0.15 (0.08-0.27)††	...	...	...
0.20-0.499	1.48 (1.07-2.04)‡	0.78 (0.63-0.97)‡	0.23 (0.17-0.32)††	4.53 (2.80-7.32)††	4.08 (2.55-6.52)††	...
0.05-0.199	1.27 (0.95-1.71)	0.82 (0.59-1.15)	0.33 (0.26-0.43)††	1.62 (1.24-2.13)††	1.35 (0.78-2.32)†	2.28 (1.70-3.01)†
0.0-0.049	1.00	1.00	1.00	1.00	1.00	1.00
Age, y						
18-34	1.15 (0.70-1.87)	1.62 (1.19-2.20)†‡	1.14 (0.78-1.67)†	1.07 (0.73-1.55)	1.35 (0.70-2.59)	0.73 (0.42-1.29)†
35-49	1.44 (0.96-2.17)	1.12 (0.86-1.46)†	0.9 (0.66-1.23)†	0.98 (0.75-1.29)	1.17 (0.54-2.55)	0.61 (0.40-0.92)†
≥50	1.00	1.00	1.00	1.00	1.00	1.00
Sex						
Women	0.64 (0.39-1.04)	1.41 (1.09-1.83)†‡	1.12 (0.80-1.58)	1.07 (0.83-1.39)	0.85 (0.46-1.56)	0.72 (0.52-1.02)
Men	1.00	1.00	1.00	1.00	1.00	1.00
Race and ethnicity						
Black	1.49 (1.06-2.09)†‡	1.62 (1.23-2.13)†‡	1.11 (0.85-1.46)	2.16 (1.54-3.05)†‡	1.40 (0.90-2.17)	1.54 (1.03-2.29)†
Latino	2.14 (1.57-2.93)†‡	1.28 (0.83-1.97)†	0.72 (0.46-1.13)	1.48 (1.10-1.99)†‡	0.80 (0.42-1.53)	1.37 (0.69-2.72)
Other	1.06 (0.40-2.84)†	1.49 (0.96-2.30)†	1.06 (0.59-1.90)	0.97 (0.48-1.94)†	0.85 (0.32-2.31)	1.80 (0.82-3.96)
White	1.00	1.00	1.00	1.00	1.00	1.00
Exposure						
Injection drug use	1.13 (0.81-1.59)	1.21 (0.92-1.59)†	1.41 (1.05-1.90)†	0.90 (0.69-1.18)	1.05 (0.67-1.67)	1.09 (0.78-1.51)
Heterosexual sex	1.42 (0.84-2.40)	0.62 (0.56-1.18)†	1.13 (0.71-1.82)	0.93 (0.67-1.29)	0.79 (0.44-1.45)	1.45 (0.90-2.34)
Other	1.92 (1.01-3.67)‡	0.77 (0.49-1.20)†	1.35 (0.88-2.06)	0.98 (0.59-1.60)	1.02 (0.50-2.10)	1.31 (0.77-2.21)
Male sex with males	1.00	1.00	1.00	1.00	1.00	1.00
Insurance						
None	1.60 (0.99-2.59)	1.45 (0.96-2.20)†	0.77 (0.45-1.33)†	1.88 (1.31-2.69)†‡	2.83 (1.38-5.79)†‡	1.13 (0.82-1.55)†
Medicaid	1.20 (0.76-1.88)	1.89 (1.29-2.78)†‡	1.37 (0.86-2.20)†	1.75 (1.15-2.64)†‡	2.23 (0.97-5.17)†	0.81 (0.59-1.11)†
Medicare	0.98 (0.62-1.55)	2.01 (1.47-2.75)†‡	1.65 (0.98-2.79)†	1.56 (1.07-2.27)†‡	2.04 (1.01-4.12)†‡	0.52 (0.37-0.71)††
Private health maintenance organization	1.04 (0.67-1.62)	1.05 (0.69-1.59)†	0.71 (0.42-1.19)†	1.27 (0.81-2.00)†	1.28 (0.56-2.95)†	0.57 (0.37-0.90)††
Private	1.00	1.00	1.00	1.00	1.00	1.00
Education, y						
<12	0.96 (0.63-1.45)	1.46 (1.00-2.12)†	1.44 (0.93-2.24)	1.33 (0.92-1.92)	1.22 (0.67-2.23)	1.96 (1.23-3.14)†
12	0.77 (0.48-1.25)	1.26 (0.91-1.74)	1.36 (0.87-2.12)	1.41 (1.07-1.87)‡	1.60 (0.92-2.79)	1.54 (1.04-2.29)‡
13-15	0.89 (0.62-1.29)	1.13 (0.80-1.59)	1.33 (0.84-2.10)	1.17 (0.82-1.67)	1.29 (0.78-2.13)	1.31 (0.89-1.93)
≥16	1.00	1.00	1.00	1.00	1.00	1.00
Region						
Midwest	0.81 (0.32-2.08)	1.31 (0.73-2.35)†	0.91 (0.48-1.70)	1.19 (0.81-1.74)	1.01 (0.50-2.02)	0.52 (0.26-1.05)†
South	1.15 (0.62-2.15)	0.72 (0.47-1.11)†	0.70 (0.50-0.98)‡	1.37 (0.78-2.39)	0.89 (0.53-1.48)	0.94 (0.65-1.36)†
West	0.99 (0.63-1.56)	0.88 (0.53-1.45)†	0.67 (0.45-1.01)	1.10 (0.70-1.75)	1.13 (0.61-2.07)	0.57 (0.38-0.85)††
Northeast	1.00	1.00	1.00	1.00	1.00	1.00

*CI indicates confidence interval; PI, protease inhibitor; NNRTI, nonnucleoside reverse transcriptase inhibitor; PCP, *Pneumocystis carinii* pneumonia; and ellipses, not applicable.

†Denotes a significant overall difference between subgroups in this category ($P < .05$) after multivariate adjustment.

‡Denotes a significantly different effect from the withheld group (see Table 1) for this variable ($P < .05$) after multivariate adjustment.

of hospitalization within CD4 cell count strata because of the strong effect of disease progression. Finally, we examined the patterns of PI and NNRTI use by additional specific dates during 1996. (Results of the regressions discussed in the text that are not presented in the tables are available from the authors on request.)

To assess change over time, we estimated the proportions for the utilization measures across subgroups at the second follow-up. To separate the effects of time vs attrition, we focused on the second follow-up sample only. As a result, our reference population for this analysis is the baseline reference population who survived until the second follow-up. We estimated this population's proportions at second follow-up, and conducted tests of these proportions adjusted for CD4 cell count. We also analyzed the percentage change since baseline in utilization proportions for this population, and we discuss some of these findings in the text.

RESULTS

Patterns of Care in 1996 and Early 1997

The HCSUS data are weighted to represent 231 400 adults who received care in the 48 contiguous United States outside of EDs, prisons, or the active military during a 2-month period in early 1996.¹³ While a majority of these persons represented by the HCSUS met the standards represented by our 6 utilization measures during 1996 and 29% were in compliance with all of them, many did not. Overall, 15% of the represented population had fewer than 2 ambulatory visits in the previous 6 months, 23% had at least 1 ED visit that did not lead directly to hospitalization, and 19% were hospitalized at least once during the same period (Table 1). Forty-one percent of those with CD4 cell counts of less than $0.50 \times 10^6/L$ had not received PI or NNRTI therapy by the end of 1996, and 30% of persons with CD4 cell counts of less than $0.20 \times 10^6/L$ had not taken medications to prevent PCP in the 6 months prior to their interview, but only 8% had never

taken any antiretroviral therapy by the time of their initial interview.

Disparities in Care

Use of needed care differed by CD4 cell count, age, sex, race or ethnicity, HIV risk-exposure group, insurance, socioeconomic status, and region (Table 1). The CD4 cell count was associated with care for all 6 measures tested, with a lower CD4 cell count being associated with more use of medications, hospitalization, and ambulatory care. The relationship between age and use of needed care was mixed; HIV-infected persons who were at least 50 years old were less likely to use EDs but were more likely not to take indicated PCP prophylaxis. Women were more likely than men to use the ED and to be hospitalized and were more likely not to have taken indicated PCP prophylaxis or to have started PI or NNRTI therapy by the end of 1996. Race or ethnicity was associated with the adequacy of care for 5 of 6 measures. Considering individual comparisons, care received by blacks and Latinos was significantly less optimal than that received by whites on 6 and 4 of 6 measures, respectively.

Exposure route was associated with care received on 4 of 6 measures. Those having either injection drug use or heterosexual contact as their risk factor had less favorable patterns of use than men who had sex with men (Table 1). The care received by both uninsured patients and those with Medicaid insurance was unfavorable compared with that received by the privately insured on 5 of 6 access measures. Medicare beneficiaries, most of whom had also had Medicaid, had high rates of ED and hospital use, similar to subjects who had Medicaid only. However, persons with Medicare coverage were more likely to have started PI or NNRTI therapy and were less likely to be deficient in PCP prophylaxis compared with those with Medicaid coverage alone. Those enrolled in HMOs had a pattern of care very similar to others with private insurance, except that they were more likely to have received appropriate PCP

prophylaxis. Those with the most education had a more desirable pattern of care than others for 4 of 6 measures, including PI and NNRTI therapy and PCP prophylaxis. The pattern of care varied by income in a similar way, with the lowest income group having the least favorable rates for most measures (data not shown). Finally, care varied by region for 4 of 6 measures. Patients in the Northeast were more likely to use an ED, be hospitalized, or miss indicated PCP prophylaxis, while those in the South were more likely to have not used a PI or NNRTI.

Changes Over Time

We reassessed compliance with the standards during the latter half of 1997 and early 1998, after a median of 15.1 months of follow-up (Table 2). At the second follow-up interview, 16% of patients represented had fewer than 2 visits per 6 months, 16% had an ED visit without hospitalization within the prior 6 months, and 14% were hospitalized at least once during the same period. In addition, 15% had not received indicated PI or NNRTI therapy by January 1998, 3% had never taken any antiretroviral therapy, and 26% had not taken indicated PCP prophylaxis. Overall, the percentage who were in compliance with all 6 indicators had increased from 29% to 47% and the percentage who were noncompliant with 2 or more measures had fallen from 34% to 17%.

Relative to baseline values, there was virtually no change in the proportion meeting the standard of 2 outpatient visits in 6 months (Table 2). Interestingly, there was an increase of 26% in the proportion not having at least 3 ambulatory visits, perhaps reflecting improving health in the population (data not shown). For the other 5 indicators, there were declines in the proportions of subjects not meeting the standards in the indicators. Of note, the improvement in proportion of persons with CD4 cell counts not receiving PCP prophylaxis (from 30%-26%) was much more modest than the decline in the proportion not having taken

VARIATIONS IN CARE OF HIV-INFECTED ADULTS

PI and NNRTI therapy (41%-15%). At each point in time, almost one quarter of persons who had initiated PI and NNRTI therapy did not receive indicated PCP prophylaxis. Significant predictors of improvement were CD4 cell count and race for 3 indicators each, and exposure and region for 1 indicator each (data not shown). Despite these improvements, there continued to be significant differences in compliance by CD4 cell count for 5 of 6 measures, by exposure group, insurance type, and region for 4 each, and by sex and race or ethnicity for 3 each (Table 2).

Multivariate Analyses

Although the unadjusted values given accurately describe variations in the care actually received by HIV-infected US

adults, we constructed multiple logistic models to test the independent fixed effects of the factors listed above. We evaluated the 6 measures with respect to 7 demographic characteristics, for a total of 42 assessments. The CD4 cell count adjustment had little impact: in the initial period, of 30 unadjusted significant overall effects within the 7 demographic variable categories (sex, age, race or ethnicity, insurance status, exposure group, education, and region) in our 6 measures (out of a possible 42), 28 effects remained significant with CD4 cell count adjustment (Table 1). Twenty-two of 42 unadjusted effects were significant in the second period examined, and 20 of these remained significant with CD4 cell count adjustment (Table 2). Although some over-

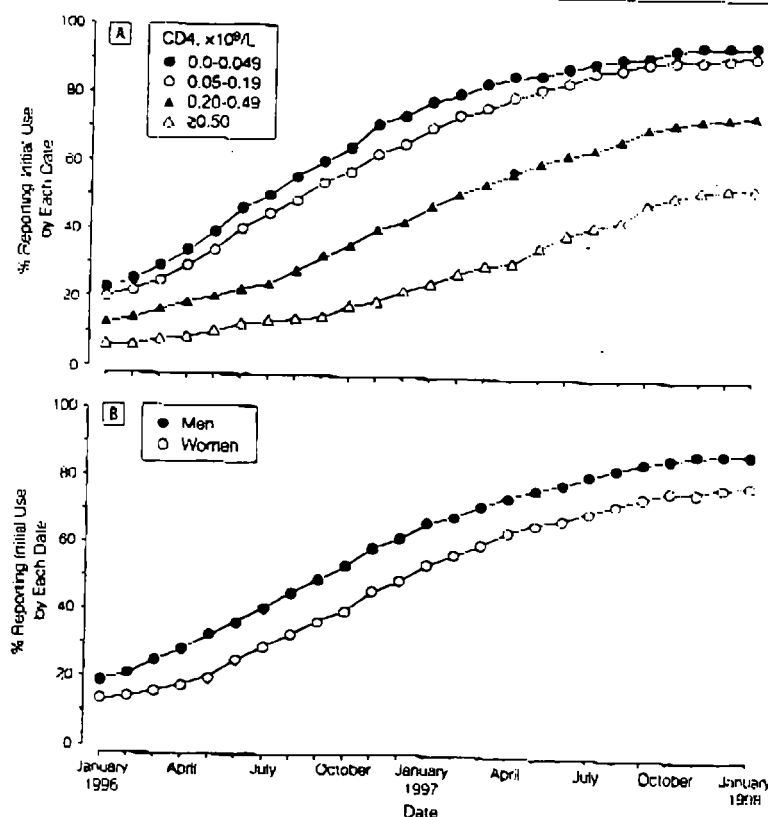
all effects within demographic variable categories lost significance, in models that included all 7 categories of variables listed above plus CD4 cell count, 15 of 42 possible effects (other than by CD4 cell count) remained significant in the initial period (Table 3). Eleven of 18 possible effects were significant in the multivariate models, for insurance, race or ethnicity, and age (including 5 of the 6 access indicators for insurance, 3 of the 6 indicators for race or ethnicity, and 3 of the 6 indicators for age), compared with 14 significant effects for these 3 variables with CD4 cell count adjustment alone. On the other hand, only 4 of 24 possible effects were significant in the multivariate models for sex, education, exposure group, and region compared with 15 effects with CD4 cell count adjustment alone.

Even with the differential improvement rates, significant differences in the presence of deficiencies persisted for 20 of 48 possible predictors at follow-up in the full multiple regression model. These included race or ethnicity for 1 of 6 indicators; age for 2; sex, insurance, and exposure group for 3 each; region for 4; and CD4 cell count for 3 (data not shown). While there was less evidence of an independent overall effect of race or ethnicity at follow-up, important CD4 cell count-adjusted differences remained between whites and blacks in PI and NNRTI use and between whites and Latinos in the pattern of ambulatory visits (Table 2).

PI and NNRTI Use Over Time

To explore further the differences in access to a key component of care over time, we examined the proportion of the HIV-infected adult population that had ever used PI or NNRTI over a 2-year period. Overall, use of these drugs grew very rapidly throughout this period among persons with a CD4 cell count lower than $0.50 \times 10^9/L$, increasing from 17% in January 1996 to 59% in January 1997, and to 85% in January 1998 (FIGURE 1). Generally, use varied inversely by CD4 cell count (Figure 1). In addition, there were clear and

Figure 1. Cumulative Unadjusted Proportions Reporting Any Prior or Current Use of Protease Inhibitors or Nonnucleoside Reverse Transcriptase Inhibitors From January 1, 1996, to January 1, 1998



Cumulative use of protease inhibitors or nonnucleoside reverse transcriptase inhibitors by lowest CD4 cell count (A) and by sex (B).

substantial differences in cumulative use of these medications by sex, race, and insurance with women, minorities, and the underinsured being less likely to have received these drugs (Figure 1 and FIGURE 2). The 24% difference in initial use of these medications in late 1996 ($P < .001$, Table 1) between blacks and whites had declined to 8% in early 1998, but remained significant, even with CD4 cell count adjustment ($P = .016$, Table 2). Similarly, the difference in treatment rates between those uninsured and those privately insured declined from 26% ($P < .001$) to 12% ($P = .016$). The rate for Medicaid beneficiaries was within 2% of the rate for the uninsured at the later date and significantly different from that of the privately insured ($P < .001$); both remained significantly different from those who were privately insured, even with multivariate adjustment ($P = .026$, Medicaid; $P = .048$, no insurance). Finally, the difference between men and women (12% in late 1996) declined very little and was 9% in early 1998 ($P = .003$, $P < .001$, respectively, with CD4 cell count adjustment).

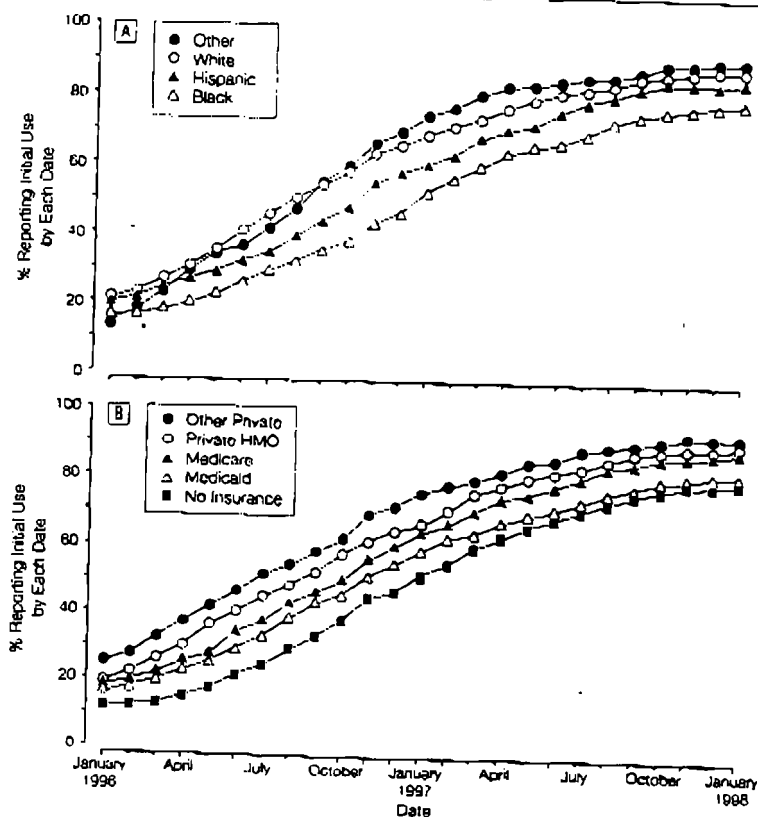
Even though the differences between certain groups abated over time, the lag in dissemination to traditionally disadvantaged groups meant that these groups waited much longer before having an opportunity to try these agents. For example, on average men waited 11.2 months from the beginning of 1996 while women waited 13.5 months ($P \leq .001$); blacks waited 13.5 months while whites waited 10.6 months ($P < .001$); uninsured persons waited 13.9 months while Medicaid beneficiaries waited 12.4; and those with private fee-for-service insurance waited 9.4 months ($P \leq .001$; $P < .002$, respectively). There were other contrasts of interest: southerners waited 13.4 months compared with 10.6 to 10.8 months elsewhere ($P = .03$). Overall, in a multiple regression model, CD4 cell count, sex, race, education, insurance, and risk or exposure were the independent significant predictors of delay in time to first use of a PI or NNRTI ($P < .05$).

COMMENT

This first detailed examination of medical care for a specific chronic condition in a nationally representative sample of Americans has yielded a mixed picture. Realized access, or use of needed care, is good for many HIV-infected patients. At the time of the first study interview, about 80% met each of our individual standards for continuity of outpatient services. About 90% of those with indications had received antiretroviral therapy, and nearly 60% had received PIs within a year of these agents' approval. However, 30% of those with indications denied taking medications to treat or prevent PCP. Moreover, less than 30% of patients were in compliance on all of the measures for which they were eligible. Finally, the deficiencies in HIV care were unevenly distributed across the population.

Disparities in HIV care cut across important population categories, with disadvantaged populations having the least favorable patterns of use. Compared with whites, use was less optimal for blacks and Latinos for 5 and 3 measures, respectively, of the 6 measures studied, in models that were statistically adjusted for CD4 cell count, age, sex, and exposure group. Addition of insurance to the models attenuated these effects for many of the measures, suggesting that insurance contributes importantly to racial and ethnic differences in receipt of care. Women and persons whose exposure group was not men having sex with men fared worse on most measures; however, most of these effects were miti-

Figure 2. Cumulative Unadjusted Proportions Reporting Any Prior or Current Use of Protease Inhibitors or Nonnucleoside Reverse Transcriptase Inhibitors From January 1, 1996, to January 1, 1998



Cumulative use of protease inhibitors or nonnucleoside reverse transcriptase inhibitors by race and ethnicity (A) and by insurance status (B). HMO indicates health maintenance organization.

VARIATIONS IN CARE OF HIV-INFECTED ADULTS

gated or eliminated by covariate adjustment, suggesting that at least some of the less desirable pattern of care experienced by women at that time was related to insurance coverage and other demographic characteristics, notably race or ethnicity.

Those who lacked health insurance fared worse in terms of most measures. Surprisingly, those with Medicaid also were deficient in many of the categorical measures relative to private insurance. We found no evidence of an unfavorable pattern of care among private HMO enrollees. Along with Medicare beneficiaries (most of whom must be followed by the health care system long enough to establish 2 years of disability), they were most likely to receive indicated prophylaxis against PCP.

The results of the interview in late 1997 and early 1998 indicate important changes in the pattern of care. The proportion of persons taking PI or NNRTI therapy for the first time continued to rise until near the end of that time, by which time 85% of all persons with CD4 cell counts of less than $0.50 \times 10^9/L$ had tried these agents. There continued to be differences in use across demographic groups, but many were of lesser magnitude than those groups that had been evident a year earlier. For example, the difference between blacks and whites had decreased from 24% to 8% and the disparities by insurance category declined by about half. On the other hand, there was no further narrowing of the gap between men and women.

At the same time, some other access measures had improved. Hospitalization rates and ED use both declined overall, and the gaps declined among subgroups. By early 1998, almost all subjects had taken an antiretroviral medicine at some time if their CD4 cell counts were less than $0.50 \times 10^9/L$. On the other hand, the proportion of persons taking PCP prophylaxis had improved only very modestly, and 26% of those with an indication reported not receiving any in the preceding 6 months.

Thus, there was a substantial improvement in access to care in 1997 and 1998

(with the proportion not deficient in any access measures for which they were eligible increasing from 29% to 46%), but some important deficiencies remained, and disparities by race, insurance status, and sex persisted, although their magnitude had lessened. Overall, the HCSUS data show that disenfranchised groups in the United States are less likely to receive medications for HIV that are potentially lifesaving, yet being in an advantaged group does not guarantee access to ongoing effective care.

As noted by Bozzette et al,¹³ the study represents only persons receiving ongoing care and used a sampling strategy that is likely to underrepresent those with very poor access, those who are less compliant, and those who are relatively healthy; however, it does account for the 32% of nonrespondents to the full interview with proxy and non-response data. The study uses self-report data. Patient reports are subject to recall bias. To minimize this, subjects were shown photographs of antiretroviral medications when questioned about their use. Patient reports of CD4 cell count have been shown to be reliable and valid in relation to critical thresholds at which the therapies queried in this article are recommended (<0.20 , or $<0.50 \times 10^9/L$).²² Data on use of newer medications represent the practices through early 1998 for persons who received ongoing care for HIV disease in early 1996 but not for persons who may have entered care after the eligibility period for this study. It is also possible that intergroup differences in use of services and medications reflect, in part, patient choice and/or nonadherence rather than social or system factors. The findings relating to regional differences in hospitalization rates may reflect, in part, regional differences in practice style; they are consistent with national data on overall hospitalization rates.²³ Finally, the 6 measures of access are not measuring independent phenomena, and there is some correlation among them.

Nonetheless, several conclusions can be drawn from the patterns of deficiencies in care uncovered by this study.

First, being uninsured and having HIV is a serious problem and places the individual at risk of not obtaining adequate care. Second, having Medicaid does not result in as appropriate a pattern of use for needed treatments as does having private insurance. Third, blacks and Latinos under care for HIV also have less favorable patterns of use of needed services than do whites, patterns that cannot be explained by other characteristics of these patients. Fourth, use varies by certain other characteristics, including sex, exposure group, income, and education. While these disparities diminished over time, they did not disappear. In the initial period, patient insurance status, race or ethnicity, and age were the most important explanatory variables; in the second period studied, sex, exposure group, insurance, and region were each an independent predictor of access for at least 3 of the 6 access variables. Strategies to ensure optimal care for persons infected with HIV in the US population need to take into account these patterns of deficiency and the fact that no one characteristic of disenfranchised populations is responsible for them.

What are the implications of these findings for the future of care for HIV disease? Up-to-date treatment for those infected with HIV offers the prospect of long-term survival, but such therapy is likely to continue to evolve rapidly. Patients need to be in continuous relationships with providers who can monitor their clinical status and their compliance with therapy and who can assess their need for modifications in their therapy if they become resistant to their regimens. As newer therapies become available, members of the medical community must be concerned that such treatments may not disseminate therapy at similar rates throughout the populations who need them, as the HCSUS data show occurred with the PI and NNRTI medications. A lag in obtaining newer therapies may well place patients at risk of death and other serious complications.

In the last 2 years, HIV has become a highly treatable disease.^{7,20} For much longer, it has been clear that good medi-

VARIATIONS IN CARE OF HIV-INFECTED ADULTS

cal care can prolong life by preventing complications and attacking the infecting organism. While access to HIV care is good for many adults and improving for others, it is still not nearly optimal. These data show a pattern of less access to high-quality HIV care for disadvantaged groups across the United States, and these data suggest the need for comprehensive efforts to improve patient care. Such efforts should include steps to ensure that lags in access to newer HIV treatments are not recapitulated with each improvement in treatment.

There have been major advances in recent years in the care of many other chronic diseases, including heart disease, diabetes mellitus, and some cancers. Representative national data regarding care for these conditions would help us to determine the extent to which variations in care are contributing to inequities in the health care of the US population. Such populations need to be monitored longitudinally because of the likelihood that the patterns of any disparities in care may well change over time as they have in the case of HIV disease.²⁴

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Acknowledgment: We thank participating subjects and sites; staff at RAND, the RAND Survey Research Group; University of California, Los Angeles, University of California, San Diego; the National Opinion Research Center; and James Tebow for technical assistance with the manuscript.

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June 1, 1999

Mr. Daniel C. Montoya
Executive Director, Presidential Advisory Council on HIV/AIDS
736 Jackson Place, N.W.
Washington, D.C. 20503

Dear Mr. Montoya:

My purpose in writing this letter is to highly recommend the appointment of Roger A. Gooden to the President's Advisory Council on HIV/AIDS. Mr. Gooden is recognized and respected as one of the most articulate advocates of persons living with HIV Disease within the Kansas City Metropolitan Area and also throughout the State of Missouri and the Mid-West.

Mr. Gooden is past Chair of the Ryan White Title I Planning Council and Title II Consortium. He has worked continuously to assure that HIV/AIDS issues are at the top of the agenda at both the city and state level. Mr. Gooden has been able to effectively work with all parts of the community to raise the level of awareness of HIV/AIDS issues.

Mr. Gooden is also known and respected throughout our Nation and internationally. He has received numerous awards and honors locally, statewide and nationally. Currently, Mr. Gooden serves as Chairman of the National Association of People with AIDS, representing and advocating for nearly one million people throughout the United States infected with the HIV virus and over forty million people throughout the world.

I can think of no other person better suited for a position on the President's Advisory Council on HIV/AIDS than Roger Gooden. He is truly an advocate and an ambassador for the HIV/AIDS community. Mr. Gooden has been instrumental in bringing issues of HIV and substance abuse to the table and educating candidates on these issues. I really appreciated his willingness to share his knowledge with myself and others. Please consider appointing him to this position. If you have any questions, feel free to contact my office at 816-274-2595.

Sincerely,

Kay Barnes

cc: Sandra L. Thurman, National Director of AIDS Policy, White House



Washington, June 3, 1999

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President William J. Clinton
The White House
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Most Esteemed President Clinton:

LLEGÓ and its many affiliates throughout the United States, Puerto Rico and Latin America work in the front lines of the struggle against AIDS. We are witnesses to the impact of HIV and AIDS in Latin America and the difficult barriers faced by those needing treatment and education. While we applaud your administration's mission to devote greater resources to the struggle against the global pandemic, we urgently need substantial resources directed toward the critical need for treatment, advocacy and education in Latin America.

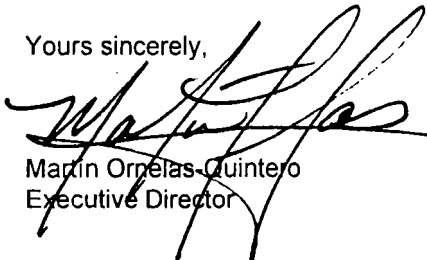
AIDS stigmas, prejudices and ignorance are facts of life confronting persons with HIV and AIDS and their health services providers. These barriers have prevailed in most countries in Latin America and cripple the delivery of services. So-called cultural factors; machismo, homophobia and corruption; have severely hindered the accountable delivery of services to persons affected by HIV and AIDS. The national health agencies are invariably burdened by less stigmatized health concerns, and often lack the insight necessary to render reliable quantitative data on local AIDS-related needs. Community-based organizations, who are in a position to know local needs and positively inclined to deliver services, find themselves unable to deliver services due to limited or no resources.

Many community-based AIDS service organizations in Latin America are located precisely in the areas where HIV/AIDS prevention education and treatment services are needed. They are composed of committed professionals and activists who are well-positioned to gather reliable and objective data about the service needs of their local communities. Being that many service providers are staffed and volunteered by clients, this significantly reduces the feeling of stigmatization by service recipients and allows for more compassionate, empathetic services.

As part of the solution to reign-in the sharp increase in HIV/AIDS infections in Latin America, and promote treatment availability and adherence, community-based organizations need a clear and reliable access to funding and resources. International aid organizations and foreign governments lending aid to Latin America would maximize the impact of each AIDS dollar by funding community-based organizations directly, be it for services, education, medications or advocacy. Dispensation of medications by local organizations means cost-effective distribution and access to updated therapies. Direct funding of community-based organizations would assure a more expedient response, providing for timely service delivery where it is needed most.

Thanks you for your consideration to the ideas we have provided. In the face of a sharp increase in HIV/AIDS infections in Latin America, a community-based approach is the best available solution, until a cure is found. Please call on me if you have any questions.

Yours sincerely,



Martin Ornelas-Quintero
Executive Director

CC: Sandra Thurman, White House Office of National AIDS Policy
Lucille Roybal-Allard, Congressional Hispanic Caucus
Daniel Montoya, Presidential Advisory Council on HIV/AIDS

The National Latina/o Lesbian, Gay, Bisexual & Transgender Organization

1612 K Street, NW, Suite 500 - Washington, DC 20006 - tel 202.466.8240 - fax 202.466.8530 - aqulgbt@llego.org - <http://www.llego.org>

Pls. draft.

response

thankyou/no
POS. avail. I will
keep in active
file + pass along
etc.

SB
SmithKline Beecham
Nigeria plc

SB
SmithKline Beecham
International

CHIEF JAY A. DROSIN, Ph.D. MPH
Managing Director - Nigeria
Regional Director - West Africa

SmithKline Beecham Nigeria Plc.
Km. 16, Ikorodu Road, Ojota. P. M. B. 21218, Ikeja. Lagos.
Direct Line: 4938001 Cellular 090-402329 Fax: 4930022

June 1, 1999

Ms. Sandra Thurman
Director, White House Office of National Aids Policy
c/o Office of the National AIDS Policy Coordinator
200 Independence Avenue, S.W.,
Washington D.C. 20201

Dear Ms. Thurman,

I was briefly in the United States recently and chanced to see the article in USA Today on your activities.

I found it fascinating but right, that you should have gone to Africa to seek some enlightenment and possible solutions to the challenges facing you on AIDS in the United States.

For the past fourteen years I have lived on the African continent, the time spent either in managing consumer product companies or directing health projects for USAID. I directed the all important and significantly successful Condom Social Marketing project in Kinshasa, Zaire in 1990-1991. During that period, abruptly cut off by the military mutiny in September of 1991 and the consequent ordered evacuation of the country, I raised monthly sales from 800.000 units to almost 4.000.000 using a palette of interpersonal communication, popular theatre, music and dance evening interlaced with condom usage education and with non traditional marketing put condoms not only in the purses of the commercial sex workers, but in bars, hotels, table top and ambulant merchants and just about everywhere with innovative promotional support from t shirts to drink coasters and leaflets, leaflets that showed women as partners and having a say in condom use.

Registered Office: Km 16, Ikorodu Road, Ojota. P. M. B. 21218, Ikeja RC 8726. Telephone: 4978600-3. Telex: 26419 Fax: 4529066 Ilupeju. Factories: 49/51, Town Planning Way, Ilupeju. Telephone: 4979091, 4979093, Agbara Factory: Km 32. Igbesa Road. Agbara Industrial Estate. Telephone: 712399, 712298.

Directors: Chief Oludolapo Ibukun Akinkugbe M. O. N., (Chairman), Chief (Dr) Jay Alvin Drosin (American) Managing, Chief Gabriel Yakubu Aduku. Izoma Philip Chikwuedo Asiodu, Mathias Kayode Akinbami, Paul Michael Barrett (British), Andrew James Morris (British). Raphael Oyeyemi Okunmuyide, Edmund Chukwunenye Onuzo, Alhaji Umaru Ali Shinkafi C.O. N., Chief Nelson Erasmus Spiiff, Folarin Rotimi Abiola Williams (Jnr) Uchechukwukah Attah (Alternate), Oladipo Ayodele Oloke (Alternate)

As an anthropologist and a businessman, married to a Congolese woman, I've had the good fortune to live and work among the Africans, to be able to perceive those communication opportunities and exploit them, given the ease in which I moved among the people. Speaking Lingala, the vehicular tongue of Zaire and having my wife at my side went a long way towards the success of the project.

I did this not only in Zaire, but Zambia, the Ivory Coast and at the request of USAID, consulted for them on project development in Mali and Kenya.

When I'm in the States, I am constantly reminded of the power of the media in general, having been in advertising many years, and constantly reminded, in my conversations with people, how little understood AIDS is and how little impact most efforts have made on the general population, in fact it is frightening how ignorant, despite the opportunities to communicate effectively, the at risk groups are.

I often thought of how successful we have been far from our own shores in getting the message across, despite cultural barriers, often turning those negatives into positives, to change peoples attitude about using barrier protection, using messages and means in a 'popular and understandable' manner. And I think how unsuccessful it seems in the States where the level of education and ability to communicate are so much higher, or seemingly so.

We should be able to take those lessons learned in Africa and apply them better to what we are doing in the States. We need more perceptive, dynamic and responsive people to make that happen.

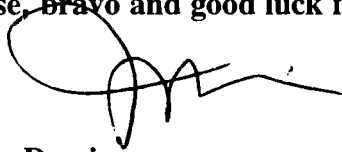
This by the way , is not necessarily a pitch for a job, how ever thinly veiled and I'm enclosing my C.V. for informational purposes so you can see my background. I've been in Africa, as I said, 14 years and the last four spent here in Lagos, Nigeria where AIDS awareness and NGO presence is just starting, managing a major international healthcare company SmithKline Beecham. I'm finishing up an already overextended contract with them and returning to the States, returning to my never lived in residence in DC, after an absence of over thirty years, a challenge unto itself to readjust.

I've a long track record of success and the desire to share these experiences in helping educate people against AIDS, having lived amongst its ravages, working with thousand of commercial sex workers, slaves with invisible chains, as well as seeing the effects in my child survival projects on the children, innocent victims of greed, ignorance and corruption.

All this is to say, that should you ever need any assistance, I'd be glad to do what I can, so feel free to get in touch with me should you wish to explore further what you can do and how I can help you.

You have a tough job, but everything is there to make it work, if you can ever get over the political nonsense and get down to what will really make a difference.

**In any case, bravo and good luck for your efforts,
Sincerely,**

A handwritten signature in black ink, appearing to be 'Jay A. Drosin', written over the word 'Sincerely,'.

**Dr. Jay A. Drosin
Managing Director, SmithKline Beecham Nigeria and West Africa**

JAY A. DROSIN

Correspondence and contact address:

c/o SmithKline Beecham Intl - Africa
SB House, Brentford, Middlesex TW8 9BD
United Kingdom

Office Telephone: Nigeria 234 1 4938001
Residence: Nigeria 234 1 2692270
Fax: Nigeria 234 1 4930022
E-mail: j.drosin@sb.com

U.S. Residence

1612 Hobart St. NW
Washington DC 20009

Telephone: 202 483 4338
Fax: 202 483 4309

EXPERIENCE

SMITHKLINE BEECHAM NIGERIA, Lagos, Nigeria

Managing Director, SB Nigeria

1995 to present

Regional Director, Anglophone West Africa

- Responsible for the management of SmithKline Beecham's total healthcare operations both in Nigeria, Ghana, Sierra Leone, Liberia, Gambia and The Democratic Republic of Congo [ex Zaire].
- Annual sales of \$40 million nutritional drinks, oral healthcare products, over-the-counter drugs, pharmaceuticals.
- Two manufacturing facilities and staff of 600 employees.
- Personally manage export sales of \$1.5 million.
- Responsible for development of new products that have successfully expanded our consumer base and brought the company into Primary Health care areas.
- Oversee all collaborative efforts with Government on Community Participation such as the construction of a Primary Health Care unit in economically deprived areas of Lagos.

Have been honoured with two traditional Chieftancy titles from local governments in both Lagos State [Basegun of Mafowoku] and Ogun State [Baba Ewe Oniyemoja] for recognition of services to the community.

UNIBRA GROUP, Brussels, Belgium

Director of Distribution and Development SKOL Breweries, Kinshasa, Zaire 1993 - 1995

- Responsible for total sales of beer and soft drinks, amounting to a high of 65,000HL per month.
- Oversee operations for sales and distribution with personnel numbering 175.
- Developed direct sales operations designed to sell to smaller sales outlets, bars, depots representing a high of 25% of total sales.
- Personally created and developed the "New Bako" soft drink, label, flavours, point of sale and merchandising materials, promotional and advertising campaigns, which at inception held 3% of market share and within a year's time grew to over 10% in direct competition with Coca-Cola.

POPULATION SERVICES INC., Washington DC

Project Manager, Abidjan, Ivory Coast

1992 - 1993

- Directed project for condom social marketing in the Ivory Coast.
- Created national distribution infrastructure using outside as well as internal means to obtain 80% market coverage.

- Sales rose from 329,000 units per month to 1,000,000 in a 11-month period.
- Top performing social marketing project in Africa with 0.84 per capita consumption and number 2 globally.
- Developed highly innovative non-traditional interpersonal communication methods adopted by numerous social marketing programs throughout Africa.
- Consulted on Kenya and Mali social marketing proposals.

Project Manager, Lusaka, Zambia

1991 - 1992

- Prepared all pre-project implementation activities for the AIDSCOM-PSI Condom Social Marketing project.

Consultant, USAID, Kinshasa, Zaire

1991

- Requested by USAID to remain after ordered evacuation of Zaire to assist in the construction of a disaster relief program dealing with the private sector, pharmaceutical distribution and general support of essential drug use through the social marketing infrastructure in Kinshasa.

Project Manager, Kinshasa, Zaire

1990 - 1991

- Directed nationwide sale, promotion and distribution of Prudence condoms, vaginal spermicides and oral contraceptives.
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- Clients numbered over 1400 in Kinshasa and the project was only national distributor of health products in Zaire.
- Stressed interpersonal communications and popular non-traditional approach to education through "Soiree Prudence", popular theatre and bar demonstrations.
- Recognised by the USAID report to Congress as the model social-marketing project in sub-Saharan Africa.

ORGANISATION FOR REHABILITATION THROUGH TRAINING, Washington DC

Project Manager and Chief of Mission, Kinshasa, Zaire

1987 - 1990

- Directed the USAID targeted feeding program for rehabilitation of malnourished children.
- Reinforced primary maternal and child healthcare infrastructure in 60 health centres and hospitals in Kinshasa.
- Trained over 1,000 outreach workers to work with health centres and the general population.
- Recognised by USAID Food for Peace as one of the most successful projects of its kind.

UNIBRA GROUP, Brussels, Belgium

Consultant to the President, Kinshasa, Zaire

1986 - 1987

- Brought from Belgium at the request of the owner of UNIBRA breweries to act as consultant in the restructuring of marketing operations for:

VAP: The manufacture of biscuits and baby foods.

SKOL Beer: The market leader. Worked in Kinshasa and Kisingani to raise market share, while serving as temporary sales manager.

BAKO Soft-drink Division: Directed marketing and sales operations in Kinshasa.

FILTISAF Textile Division: Assisted in the restructuring of the textile operations.

BEATRICE FOODS INC., Brussels, Belgium
Marketing Manager, European Dairy Products

1983 - 1986

- Supervised all marketing operations for \$120 million dairy division, 6 countries and 11 factories. Oversaw pan-European product and development activities, packaging and promotion. Responsible for development of UK private label business. Developed sales infrastructure in West Africa for Spanish subsidiaries.

ALLIE SOCOOP, Brussels, Belgium
Private Consultant Europe

1980 - 1983

- Consultant to industry in the fields of food, cosmetics, toys and communications.

BASKIN-ROBBINS ICE CREAM INC., Burbank, California
Managing Director Europe, Brussels, Belgium

1973 - 1980

- Introduced the Baskin-Robbins franchise to Europe and established 70 operating units throughout Europe. Responsible for all aspects of franchising, training, advertising and public relations.

BARCLAYS SECURITIES HOLDING COMPANY, London, UK
Marketing Manager Europe, Brussels, Belgium

1971 - 1973

- Responsible for acquisitions and mergers in the fields of toys, cosmetics and communications throughout Europe.

MATTEL TOYS INC., Hawthorne, California
Marketing Manager Europe, Brussels, Belgium

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CARSON ROBERTS ADVERTISING, Los Angeles, California
Film Producer, Account Executive, London, England

1967 - 1969

- Serviced pan-European clients.

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EDUCATION

Pacific Western University, New Orleans, Louisiana

- Masters of Public Health
- Ph.D. in Cultural Anthropology

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DOCUMENT NO. AND TYPE	SUBJECT/TITLE	DATE	RESTRICTION
001. resume	re: Jay Drosin [Personally Identifiable Information] [partial] (1 page)	06/01/1999	b(6)

COLLECTION:

Clinton Presidential Records
National AIDS Policy Office

OA/Box Number: 19398

FOLDER TITLE:

Correspondence - SLT - Incoming - 6/99 [2]

2018-0764-F
jm2095

RESTRICTION CODES

Presidential Records Act - [44 U.S.C. 2204(a)]

- P1 National Security Classified Information [(a)(1) of the PRA]
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PRM. Personal record misfile defined in accordance with 44 U.S.C. 2201(3).

RR. Document will be reviewed upon request.

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PERSONAL

- ☛ U.S. Citizen
- ☛ Born: [redacted] (b)(6) [001]
- ☛ Married - 3 children
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- ☛ Published works include:
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