

FOIA MARKER

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

Collection/Record Group: Clinton Presidential Records

Subgroup/Office of Origin: National AIDS Policy Office

Series/Staff Member: Todd Summers

Subseries:

OA/ID Number: 21086

FolderID:

Folder Title:

Conference - 4/98 - FCHR [Forum for Collaborative HIV Research] - Info Dissemination

Stack:

S

Row:

66

Section:

6

Shelf:

1

Position:

3

FCHR Project on the Dissemination and Evaluation of the HIV Clinical Practice Guidelines

**Holiday Inn Downtown
1155 14th Street NW
Washington, DC**

May 11 - 12, 1998

Meeting Agenda

Monday, May 11th

9:00 - 9:30: Continental breakfast

9:30 - 10:00: Welcome and Introductions -

David Barr, J.D. - Director
Forum for Collaborative HIV Research

Sophia W. Chang, M.D., M.P.H. - Director of HIV/AIDS Programs
Henry J. Kaiser Family Foundation

10:00 - 10:45: Overview of the Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents, Pediatrics and during Pregnancy -

Eric P. Goosby, M.D. - Director,
HHS Office of HIV/AIDS Policy

Lynne Mofenson, M.D. - Associate Branch Chief for Clinical Research
National Institute of Child Health and Human Development

10:45 - 11:15: The Need for Dissemination of the HIV Clinical Practice Guidelines -

Charles van der Horst, M.D. - Associate Professor of Medicine
Department of Medicine - University of North Carolina, Chapel Hill

11:15 - 11:30: Break

11:30 - 12:00: Successful Dissemination and Implementation of Clinical Practice Guidelines -

John Byrnes, M.D. - Senior Vice-President of Improvement and Innovation
St. Francis Medical Center

12:00 - 12:30 : Patient Comprehension and Retention of Medical Information -

Seth Kalishman, Ph.D. - Associate Professor of Medicine
Center for AIDS Intervention Research - University of Wisconsin

12:30 - 1:30: Lunch

1:30 -2:15: Target Audiences: Identification and Needs Assessment

Health care providers:	Linda Frank, R.N., Ph.D. - Director Pennsylvania AIDS Education Training Center Graduate School of Public Health - Univ. of Pittsburgh
Patients:	Billy Pick - Minority Initiatives Counselor San Francisco Department of Public Health
Service Providers:	Moises Agosto - Director of Treatment Advocacy National Minority AIDS Council
Health care plans:	John Ludden, M.D. - Senior Vice-President Harvard Pilgrim Health Care

2:15 - 3:15: Current HIV Treatment Information Dissemination Efforts

Federal Government:	Deborah Katz, R.N. - Director Office of Program Operations & Scientific Information National Institute of Allergies and Infectious Disease
State Government:	Bruce Agins, M.D., M.P.H. - Medical Director New York State AIDS Institute
Community Organizations:	Pablo Colon - Director, Dept. of Treatment Education & Advocacy Gay Men's Health Crisis
Professional Associations:	John Henning, Ph.D. - Director, Dept. of STD/HIV American Medical Association
Pharmaceutical Industry:	Martin Mattingly, Pharm.D. Director of Marketing Agouron Pharmaceuticals

3:15 - 3:30: Break

3:30 - 4:15: Evaluation of Clinical Practice Guideline Dissemination

Steven Asch, M.D., M.P.H. - Resident Consultant
RAND Corporation

Leonna Markson, ScD. - Director - Outcomes Research & Management /
Merck and Co.

4:15 - 5:30: Current Research Findings

Meeting participants will present findings from current research

5:30 - 6:30: Reception

Tuesday, May 12th

8:30 - 9:00: Continental breakfast

9:00 - 9:45: Challenges to Successful Dissemination

Tim Westmoreland
Federal Legislation Clinic, Georgetown Law School

Richard Jeffreys - Access Project Director
AIDS Treatment Data Network

9:45 - 10:00: Charge to Workgroups

David Barr - Forum for Collaborative HIV Research

10:00 - 10:15: Break

10:15 - 2:00: Workgroup Sessions (a working lunch will be available at 12:30)

2:00 - 3:00: Reports from Working Group/Close

FCHR Project on Dissemination and Evaluation
of the HIV Clinical Practice Guidelines

Tasks/Questions for Work Groups - Tuesday, May 12, 1998

1. Identify the needs for information dissemination to your target audience, including the special concerns for sub-populations in your audience, and the formats of information transfer that may best serve your audience(s).
2. What strategies for information dissemination and implementation are recommended for your target audience?
3. What are the possible roles of federal/state government, community, professional organizations, health care provision and the pharmaceutical industry in creating and implementing dissemination efforts for your target audience?
4. What formats are recommended for evaluation of dissemination and implementation strategies to your target audience, including possible performance measures that can be built into dissemination programs?

**FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice
Guidelines**

Workgroups - Tuesday, May 12th

Health Care Providers/Payers

Leslie Hardy - Facilitator
Susan Dooha - Rapporteur
John Ludden
Donald Young
Rodney Armstead
Jeffery Fessel
Annette Hanson
Mel Chang
John Bartlett
Sissi Pham
Leonna Markson
Violet Baxter
Lawrence Deyton
Joe Kelly
Tim Westmoreland
Carol Brosgart
John Byrne
Steve Asch
Julia Hidalgo
Sam Bozzette

**FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice
Guidelines**

Workgroups - Tuesday, May 12th

Social Service Providers

David Barr - Facilitator

Bonnie Lubin - Rapporteur

Pablo Colon

Jeff Jacobs

Jean McGuire

Marion Warwick

Dianne Rausch

Todd Summers

Chris Collins

Barbara Silver

Cornelius Baker

Jane Silver

Moises Agosto

Gail Grabczynski

Sophia Chang

Juanita Koziol

Martin Mattingly

James Gilpin

Elaine Daniels

**FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice
Guidelines**

Workgroups - Tuesday, May 12th

Patients

Billy Pick - Facilitator

Thaddeus Grimes Gruzcka - Rapporteur

Randall Pope

Vince Collins

Brenda ??? - CDC

John Palinicek

Gale Dutcher

Richard Jeffreys

Clark Moore

Scott Sanders

Annette Brands

Spencer Cox

Charles Nelson

James Dearing

Seth Kalichman

Michele Kofman

Katherine Wilfert

Adele Witenstein

Henry Chang

Cindy Paul

**FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice
Guidelines**

Workgroups - Tuesday, May 12th

Health Care Workers

Deborah Katz - Facilitator

Paul Gaist - Rapporteur

Marg Plumb

Cynthia Cadden

Steve Schnittman

Bruce Agins

Paul Arons

Steve Jennison

Kenneth Mortisugu

Jon Kaplan

Richard Klein

June Lunney

Kim Johnson

Charles van der Horst

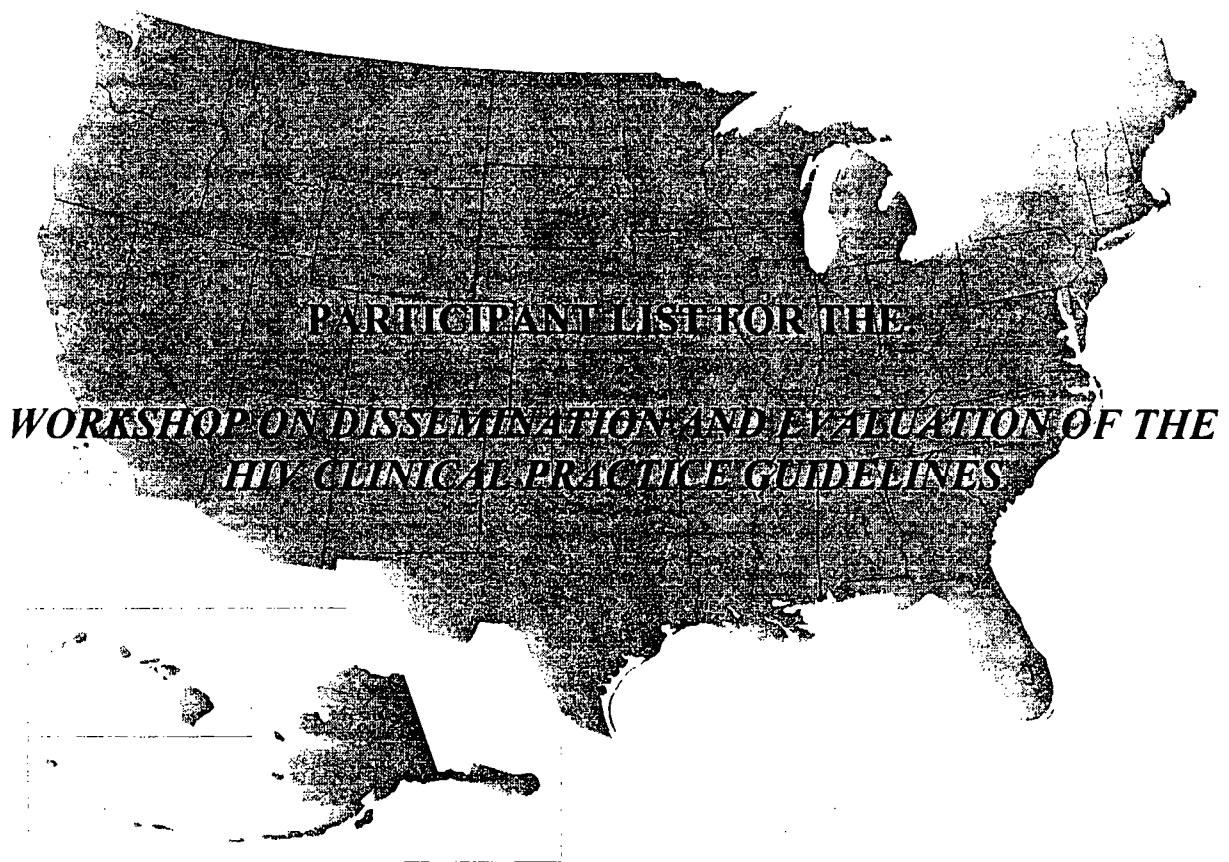
Harvey Makadon

Victoria Sharp

Linda Frank

John Henning

Rose Gonzalez



MAY 11TH & 12TH 1998

Bruce Agins, MD., MPH Medical Director New York State AIDS Institute NYS Dept. of Health 5 Penn Plaza New York, NY 10001 bda01@health.state.ny.us Office: 212-613-2428 / Fax: 212-613-4994
Paul Arons, MD State of FL Bureau of HIV/AIDS 1317 Winewood Blvd. - Bldg. 6 - Room 402 Tallahassee, FL 32399-0700 paul_aron@do.h.state.fl.us Office: 850-921-2202 Fax: 850-414-6719
John Bartlett, MD Director, Division of Infectious Diseases Johns Hopkins University Ross Research Building, Room 1159 780 Rutland Avenue Baltimore, MD 21205 jb@welchlink.welch.jhu.edu Office: 410-614-3631 / Fax: 410-955-7889
Annette Brands Executive Director Project Inform 205 13th Street Suite 2001 San Francisco, CA 94103 abrands@projinf.org Office: 415-558-8669 / Fax: 415-558-0684
Cynthia Cadden, Rn, MSN HIV/AIDS Treatment Information Service (ATIS) 2275 Research Boulevard Rockville, MD 20849 ccaden@cdcnac.org Office: 301-519-5750 Fax: 301-519-6616
Sophia Chang, MD., MPH Director of HIV Programs The Henry J. Kaiser Family Foundation 2400 Sand Hill Road Menlo Park, CA 94025 schang@kff.org Office: 415-854-9400x122 Fax: 415-854-4800
Pablo Colon GMHC 119 West 24th Street New York, NY 10011 pabloc@gmhc.org Office: 212-367-1450 Fax: 212-337-3684
James W. Dearing Associate Professor Michigan State University Department of Communications, MSV East Lansing, MI 48824-1212 dearjim@pilot.msu.edu Office: 517-355-1820 Fax: 517-432-1192
Gale Dutcher Special Assistant to the Associate Director National Library of Medicine 8600 Rockville Pike Bethesda, MD 20894 dutcher@nlm.nih.gov Office: 301-496-5082 Fax: 301-4803537
Paul A. Gaist, Ph.D, MPH Chair, Information Dissemination Coordinating Committee Office of AIDS Research, NIH Building 31, Room 4C06 31 Center Drive Bethesda, MD 20892 gaistp@nih.gov Office: 301-402-3555 / Fax: 301-496-4843

Moises Agosto Director of Treatment and Research National Minority AIDS Council (NMAC) 1931 13th Street, NW Washington, DC 20009 moisesa@aol.com Office: 202-483-6622 Fax: 202-483-1135
Steven Asch, MD., MPH Resident Consultant RAND P.O. Box 2138 Santa Monica, CA 90407-2138 steven_asch@rand.org Office: 310-393-0411 x6516 Fax: 310-393-4818
Violet Baxter Health Insurance Specialist HCFA - Center for Medicaid & State Operations 7500 Security Boulevard - C4-25-02 Baltimore, MD 21244 vbaxter@hcfa.gov Office: 410-786-4577 Fax: 410-786-3252
Carol Brosgart, MD Medical Director East Bay AIDS Center 3031 Telegraph Avenue Suite 235 Berkley, CA 94705 clbatebac@aol.com Office: 510-204-1383 / Fax: 510-848-9764
Henry Chang Scientific Director DuPont-Merck 974 Centre Road - WR 1074 Wilmington, DE 19805 Office: 302-892-7246 Fax: 302-992-2220
Chris Collins Appropriations Associate c/o Rep. Nancy Pelosi Rayburn Building - Room 2457 Washington, DC 20515-0508 chris.collins@mail.house.gov Office: 202-225-4965 Fax: 202-225-8259
Spencer Cox Treatment Action Group 200 East 10th Street New York, NY 10003 TAG-NYC@MSN.com Office: 212-675-1274 Fax: 212-260-8561
Lawrence Deyton, MD., MSPH (132) VA Headquarters 810 Vermont Avenue, NW Washington, DC 20420 dr.bopper.deyton@mail.va.gov Office: (202) 273-8567 Fax: (202) 273-9080
Jeffrey Fessel, MD Director - HIV Research Unit Kaiser Foundation Health Plan - Northern California 2200 O'Farrell Street San Francisco, CA 94115 Office: 415-202-2854 Fax: 415-202-2901
Rose Gonzalez, RN Associate Director American Nurses Association 600 Maryland Avenue, SW Washington, DC 20024 Office: 202-651-7098 Fax: 202-554-0189

Rodney Armstead, MD., FACP Executive Vice President Watts Health Foundation, Inc. United Health Plan 3405 Imperial Highway - Suite 304 Inglewood, CA 90056 rcarmstead_compuserv_com@compuserv.com Office: 310-671-3465 / Fax: 310-412-4198
A. Cornelius Baker Executive Director National Association of People with AIDS 1413 K Street, NW - 7th Floor Washington, DC 20005-3442 napa@thecure.org Office: 202-898-0414 Fax: 202-898-0435
Sam A. Bozzette, MD, PhD Senior Research Associate SDVA Medical Center VAMC: HRSD #111 N-1 3350 LaJolla Village Drive San Diego, CA 92161 sbozzette@ucsd.edu Office: 619-552-4324 / Fax: 619-552-4321
John Byrnes, MD Senior VP of Quality Improvement & Innovations St. Francis Health System 6161 South Yale Ave. Tulsa, OK 74136 jjbyrnes@saintfrancis.com Office: 918-494-1389 Fax: 918-494-4501
Mel Chang Senior Health Policy Analyst Agency for Health Care Admin. - Off. of Health Policy 2727 Maham Drive - Fort Knox Office Complex Bldg. 3 - Suite 1103B Tallahassee, FL 32308 changm@fdhc.state.fl.us Office: 850-922-5530 / Fax: 850-922-2897
Vince Collins, MSW Policy & Program Development Administrator Washington State Department of Health P.O. Box 47841 Olympia, WA 98504-7841 txf0303@hub.doh.wa.gov Office: 360-236-3453 Fax: 360-664-2216
Elaine M. Daniels, MD., PhD Associate Director for Science Policy Office of HIV / AIDS Policy, OPHS, OS Room 736-E, Humphrey Building 200 Independence Avenue, SW Washington, DC 20201 edaniels@osophs.dhhs.gov Office: 202-690-5560 / Fax: 202-690-7560
Susan M. Dooha Director of Health Care Access GMHC 119 W. 24th Street New York, NY 10011 susand@gmhc.org Office: 212-367-1228 Fax: 212-367-1235
Linda Frank, PhD., MSN Director PA - AETC 418 Parrish Hall Pittsburgh, PA 15261 frankie@univx.cis.pitt.edu Office: 412-624-9118 / Fax: 412-624-4767
James Gilpin President Interactive Training Media 1725 Mahan Drive Tallahassee, FL 32308 itm@itm-info.com Office: 850-877-5865 Fax: 850-877-7936

Eric Goosby, MD Director Department of Health and Human Services Hubert H. Humphry Building 200 Independence Ave., SW, 736E Washington, DC 20201 egoosby@osophs.dhhs.gov Office: 202-690-5560 / Fax: 202-690-7560
Annette Hanson, MD Medical Director MA DoH - Division of Medical Assistance 600 Washington Street Boston, MA 02111 ahanson@nt.dma.state.ma.us Office: 617-210-5683 Fax: 617-210-5003
John J. Henning, PhD Director Department of STD & HIV American Medical Association 515 North State Street Chicago, IL 60610 john_henning@ama-assn.org Office: 312-464-4566 / Fax: 312-464-5841
Richard Jeffreys Access Project Director AIDS Treatment Data Network 611 Broadway Suite 613 New York, NY 10012 rjefferys@health.nyam.org Office: 212-260-3084 / Fax: 212-260-8869
Seth Kalichman, MD Associate Professor Center for AIDS Intervention Research Medical College of Wisconsin 8700 Watertown Plank Road Milwaukee, WI 53226 psysck@panther.gsu.edu Office: 414-456-7700 / Fax: 414-287-4209
Joseph F. Kelly Deputy Director NASTAD 444 North Capitol Street, NW Suite 339 Washington, DC 20001 Office: 202-434-8040 Fax: 202-434-8092
Juanita Koziol, MS., CS., RN Public Health Analyst HRSA/HAB - National AETC Program Parklawn Building - Room 9A39 5600 Fishers Lane Rockville, MD 20857 jkoziol@hrsa.dhhs.gov Office: 301-443-6068 / Fax: 301-443-9887
John Ludden, MD Senior Vice President Medical Affairs Harvard Pilgrim Health Care 10 Brookline Place, West Brookline, MA 02146 john_ludden@hphc.org Office: 617-730-7844 / Fax: 617-730-7852
Leonna Markson, ScD Director - Outcomes Research & Management Merck & Co., Inc. P.O. Box 4 - WP39-164 West Point, PA 19486-0004 leonna_markson@merck.com Office: 215-652-6098 Fax: 215-652-0860
Lynne Mofenson, MD NICMO, NIH 6100 executive Blvd. Room 4B11 Rockville, MD 20852 lm65d@nih.gov Office: 301-496-7339 Fax: 301-496-8678

Gail Grabczynski Managing Partner Making the Difference International, Inc. 101 N. Wacker Drive - Suite CM166 Chicago, IL 60606 thedifference@mindspring.com Office: 312-607-1385 Fax: 773-643-1435
Leslie Hardy, MPH U.S. Dept. Of Health & Human Services Office of the Assistant Secretary for Planning and Evaluation 200 Independence Ave., SW, Room 442E Washington, DC 20201 lhardy@osaspe.dhhs.gov Office: 202-260-5156 / Fax: 202-690-6167
Julia Hidalgo, ScD, MSW, MPH Senior Staff Scientist Center for Health Policy Research George Washington University 2021 K Street, NW - Suite 800 Washington, DC 20006 ihjxh@gwu.edu Office: 202-530-2375 / Fax: 202-296-0025
Steven A. Jennison, MD Medical Director - HIV/AIDS/STD Bureau New Mexico Department of Health 525 Camino de los Marquez Suite 1 (Marquez Place) Santa Fe, NM 87501 stevej@doh.state.nm.us Office: 505-476-8452 / Fax: 505-476-8527
Jonathan Kaplan, MD Assistant for Opportunistic Diseases Branch CDC&P 1 Mail Stop G-29 1600 Clifton Road, NE Atlanta, GA 30333 jxk2@cdc.gov Office: 404-639-2004 / Fax: 404-639-2029
Richard Klein HIV / AIDS Program Director Office of Special Health Issues FDA - Parklawn Building 5600 Fishers Lane - Rm. 9-49, HF-12 Rockville, MD 20857 rklein@oc.fda.gov Office: 301-827-4460 / Fax: 301-443-4555
Nathan Linsk, Ph.D Partner Midwest AIDS Training and Education partners The Hektoen Institute 627 South Wood Street - Suite 211 Chicago, IL 60612-3810 Office: 312-572-3796 Fax: 312-738-3102
June Lunney, PhD., RN AIDS Coordinator NINR - NIH Bldg. 45 - Room JAN-12 9000 Rockville Pike Bethesda, MD 20892-6300 June-lunney@nih.gov Office: 301-594-6908 / Fax: 301-480-8260
Martin Mattingly, Pharm.D Director of Marketing Agouron Pharmaceuticals, Inc. 3301 N. Torrey Pines Court La Jolla, CA 92037 martin.mattingly@agouron.com Office: 619-622-3250 Fax: 619-622-8054
Clark Moore Associate Director AIDS Policy Center for Children, Youth & Families 918 16th Street, NW - Suite 901 Washington, DC 20006 cmoore@aidspolicycenter.org Office: 202-785-3564 Fax: 202-785-3579

Thaddeus Grimes Gruzcka, MA Associate Director Interscience 1675 Broadway - 5th Floor New York, NY 10019 tgrimes@intersciencepr.com Office: 212-468-3148 Fax: 212-468-3620
David Harvey Executive Director AIDS Policy Center for Children, Youth & Families 918 16th Street, NW - Suite 201 Washington, DC 20006 harveyapc@aol.com Office: 202-785-3574 Fax: 202-785-3579
Jeff Jacobs Director Government Affairs AIDS Action Council 1875 Connecticut Ave., NW, Suite 700 Washington, DC 20009 jjacobs@aidsaction.org Office: 202-986-1300 / 202-986-1345
Kim Johnson Health Policy Analyst American Public Welfare Association 801 First Street, NE - Suite 500 Washington, DC 20002 kjohnson@apwa.org Office: 202-682-0100 Fax: 202-289-6555
Deborah Katz, R.N. Director, Office of Program Operations & Scientific Information National Institutes of Health Solar Building, Room 2A20 Rockville, MD 20892 dk30f@nih.gov Office: 301-496-0545 / Fax: 301-402-1505
Michelle Kofman, MPH Manager - Outreach & Health Education St. Lukes Roosevelt - HIV/AIDS Center 1000 10th Avenue - Room 14A-36 New York, NY 10019 mdkof@aol.com Office: 212-523-6046 Fax: 212-523-6023
Bonnie Lubin, Ph.D Associate Administrator Hektoen Institute 627 South Wood Street - Suite 211 Chicago, IL 60612 blubin@hektoen.org Office: 312-572-3796 Fax: 312-738-3102
Harvey Makadon, MD Beth-Israel Medical Center 330 Brookline Avenue Boston, MA 02215 hmakadon@bidmc.harvard.edu Office: 617-667-3996 Fax: 617-667-8900
Jean F. McGuire MA Department of Public Health HIV/AIDS Bureau 250 Washington Street - 3rd Floor Boston, MA 02108-4619 jean.mcguire@state.ma.us Office: 617-624-5303 / Fax: 617-624-5399
Kenneth P. Moritsugu, MPH., MD Assistant Surgeon General & Medical Director Federal Bureau of Prisons 320 First Street, NW - Room 1054 Washington, DC 20534 Office: 202-307-3055 Fax: 202-307-0826

Charles Nelson Associate Director of Health Education National Association of People with AIDS 1413 K Street, NW - 7th Floor Washington, DC 20005-3442 napa@thecure.org Office: 202-898-0414 Fax: 202-898-0435
Sissi Pham, Pharm.D Principal Pharmacoeconomic Scientist Glaxo Wellcome, Inc. Five Moore Drive Research Triangle Park, NC 27709 Office: 919-483-3689 Fax: 919-483-8775
Randall S. Pope Director HIV / AIDS Prevention and Intervention Section Michigan Department of Community Health 3423 N. Martin Luther King, Jr. Blvd. P.O. Box 30195 Lansing, MI 48909 Office: 517-335-8468 / Fax: 517-335-9611
Steve Schnittman, MD Bristol Meyers Squibb 5 Research Parkway Wallingford, CT 06492 steven_schnittman@ccmail.bms.com Office: 203-284-7560 Fax: 203-284-6852
Barbara J. Silver, Ph.D Director - HIV/AIDS Education Program Center for Mental Health Services / SAMHSA 5600 Fishers Lane - Suite 15-81 Rockville, MD 20857 bsilver@samhsa.gov Office: 301-443-7817 Fax: 301-443-0737
Charles van der Horst, MD., FACP Professor of Medicine / PI - UNC ACTU University of North Carolina CB#7030 Chapel Hill, NC 27599-7030 cvdh@mpd.unc.edu Office: 919-966-2536 Fax: 919-966-6714
Catherine Wilfert, MD Professor Emeritus Duke University Medical Center Room 1079 Duke South - Box 2951 Durham, NC 27710 wilfe001@mc.duke.edu Office: 919-684-8772 / Fax: 919-684-8514

John Palinicek Department of Health & Human Services HRSA AIDS Program Office 5600 Fishers Lane - Room 7-20 Rockville, MD 20857 jpalinicek@hrsa.dhhs.gov Office: 301-443-4274 Fax: 301-443-3323
Billy Pick, JD., MSW Community Constituency Group University of California, San Francisco Community Advisory Board 1163 Fell Street San Francisco, CA 94117 billy_pick@dph.sf.ca.us Office: 415-554-9048 / Fax: 415-431-7547
Dianne Rausch, Ph.D Deputy Director - National Institute of Mental Health Office of AIDS Research 5600 Fishers Lane - Room 18-101 Rockville, MD 20857 dr89b@nih.gov Office: 301-443-6100 Fax: 301-443-9719
Terry E. Shannon, MPH Center for Health Information Dissemination AHCPR 2101 East Jefferson Street - Suite 501 Rockville, MD 20852 tshannon@ahcpr.gov Office: 301-594-1362 x-1398 Fax: 301-594-2286
Jane Silver Director of Public Policy AmFAR 1828 L Street, NW Suite 802 Washington, DC 20036 jane.silver@amfar.org Office: 202-331-8600 / Fax: 202-331-8606
Marion Warwick, MD Medical Consultant MO-DoH - Bureau of HIV/AIDS & Prevention 930 Wildwood Jefferson City, MO 65109 warwim@mail.health.state.mo.us Office: 573-751-6475 Fax: 573-751-6447
Adele Witenstein Manager - Health Economics Policy Glaxo Wellcome 1500 K Street, NW - Suite 650 Washington, DC 20005 arw31176@glaxowellcome.com Office: 202-783-1277 Fax: 202-783-1740

Cindy Paul Division of AIDS Prevention NJ Department of Health & Senior Services 50 East State Street P.O. Box 363 Trenton, NJ 08625 Office: 609-984-5980 / Fax: 609-984-2455
Marj Plumb GLMA 459 Fulton Street Suite 107 San Francisco, CA 94102 mplumb@glma.org Office: 415-255-4547 Fax: 415-255-4784
Scott Sanders Associate Director for Public Policy AmFAR 1828 L Street, NW - Suite 802 Washington, DC 20036 Office: 202-331-8600 Fax: 202-331-8606
Victoria Sharp, MD Director - HIV Center St. Luke's Roosevelt Hospital Center 1000 10th Avenue New York, NY 10018 Office: 212-523-6050 Fax: 212-523-6023
Todd Summers Deputy Director White House Office of National AIDS Policy 736 Jackson Place, NW Washington, DC 20503 Office: 202-456-2437 Fax: 202-456-2438
Tim Westmoreland Federal Legislation Clinic Georgetown University Law Center 111 F Street, NW - Room 340 Washington, DC 20001 westmort@law.georgetown.edu Office: 202-662-9595 Fax: 202-662-9682
Donald Young, MD Senior Vice President for Clinical Affairs American Association of Health Plans 1129 20th Street, NW - Suite 600 Washington, DC 20036-3421 dyoung@aahp.org Office: 202-861-1476 Fax: 202-331-7487

Eric

If the "short-course" AZT protocol proved effective (no IV treatment), why would it make sense to do IV therapy for a woman who presents in labor with no previous AZT treatment?

Wouldn't the efficacy of the short-course lead us to believe that the IV therapy is not that important?

The short course AZT was only determined in small numbers and showed a 50% reduction in transmission mother $\rightarrow$ fetus. The AZT-076 protocol showed a 3/4 (75%) reduction in transmission. Therefore, the "short course" data did not displace the relative utility of 076 protocol-AZT. What you bring up however is precisely what data will show in the future - for those intolerant to IV Rx (rare) or if they had no prenatal care (and no IV) - oral Rx may be a less ideal position - Σ If would the tx guidelines apply regardless of subtype or clade?



FORUM FOR COLLABORATIVE HIV RESEARCH

April 15, 1998

Dear Colleague:

Thank you for agreeing to participate in the FCHR May 11th and 12th Workshop on Dissemination and Evaluation of the HIV Clinical Practice Guidelines. Enclosed you will find the workshop agenda, the list of participants, logistical information and a reimbursement form.

The Workshop will be held at the **Holiday Inn Downtown, 1155 14 Street NW (at Massachusetts Avenue)**, Washington, DC. The hotel phone number is 202-737-1200. If you have not made your hotel reservations yet, please do so as soon as possible and no later than April 29th. The Metro stop is MacPherson Square on the Orange or Blue lines. (The Blue line stops at National Airport, as well).

The workshop will begin at 9:30 on Monday morning. Continental breakfast will be available starting at 9:00 AM. We will provide breakfast and lunch on both days. Dinner is on your own and a list of restaurants in the area is enclosed. We will have a reception on Monday evening at 5:00 after the workshop. The workshop will run from 9:00 AM - 3:00 PM on Tuesday, leaving people time to travel home that day.

The first day of the workshop will consist of a series of presentations to describe the guidelines and research regarding dissemination and implementation of practice guidelines. On the second day, participants will be divided into workgroups to outline the needs for dissemination to different populations and develop recommendations for dissemination to those groups. The outcome of the workgroup discussions will be compiled into a strategic plan for dissemination and evaluation of the guidelines and be included in the post-conference report. Therefore, your participation on the second day of the workshop is extremely important to the success of the overall project.

The last session on Monday is devoted to presentations of relevant current research findings from meeting participants. If you have data that you would like to present, please contact me. Let me know if you will need a slide projector or overhead

viewer. We can make copies of materials for distribution at the meeting if received ahead of time.

In the coming weeks, you will receive background materials for the meeting. If you have any questions about hotel or travel arrangements, please call William Gist at 202-530-2330. If you have questions about the agenda, please call me at 202-530-2307.

I look forward to seeing you on May 11th for what promises to be an exciting and informative workshop.

Yours truly,

A handwritten signature in black ink, appearing to read 'David Barr', with a stylized, flowing script.

David Barr
Director

FCHR Project on the Dissemination and Evaluation of the HIV Clinical Practice Guidelines

**Holiday Inn Downtown
1155 14th Street NW
Washington, DC**

May 11 - 12, 1998

Meeting Agenda

Monday, May 11th

9:00 - 9:30: Continental breakfast

9:30 - 10:00: Welcome and Introductions -

David Barr, J.D. - Director
Forum for Collaborative HIV Research

Sophia W. Chang, M.D., M.P.H. - Director of HIV/AIDS Programs
Henry J. Kaiser Family Foundation

10:00 - 10:45: Overview of the Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults and Adolescents, Pediatrics and during Pregnancy -

Eric P. Goosby, M.D. - Director,
HHS Office of HIV/AIDS Policy

Lynne Mofenson, M.D. - Associate Branch Chief for Clinical Research
National Institute of Child Health and Human Development

10:45 - 11:15: The Need for Dissemination of the HIV Clinical Practice Guidelines -

Charles van der Horst, M.D. - Associate Professor of Medicine
Department of Medicine - University of North Carolina, Chapel Hill

11:15 - 11:30: Break

11:30 - 12:00: Successful Dissemination and Implementation of Clinical Practice Guidelines -

John Byrnes, M.D. - Senior Vice-President of Improvement and Innovation
St. Francis Medical Center

12:00 - 12:30 : Patient Comprehension and Retention of Medical Information -

Seth Kalishman, Ph.D. - Associate Professor of Medicine
Center for AIDS Intervention Research - University of Wisconsin

12:30 - 1:30: Lunch

1:30 -2:15: Target Audiences: Identification and Needs Assessment

Health care providers:	Linda Frank, R.N., Ph.D. - Director Pennsylvania AIDS Education Training Center Graduate School of Public Health - Univ. of Pittsburgh
Patients:	Billy Pick - Minority Initiatives Counselor San Francisco Department of Public Health
Service Providers:	Moises Agosto - Director of Treatment Advocacy National Minority AIDS Council
Health care plans:	John Ludden, M.D. - Senior Vice-President Harvard Pilgrim Health Care

2:15 - 3:00: Current HIV Treatment Information Dissemination Efforts

Federal Government:	Deborah Katz, R.N. - Director Office of Program Operations & Scientific Information National Institute of Allergies and Infectious Disease
State Government:	Bruce Agins, M.D., M.P.H. - Medical Director New York State AIDS Institute
Community Organizations:	Pablo Colon - Director, Dept. of Treatment Education & Advocacy Gay Men's Health Crisis
Professional Associations:	John Henning, Ph.D. - Director, Dept. of STD/HIV American Medical Association

3:00 - 3:15: Break

3:15 - 4:00: Evaluation of Clinical Practice Guideline Dissemination

Steven Asch, M.D., M.P.H. - Resident Consultant RAND Corporation
Leonna Markson, ScD. - Director - Outcomes Research & Management Merck and Co.

4:00 - 5:00: Current Research Findings

Meeting participants will present findings from current research

5:00: Reception

PARTICIPANT LIST FOR THE
WORKSHOP ON DISSEMINATION AND EVALUATION OF THE
HIV CLINICAL PRACTICE GUIDELINES

MAY 11TH & 12TH 1998

Bruce Agins, MD., MPH Medical Director New York State AIDS Institute NYS Dept. of Health 5 Penn Plaza New York, NY 10001 bda01@health.state.ny.us Office: 212-613-2428 / Fax: 212-613-4994
Paul Arons, MD State of FL Bureau of HIV/AIDS 1317 Winewood Blvd. - Bldg. 6 - Room 402 Tallahassee, FL 32399-0700 paul_aron@doh.state.fl.us Office: 850-921-2202 Fax: 850-414-6719
Sam A. Bozzette, MD, PhD Senior Research Associate SDVA Medical Center VAMC; HRSD #111 N-1 3350 LaJolla Village Drive San Diego, CA 92161 sbozzette@ucsd.edu Office: 619-552-4324 / Fax: 619-552-4321
John Byrnes, MD Senior VP of Quality Improvement & Innovations St. Francis Health System 6161 South Yale Ave. Tulsa, OK 74136 jjbyrnes@saintfrancis.com Office: 918-494-1389 Fax: 918-494-4501
Sophia Chang, MD., MPH Director of HIV Programs The Henry J. Kaiser Family Foundation 2400 Sand Hill Road Menlo Park, CA 94025 schang@kff.org Office: 415-854-9400x122 Fax: 415-854-4800
Mariella Cummings, RN., MS Washington State Department of Health P.O. Box 47844 Olympia, WA 98504-7844 Office: 360-236-3466 Fax: 360-586-5440
Lawrence Deyton, MD., MSPH (132) VA Headquarters 810 Vermont Avenue, NW Washington, DC 20420 dr.bopper.deyton@mail.va.gov Office: (202) 273-8567 Fax: (202) 273-9080
Jeffrey Fessel, MD Director - HIV Research Unit Kaiser Foundation Health Plan - Northern California 2200 O'Farrel Street San Francisco, CA 94115 Office: 415-202-2854 Fax: 415-202-2901
Paul A. Gaist, Ph.D, MPH Chair, Information Dissemination Coordinating Committee Office of AIDS Research, NIH Building 31, Room 4C06 31 Center Drive Bethesda, MD 20892 gaistp@nih.gov Office: 301-402-3555 / Fax: 301-496-4843
Eric Goosby, MD Director Department of Health and Human Services Hubert H. Humphry Building 200 Independence Ave., SW, 736E Washington, DC 20201 egoosby@osophs.dhhs.gov Office: 202-690-5560 / Fax: 202-690-7560

Moises Agosto Director of Treatment and Research National Minority AIDS Council (NMAC) 1931 13th Street, NW Washington, DC 20009 moisesa@aol.com Office: 202-483-6622 Fax: 202-483-1135
Steven Asch, MD., MPH Resident Consultant RAND P.O. Box 2138 Santa Monica, CA 90407-2138 steven_asch@rand.org Office: 310-393-0411 x6516 Fax: 310-393-4818
Annette Brands Executive Director Project Inform 205 13th Street Suite 2001 San Francisco, CA 94103 abrands@projinf.org Office: 415-558-8669 / Fax: 415-558-0684
Cynthia Cadden, Rn, MSN HIV/AIDS Treatment Information Service (ATIS) P.O. Box 6303 Rockville, MD 20849-6303 ccadden@cdenac.org Office: 301-519-5750 Fax: 301-519-6616
Chris Collins Appropriations Associate c/o Rep. Nancy Pelosi Rayburn Building - Room 2457 Washington, DC 20515-0508 chris.collins@mail.house.gov Office: 202-225-4965 Fax: 202-225-8259
Elaine M. Daniels, MD., PhD Associate Director for Science Policy Office of HIV / AIDS Policy, OPHS, OS Room 736-E, Humphrey Building 200 Independence Avenue, SW Washington, DC 20201 edaniels@osophs.dhhs.gov Office: 202-690-5560 / Fax: 202-690-7560
Susan M. Dooha Director of Health Care Access GMHC 119 W. 24th Street New York, NY 10011 susand@gmhc.org Office: 212-367-1228 Fax: 212-367-1235
Laurent Fischer, MD Vice President - Virology Group DuPont-Merck Hickory Run 2055 P.O. Box 80723 Wilmington, DE 19880-0723 laurent.fischer@dupontmerck.com Office: 302-992-4827 / Fax: 302-892-1744
James Gilpin President Interactive Training Media 1725 Mahan Drive Tallahassee, FL 32308 itm@itm-info.com Office: 850-877-5865 Fax: 850-877-7936
Gail Grabczynski Managing Partner Making the Difference International, Inc. 101 N. Wacker Drive - Suite CM166 Chicago, IL 60606 thedifference@mindspring.com Office: 312-607-1385 Fax: 773-643-1435

Rodney Armstead, MD., FACP Executive Vice President Watts Health Foundation, Inc. United Health Plan 3405 Imperial Highway - Suite 304 Inglewood, CA 90056 rcarmstead_compuserv_com@compuserv.com Office: 310-671-3465 / Fax: 310-412-4198
A. Cornelius Baker Executive Director National Association of People with AIDS 1413 K Street NW, 7th Floor Washington, DC 20005-3442 napa@thecure.org Office: 202-898-0414 Fax: 202-898-0435
Carol Brosgart, MD Medical Director East Bay AIDS Center 3031 Telegraph Avenue Suite 235 Berkley, CA 94705 clbateac@aol.com Office: 510-204-1383 / Fax: 510-848-9764
Mel Chang Senior Health Policy Analyst Agency for Health Care Admin. - Offc. of Health Policy 2727 Maham Drive - Fort Knox Office Complex Bldg. 3 - Suite 1103B Tallahassee, FL 32308 changm@fdhcs.state.fl.us Office: 850-922-5530 / Fax: 850-922-2897
Pablo Colon GMHC 119 West 24th Street New York, NY 10011 pabloc@gmhc.org Office: 212-367-1450 Fax: 212-337-3684
James W. Dearing Associate Professor Michigan State University Department of Communications, MSV East Lansing, MI 48824-1212 dearjim@pilot.msu.edu Office: 517-355-1820 Fax: 517-432-1192
Gale Dutcher Special Assistant to the Associate Director National Library of Medicine 8600 Rockville Pike Bethesda, MD 20894 dutcher@nlm.nih.gov Office: 301-496-5082 Fax: 301-4803537
Linda Frank, Ph.D., MSN Director PA - AETC 418 Parran Hall Pittsburgh, PA 15261 frankie@unix.cis.pitt.edu Office: 412-624-9118 Fax: 412-624-4767
Diane Goodwin, PharmD U.S. Medical Affairs Glaxo Wellcome Inc. 5 Moore Drive Research Triangle Park, NC 27709-3398 dg24105@glaxowellcome.com Office: 919-483-8855 Fax: 919-315-6029
Randy Graydon Director of the Division of Advocacy and Special Issues HCFA 7500 Security Boulevard Mail Stop: C4-25-02 Baltimore, MD 21244 rgraydon@hcfa.gov Office: 410-786-1357 / Fax: 410-786-3252

Thaddeus Grimes Gruzcka, MA Associate Director Interscience 1675 Broadway - 5th Floor New York, NY 10019 tgrimes@intersciencepr.com Office: 212-468-3148 Fax: 212-468-3620
David Harvey Executive Director AIDS Policy Center for Children, Youth & Families 918 16th Street, NW - Suite 201 Washington, DC 20006 harveyapc@aol.com Office: 202-785-3574 Fax: 202-785-3579
Jeff Jacobs Director Government Affairs AIDS Action Council 1875 Connecticut Ave., NW, Suite 700 Washington, DC 20009 jjacobs@aidsaction.org Office: 202-986-1300 / 202-986-1345
Seth Kalichman, MD Associate Professor Center for AIDS Intervention Research Medical College of Wisconsin 8700 Watertown Plank Road Milwaukee, WI 53226 psysck@panther.gsu.edu Office: 414-456-7700 / Fax: 414-287-4209
Joseph F. Kelly Deputy Director NASTAD 444 North Capitol Street, NW Suite 339 Washington, DC 20001 Office: 202-434-8040 Fax: 202-434-8092
John Ludden, MD Senior Vice President Medical Affairs Harvard Pilgrim Health Care 10 Brookline Place, West Brookline, MA 02146 john_ludden@hphc.org Office: 617-730-7844 / Fax: 617-730-7852
Leonna Markson, ScD Director - Outcomes Research & Management Merck & Co., Inc. P.O. Box 4 - WP39-164 West Point, PA 19486-0004 leonna_markson@merck.com Office: 215-652-6098 Fax: 215-652-0860
Clark Moore Associate Director AIDS Policy Center for Children, Youth & Families 918 16th Street, NW - Suite 901 Washington, DC 20006 cmoore@aidspolicycenter.org Office: 202-785-3564 Fax: 202-785-3579
Billy Pick, JD., MSW Community Constituency Group University of California, San Francisco Community Advisory Board 1163 Fell Street San Francisco, CA 94117 billy_pick@dph.sf.ca.us Office: 415-554-9048 / Fax: 415-431-7547
Dianne Rausch, Ph.D Deputy Director - National Institute of Mental Health Office of AIDS Research 5600 Fishers Lane - Room 18-101 Rockville, MD 20857 dr89b@nih.gov Office: 301-443-6100 Fax: 301-443-9719

Annette Hanson, MD Medical Director MA DoH - Division of Medical Assistance 600 Washington Street Boston, MA 02111 ahanson@nt.dma.state.ma.us Office: 617-210-5683 Fax: 617-210-5003
John J. Henning, PhD Director Department of STD & HIV American Medical Association 515 North State Street Chicago, IL 60610 john_henning@ama-assn.org Office: 312-464-4566 / 312-464-5841
Richard Jeffreys Access Project Director AIDS Treatment Data Network 611 Broadway Suite 613 New York, NY 10012 rjefferys@health.nyam.org Office: 212-260-3084 / Fax: 212-260-8869
Jonathan Kaplan, MD Assistant for Opportunistic Diseases Branch CDC&P 1 Mail Stop G-29 1600 Clifton Road, NE Atlanta, GA 30333 jxk2@cdc.gov Office: 404-639-2004 / Fax: 404-639-2029
Richard Klein HIV / AIDS Program Director Office of Special Health Issues FDA - Parklawn Building 5600 Fishers Lane - Rm. 9-49, HF-12 Rockville, MD 20857 rklein@oc.fda.gov Office: 301-827-4460 / Fax: 301-443-4555
June Lunney, PhD., RN AIDS Coordinator NINR - NIH Bldg. 45 - Room 3AN-12 9000 Rockville Pike Bethesda, MD 20892-6300 June-lunney@nih.gov Office: 301-594-6908 / Fax: 301-480-8260
Jean F. McGuire MA Department of Public Health HIV/AIDS Bureau 250 Washington Street - 3rd Floor Boston, MA 02108-4619 jean.mcguire@state.ma.us Office: 617-624-5303 Fax: 617-624-5399
Kenneth P. Moritsugu, MPH., MD Assistant Surgeon General & Medical Director Federal Bureau of Prisons 320 First Street, NW Washington, DC 20534 Office: 202-307-3055 Fax: 202-307-0826
Marj Plumb GLMA 459 Fulton Street Suite 107 San Francisco, CA 94102 mplumb@glma.org Office: 415-255-4547 Fax: 415-255-4784
Scott Sander Associate Director for Public Policy AmFAR 1828 L Street, NW - Suite 802 Washington, DC 20036 Office: 202-331-8600 Fax: 202-331-8606

Leslie Hardy, MPH U.S. Dept. Of Health & Human Services Office of the Assistant Secretary for Planning and Evaluation 200 Independence Ave., SW, Room 442E Washington, DC 20201 lhardy@osaspe.dhhs.gov Office: 202-260-5156 / Fax: 202-690-6167
Julia Hidalgo, ScD, MSW, MPH Senior Staff Scientist Center for Health Policy Research George Washington University 2021 K Street, NW - Suite 800 Washington, DC 20006 ihjxh@gwumc.edu Office: 202-530-2375 / Fax: 202-296-0025
Steven A. Jennison, MD Medical Director - HIV/AIDS/STD Bureau New Mexico Department of Health 525 Camino de los Marquez Suite 1 (Marquez Place) Santa Fe, NM 87501 stevej@doh.state.nm.us Office: 505-476-8452 / Fax: 505-476-8527
Deborah Katz, R.N. Director, Office of Program Operations & Scientific Information National Institutes of Health Solar Building, Room 2A20 Rockville, MD 20892 dk30f@nih.gov Office: 301-496-0545 / Fax: 301-402-1505
Michelle Kolman, MPH Manager - Outreach & Health Education St.Lukes Roosevelt - HIV/AIDS Center 1000 10th Avenue - Room 14A-36 New York, NY 10019 mdkol@aol.com Office: 212-523-6046 Fax: 212-523-6023
Harvey Makadon, MD Beth-Israel Medical Center 330 Brookline Avenue Boston, MA 02215 hmakadon@bidmc.harvard.edu Office: 617-667-3996 Fax: 617-667-8900
Lynne Mofenson, MD NICMO, NIH 6100 executive Blvd. Room 4B11 Rockville, MD 20852 lm65d@nih.gov Office: 301-496-7339 Fax: 301-496-8678
John Palincek Department of Health & Human Services HRSA AIDS Program Office, Room 7-20 5600 Fishers Lane - Room 7-20 Rockville, MD 20857 jpalincek@hrsa.dhhs.gov Office: 301-443-4274 / Fax: 301-443-3323
Randall S. Pope Director HIV / AIDS Prevention and Intervention Section Michigan Department of Community Health 3423 N. Martin Luther King, Jr. Blvd. P.O. Box 30195 Lansing, MI 48909 Office: 517-335-8468 / Fax: 517-335-9611
Terry E. Shannon, MPH Center for Health Information Dissemination AHCPR 2101 East Jefferson Street - Suite 501 Rockville, MD 20852 tshannon@ahcpr.gov Office: 301-594-1362 x-1398 Fax: 301-594-2286

Victoria Sharp, MD
Director - HIV Center
St. Luke's Roosevelt Hospital Center
1000 10th Avenue
New York, NY 10018

Office: 212-523-6050
Fax: 212-523-6023

Charles van der Horst, MD., FACP
Professor of Medicine / PI -UNC ACTU
University of North Carolina
CB#7030

Chapel Hill, NC 27599-7030
cvdh@mpd.unc.edu
Office: 919-966-2536
Fax: 919-966-6714

Donald Young, MD
Senior Vice President for Clinical Affairs
American Association of Health Plans
1129 20th Street, NW - Suite 600
Washington, DC 20036-3421
dyoung@aahp.org
Office: 202-861-1476
Fax: 202-331-7487

Renslow Sherer, MD
Director - HIV Center
Cook County Hospital
1900 West Polk
Room 1200
Chicago, IL 60612
rsherer@hektoen.org
Office: 312-633-3004 / Fax: 312-633-3002

Marion Warwick, MD
Medical Consultant
MO-DoH - Bureau of HIV/AIDS & Prevention
930 Wildwood
Jefferson City, MO 65109
warwim@mail.health.state.mo.us
Office: 573-751-6475
Fax: 573-751-6447

Sharilyn K. Stanley, MD
Special Liason for Science & Health Policy
NIAID,NIH c/o
TX DoH
1100 West 49th Street - Bldg. T-801
Austin, TX 78756
sharilyn.stanley@tdh.state.tx.us
Office: 512-458-7676 / Fax: 512-458-7617

Catherine Wilfert, MD
Professor Emeritus
Duke University Medical Center
Room 1079
Duke South - Box 2951
Durham, NC 27710
wilfe001@mc.duke.edu
Office: 919-684-8772 / Fax: 919-684-8514

Data Entry Form

Letter ID

Writer First Name

Writer Last Name

Received Date

Subject

10735

David

Barr

4/23/98

Workshop agenda

☐ Response Required?

Response Type

Response Date

Responder ID

Responder Name

Action Promised

Action Completed

Action Date

Addressed To

Notes

Sender's Organization

Sender's Street1

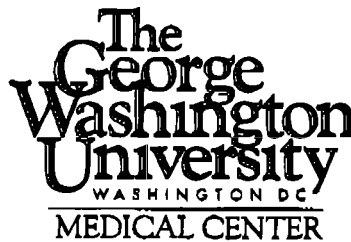
Sender's Street2

George Washington Univ.

Sender's City

Sender's State

Sender's Zip



FORUM FOR COLLABORATIVE HIV RESEARCH

To: Todd Summers - Office of National AIDS Policy
From: David Barr
Re: FCHR Project on Dissemination and Evaluation of HIV Clinical Practice Guidelines
Date: April 9, 1998

When we spoke the other night, you said that you were not sure what role you could play at the workshop on May 11th and 12th. So here are my thoughts about this:

1. Although you said that you felt you had little expertise to offer on the subject, you sell yourself short. Your comments at the Planning Committee meeting were useful and on point. In any case, the workshop will provide you with an opportunity to learn more about the subject.
2. The purpose of this workshop is to develop a strategy for the dissemination and implementation of these guidelines. Doing so is essential for the success of this treatment strategy, in which the federal government is placing its faith and a huge amount of resources. Without proper information dissemination to health care providers and patients, the treatment strategy will fail, the resources will be wasted, and the HIV epidemic will worsen. These kinds of treatment education efforts are currently lacking and no federal agency has claimed responsibility for these tasks. Although it doesn't receive the same kind of attention, this issue is as important as ADAP and Medicaid-expansion. Several federal agencies must play a role in this effort and coordination between these agencies is essential. While you may feel that you do not have expertise in information dissemination, your office does have responsibility for moving forward and assisting in the coordination of the federal response to HIV. Your expertise in this regard would be extremely helpful when we discuss how to implement the strategies that are recommended.
3. At this point, the following agencies/institutes will be represented at the workshop: CDC, HRSA, FCFA, SAMHSA, NIH/OAR, NIMH, NIAID, NLM, NICHD, VA, AHCPR, FDA, OHAP. The attending participants from the various federal agencies are people who would like to see this effort move ahead and have to advocate for this within their respective workplaces. It will be useful for them to have ONAP at the meeting, sending a message that the White House is supportive of these efforts.
4. The Forum for Collaborative HIV Research is a project that was started by the Clinton Administration through the Vice-President's Office. It would be helpful for the FCHR if the Administration's AIDS policy office were supportive of our activities. I would certainly appreciate it if you were there.

**FORUM FOR COLLABORATIVE HIV RESEARCH PROJECT ON THE DISSEMINATION
AND EVALUATION OF THE HIV CLINICAL PRACTICE GUIDELINES**

NAME, TITLE, & SSN*: Todd Summers
ORGANIZATION: White House Office of Nat'l AIDS Policy
ORG. ADDRESS: 736 Jackson Place
Washington DC 200 20503
PHONE/FAX/E-MAIL: (202) 456-2437 / 456-2438 (fax)

PART II.

☒ YES, I WILL BE ATTENDING THE TWO-DAY MEETING IN WASHINGTON, DC.

☐ NO, I WILL NOT ATTEND THE TWO-DAY MEETING IN WASHINGTON, DC

PART III.

☐ YES, I WILL NEED HOTEL ACCOMMODATIONS.**

☒ NO, I WILL NOT NEED HOTEL ACCOMMODATIONS.

PART IV.

☐ YES, I WILL NEED AIRFARE ACCOMMODATIONS.***

☐ AND YES, I CAN RECEIVE GOVERNMENT RATES FOR MY TRAVEL.****

☐ AND NO, I CANNOT RECEIVE GOVERNMENT RATES FOR MY TRAVEL.

☒ NO, I WILL NOT NEED AIRFARE ACCOMMODATIONS. (NOTE, THE FORUM WILL NOT REIMBURSE YOUR AIRFARE).

PART V.

LEGEND:

*GW will need your SSN for identifying costs and reimbursements.

**Your hotel accommodations have been reserved at the Holiday Inn, Downtown (Washington, DC). You will need to call the Hotel (202-737-1200) no later than Wednesday April 29, 1998 to confirm your reservation and secure your room.

***You are responsible for arranging your airfare no later than Wednesday April 22, 1998 with our Travel Agent: Heritage World, Phone: 888-336-9187 or 202-518-5300 / fax 202-518-5333.

****If you are eligible to receive government rates for air-travel, we suggest that you purchase your airline ticket and submit the travel receipts to the *Forum* for reimbursement.

→Note, attached is a *Reimbursement Record* form. You will need to complete this form and attach it with receipts for reimbursable expenses.

☒ THIS NOTICE HAS TO BE FAXED ASAP TO: WILLIAM GIST AT 202-296-0025 ☒



FORUM FOR COLLABORATIVE HIV RESEARCH

To: Workshop Invitees

From: David Barr, Director - Forum for Collaborative HIV Research

Re: FCHR Project on the Dissemination and Evaluation of HIV Clinical Practice Guidelines

Date: March 28, 1998

On May 11th and 12th, The Forum for Collaborative HIV Research is holding a two-day workshop to develop a strategic plan for the dissemination of the HIV Clinical Practice Guidelines. You should have received an invitation to the workshop about two weeks ago. This note is a reminder of that invitation and a request to fax your response form to let us know if you will be attending the workshop. The original letter of invitation is attached along with the response form.

The workshop will bring together representatives from government, industry, academia, health care delivery and management, and patient advocacy. We will present background information about guideline dissemination and evaluation, as well as information about the HIV guidelines. We will then work as a group to determine the needs of the target populations and strategize as to how to best meet those needs and evaluate the efforts. As only a limited number of people are invited to the workshop, we need to know if you will be able to attend.

Please FAX the form back to William Gist at 202-296-0025 ASAP. If you have any questions, please call me at 202-530-2307. I look forward to seeing you on May 11th and 12th.



FORUM FOR COLLABORATIVE HIV RESEARCH

March 12, 1998

Dear Colleague:

On May 11th and 12th, the Forum for Collaborative HIV Research (FCHR) will conduct a two-day workshop to develop a strategic plan for the dissemination and evaluation of the recently released Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults, Adolescents and Children. I am writing on behalf of the Planning Committee to invite you to participate.

The development of new and more effective treatment strategies for HIV disease, including combination anti-viral therapy and viral load testing, create the possibility of turning HIV disease into a chronic, but manageable illness. However, these treatment regimens are complicated to take, difficult to adhere to, and must be taken for a lifetime. Determining how best to use these drugs and the development of long-term strategies for successful treatment is a challenge for even the most experienced physician and patient. Information about how to best utilize these therapies changes rapidly as new information from clinical studies emerges. Because of the emergence of drug resistance, improper use of anti-viral medication will significantly reduce the benefit to patients and could cause the development of transmission of drug -resistant strains of HIV, which would vitiate much of the progress made to date.

Recently released clinical practice guidelines offer health care providers and patients up-to-date information about anti-viral therapy and a framework for decision-making in the use of these drugs. These guidelines, developed by the federal government, through a process co-sponsored by the Henry J. Kaiser Family Foundation, are updated regularly and help to ensure that people with HIV get the safest and most effective outcome from these therapies. The guidelines provide information about how to: (1) monitor HIV viral levels and immune system function; (2) assess when to begin therapy and how to choose a combination that will best suit a patient's needs and ability to comply with the regimen; (3) monitor side effects, and (4) provide suggestions for switching therapies for patients who are not responding to treatment. There is an additional guideline for the use of anti-viral therapy during pregnancy.

It is essential that the information contained in these guidelines be disseminated to health care providers, patients and caregivers to ensure the optimal use of these therapeutic regimens. While there is a group of physicians who are able to keep up with the ever-changing status of HIV treatment information, most physicians are unfamiliar with the latest approaches in the use of anti-viral therapy. Patients need information to make informed treatment decisions and assist with adherence efforts. Additionally, social service providers and educators need treatment information in order to provide a high quality of service to their clients. Public and private third-party payors are another important target for this information as they manage health care delivery, including the

development of drug formularies. Educational efforts must be tailored to meet the needs of diverse populations with HIV, taking into account differences in language, literacy skills, cultural and economic differences. Educational efforts need to be on-going in order to provide support for adherence strategies and to effectively manage toxicities and drug interactions. The translation and dissemination of the HIV clinical practice guidelines will require a joint effort of multiple parties, including federal, state and local governments, pharmaceutical companies, pharmacists, clinical research programs, community-based organizations, health care providers and third-party payors.

Any strategy for dissemination of HIV medical information must include plans for the evaluation of such efforts. The evaluation must look at both the success of the dissemination efforts themselves, e.g. did the information get to targeted populations, and at whether the information has been incorporated into clinical practice. Past experience shows that without an evaluation component, guidelines are not well utilized by providers. Clinical managers of population health care delivery systems want a simple set of management strategies that couple whatever the technical, science-based guidelines are to a clinical performance measure, which must be available in a timeframe that allows for quality improvement. Measured performance will determine if the guidelines are incorporated into care, not if the guideline is effective. It needs to be determined how to carry out the evaluations, which measures are best, and at which points within health care delivery to implement the evaluation.

The FCHR project will bring together representatives from government, industry, health care delivery, academia and patient advocacy to discuss their respective roles in the dissemination effort. The project will identify the target audiences for the dissemination of the guidelines, and determine the needs of those populations in understanding and incorporating the information. The participants will then develop strategies for the dissemination of information and make recommendations as to how to carry out those strategies, articulating roles for government, community, industry and health-care providers. The participants will also discuss and recommend methods for evaluation of the dissemination strategies. The project will include all three clinical practice guidelines - adults, children and pregnancy. To guide participant's in their discussion, the project will provide both reports about current HIV information dissemination efforts and background information about information dissemination techniques, including an overview of research in information comprehension and evaluation techniques.

The workshop will be held in Washington, D.C. Expenses for your participation will be covered by the FCHR. Attached is list of Planning Committee members and the agenda for the meeting. Speakers are still being confirmed and are, therefore, not included in the agenda. In the coming weeks you will receive the list of speakers, attendees and background materials for the workshop. If you have any questions or comments, please call me at (202) 530-2307 or e-mail: ihodxb@gwumc.edu Please return the attached attendance form as quickly as possible.

I hope you will be able to join in our work on this important issue.

Yours truly,



David Barr
Director



FORUM FOR COLLABORATIVE HIV RESEARCH

March 12, 1998

Dear Colleague:

On May 11th and 12th, the Forum for Collaborative HIV Research (FCHR) will conduct a two-day workshop to develop a strategic plan for the dissemination and evaluation of the recently released Guidelines for the Use of Antiretroviral Agents in HIV-Infected Adults, Adolescents and Children. I am writing on behalf of the Planning Committee to invite you to participate.

The development of new and more effective treatment strategies for HIV disease, including combination anti-viral therapy and viral load testing, create the possibility of turning HIV disease into a chronic, but manageable illness. However, these treatment regimens are complicated to take, difficult to adhere to, and must be taken for a lifetime. Determining how best to use these drugs and the development of long-term strategies for successful treatment is a challenge for even the most experienced physician and patient. Information about how to best utilize these therapies changes rapidly as new information from clinical studies emerges. Because of the emergence of drug resistance, improper use of anti-viral medication will significantly reduce the benefit to patients and could cause the development of transmission of drug -resistant strains of HIV, which would vitiate much of the progress made to date.

Recently released clinical practice guidelines offer health care providers and patients up-to-date information about anti-viral therapy and a framework for decision-making in the use of these drugs. These guidelines, developed by the federal government, through a process co-sponsored by the Henry J. Kaiser Family Foundation, are updated regularly and help to ensure that people with HIV get the safest and most effective outcome from these therapies. The guidelines provide information about how to: (1) monitor HIV viral levels and immune system function; (2) assess when to begin therapy and how to choose a combination that will best suit a patient's needs and ability to comply with the regimen; (3) monitor side effects, and (4) provide suggestions for switching therapies for patients who are not responding to treatment. There is an additional guideline for the use of anti-viral therapy during pregnancy.

It is essential that the information contained in these guidelines be disseminated to health care providers, patients and caregivers to ensure the optimal use of these therapeutic regimens. While there is a group of physicians who are able to keep up with the ever-changing status of HIV treatment information, most physicians are unfamiliar with the latest approaches in the use of anti-viral therapy. Patients need information to make informed treatment decisions and assist with adherence efforts. Additionally, social service providers and educators need treatment information in order to provide a high quality of service to their clients. Public and private third-party payors are another important target for this information as they manage health care delivery, including the

development of drug formularies. Educational efforts must be tailored to meet the needs of diverse populations with HIV, taking into account differences in language, literacy skills, cultural and economic differences. Educational efforts need to be on-going in order to provide support for adherence strategies and to effectively manage toxicities and drug interactions. The translation and dissemination of the HIV clinical practice guidelines will require a joint effort of multiple parties, including federal, state and local governments, pharmaceutical companies, pharmacists, clinical research programs, community-based organizations, health care providers and third-party payors.

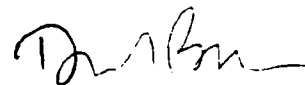
Any strategy for dissemination of HIV medical information must include plans for the evaluation of such efforts. The evaluation must look at both the success of the dissemination efforts themselves, e.g. did the information get to targeted populations, and at whether the information has been incorporated into clinical practice. Past experience shows that without an evaluation component, guidelines are not well utilized by providers. Clinical managers of population health care delivery systems want a simple set of management strategies that couple whatever the technical, science-based guidelines are to a clinical performance measure, which must be available in a timeframe that allows for quality improvement. Measured performance will determine if the guidelines are incorporated into care, not if the guideline is effective. It needs to be determined how to carry out the evaluations, which measures are best, and at which points within health care delivery to implement the evaluation.

The FCHR project will bring together representatives from government, industry, health care delivery, academia and patient advocacy to discuss their respective roles in the dissemination effort. The project will identify the target audiences for the dissemination of the guidelines, and determine the needs of those populations in understanding and incorporating the information. The participants will then develop strategies for the dissemination of information and make recommendations as to how to carry out those strategies, articulating roles for government, community, industry and health-care providers. The participants will also discuss and recommend methods for evaluation of the dissemination strategies. The project will include all three clinical practice guidelines - adults, children and pregnancy. To guide participant's in their discussion, the project will provide both reports about current HIV information dissemination efforts and background information about information dissemination techniques, including an overview of research in information comprehension and evaluation techniques.

The workshop will be held in Washington, D.C. Expenses for your participation will be covered by the FCHR. Attached is list of Planning Committee members and the agenda for the meeting. Speakers are still being confirmed and are, therefore, not included in the agenda. In the coming weeks you will receive the list of speakers, attendees and background materials for the workshop. If you have any questions or comments, please call me at (202) 530-2307 or e-mail: ihodxb@gwumc.edu Please return the attached attendance form as quickly as possible.

I hope you will be able to join in our work on this important issue.

Yours truly,

A handwritten signature in dark ink, appearing to read 'David Barr', with a stylized flourish at the end.

David Barr
Director

FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice Guidelines

Development of a Strategic Plan for the Dissemination of Information from the HIV Clinical Practice Guidelines

Goal: To develop a strategic plan for the dissemination of the information contained in the HIV Clinical Practice Guideline for health care providers, patients and caregivers. The Plan will include a determination of who needs the information and address the formats in which the information should be provided. The plan will provide strategies for both dissemination of information and the evaluation of the effectiveness of those dissemination efforts and whether the guidelines have been implemented in clinical practice. Finally, the plan will provide recommendations for the implementation of the proposals.

The project will consist of three components:

- (1) preparation for a two-day workshop to examine the needs and strategies for information dissemination, including the preparation of a bibliography and summary of current knowledge about information dissemination and evaluation techniques;
- (2) the two-day workshop, which will provide participants with information about current dissemination efforts, identify gaps in those efforts, and determine strategies for filling those gaps and evaluating those strategies;
- (3) the preparation of a written strategic plan based on the outcome of discussion from the workshop, along with recommendations for implementation of the plan.

Preparation for Two-day Workshop

The preparation for the workshop will consist of drafting the agenda for the workshop with the Project Planning Committee, compiling a list of speakers and attendees, and preparing materials for distribution. The materials, prepared by FCHR staff, would provide overviews of: (1) current efforts to distribute HIV-related medical information to physicians, service providers and patients; (2) the literature describing methods for the dissemination of clinical practice guidelines; (3) the literature describing how patients and practitioners comprehend, retain and utilize medical information; (4) literature regarding methods to evaluate guideline dissemination to health care practitioners; and (5) information about how patients are receiving health care. A draft of the meeting agenda will be developed by FCHR staff, circulated to the members of the Project Planning Committee and then discussed by the Committee via teleconference. Committee members will provide names for speakers and attendees for the workshop. FCHR staff will manage the logistics for meeting, including obtaining meeting space, making travel arrangements for participants, arranging for recording of the meeting, etc.

Workshop Agenda

The two-day workshop would bring together experts from academia, community, government, industry and health-care delivery. The first day would be a series of presentations and panel discussions. The second day, participants would be divided into work groups to strategize how to disseminate the clinical practice guidelines and how to evaluate those efforts.

Day One

Presentation: Overview of the HIV Clinical Practice Guidelines

- The purpose of this overview would be to provide a foundation for our discussion about how to disseminate the information. It would provide a brief overview of the Principles of Therapy and the three Clinical Practice Guidelines (copies would pre-distributed to all participants). The presentation should provide some background information about the current state of HIV disease and treatment, including background on the numbers of people on anti-viral therapy and those who will consider anti-viral therapy in the near future, background information about drug resistance, adherence, and monitoring of viral levels and immune system functions, choosing treatment regimens and addressing treatment toxicities and failures.

Presentation: The Need for Information Dissemination: The Effect on Patient's Lives and on the Public Health

- will provide a framework for our discussion by raising relevant issues about why the guidelines are important, including the impact that sub-optimal standards of care have on both individual patients and the public health; the role that information dissemination plays in choosing therapy, assisting adherence efforts, managing toxicities, controlling health care costs, and aiding prevention efforts

Presentation: How do you disseminate clinical practice guidelines?

- will provide an overview of how clinical practice guidelines have been translated and disseminated to different audiences, using examples from other diseases. The presentation should cover the results of research on information dissemination to doctors, patients and the incorporation of standards of care into health care delivery systems. This would include information on methods for distribution of information, how people comprehend and retain medical information and how to incorporate that information into practice.

Panel: Target Audiences - will identify the populations that need information, why they need it, how to reach them, identify special needs

- Health care providers
- Patients
- Social Service Providers
- Third-party payors
- the panel will consist of representatives from each of these sectors, discussing why they need this information, what their informational needs are, the formats in which information

is best received, and what special considerations will exist for different populations within each group

Panel: Current Dissemination Efforts

- federal government
- state and local governments
- community organizations
- pharmaceutical industry
- health care providers/professional organizations

- the panel will consist of representatives from each of these sectors, each describing the current efforts to translate and disseminate treatment information to physicians, patients, health care providers and others

Presentation: Evaluating Dissemination and Utilization of Clinical Practice Guidelines

- the presentation will provide an overview of methods used to evaluate the dissemination and utilization of clinical practice guidelines in health care delivery, including a discussion about why the evaluation of such efforts is essential to the incorporation of guidelines into practice.

Panel: Measurements for Evaluating Dissemination Efforts

- What do we want from a measurement?
- What types of measurements are feasible?
- Where can measures be taken? - Medicaid programs, managed care organizations, pharmacies, etc.

Panel: Challenges to successful dissemination and incorporation of the clinical practice guideline

- rapidly changing information
- lack of long-term data
- complexity of the treatment strategy
- diverse methods of health-care delivery

- this panel will help to set the stage for the second day of discussion by outlining some of the challenges we face in implementing these clinical practice guidelines. Three speakers - representing health care delivery, patient advocacy, and academia - will present their viewpoints.

Day Two

On the second day of the workshop, participants will be divided into work groups. Each group will be asked to focus on a particular target population. A designated facilitator would lead the group in discussion about the topic. A rapporteur would record the discussion and report back to the full group. The work groups will be able to discuss in greater depth: (1) the needs of the assigned population in the dissemination of information, (2) strategize as to how best to meet those needs, and (3) how to evaluate whether those efforts have led to the incorporation of the guidelines into clinical practice.

There will be four work groups:

- Patients
- Physicians and health care providers
- Health care managers
- Social service workers

Each group will be asked to identify the following:

- the needs for information within their target group, including special needs for sub-groups;
- what additional data may be required to better understand how their population comprehends and retains medical information;
- the formats in which information be provided to their population group;
- the proposed role of government, community, health care deliverers, pharmaceutical industry and professional organizations in the dissemination of information;
- proposed methods for evaluation of the dissemination strategies;
- proposed methods for evaluation of how the guidelines have been incorporated into care, including possible markers to use as performance measures.

Report back from Work Groups

Post-Workshop

Following the workshop, a report will be prepared by FCHR staff from the minutes of the workshop presentations and work group discussions. The report will include the background information developed before the workshop, summaries of the presentations and a strategic plan for dissemination of the Guidelines. The draft of the strategic plan will be distributed to the members of the Project Planning Committee for review and comment. Those comments will be incorporated into the document and the report will be released publicly. The Project Planning Committee will then meet again to discuss recommendations for implementation of the plan. At this meeting, Committee members will report on how their respective agencies, companies and organizations are moving toward implementation of the ideas expressed in the Report.

FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice Guidelines

Planning Committee

Bruce Agins, M.D., M.P.H.
Medical Director
New York State AIDS Institute
NYS Dept. of Health
5 Penn Plaza
New York, NY 10001
bda01@health.state.ny.us
Office: 212-613-2428
Fax: 212-613-4994

Donald Conway, MD., MBA
Director, Epidemiology and Outcomes
Research
Abbott Laboratories
Building AP6C-1, Room D42J
100 Abbott Park Road
Abbott Park, IL 60064-3500
donald.conway@abbott.com
Office: 847-937-4809
Fax: 847-937-1992

John Bartlett, MD
Director, Division of Infectious Diseases
Johns Hopkins University
Ross Research Building, Room 1159
780 Rutland Avenue
Baltimore, MD 21205
jb@welchlink.welch.jhu.edu
Office: 410-614-3631
Fax: 410-955-7889

Deb Dawson
Principal Clinical Research Scientist
Glaxo-Wellcome
3030 Cornwallis Drive, MAI-C4418
Research Triangle Park, NC 27709
dd27947@glaxo.com
Office: 919-483-8419
Fax: 919-315-8513

Sam A. Bozzette, MD, PhD
Senior Research Associate
SDVA Medical Center
VAMC; HRSD #111 N-1
3350 LaJolla Village Drive
San Diego, CA 92161
sbozzette@ucsd.edu
Office: 619-552-4324
Fax: 619-552-4321

Ruth Finkelstein, ScD
Health Policy Analyst
New York Academy of Medicine
1216 Fifth Avenue
New York, NY 10029-5293
rfinkelstein@nyam.org
Office: 212-822-7266
Fax: 212-876-4220

Sophia Chang, MD., MPH
Director of HIV Programs
The Henry J. Kaiser Family Foundation
2400 Sand Hill Road
Menlo Park, CA 94025
schang@kff.org
Office: 415-854-9400x122
Fax: 415-854-4800

Randy Graydon
Director of the Division of Advocacy and
Special Issues
HCFA
7500 Security Boulevard
Mail Stop: C4-25-02
Baltimore, MD 21244
rgraydon@hcfa.gov
Office: 410-786-1357
Fax: 410-786-3252

Leslie Hardy, MPH
U.S. Dept. Of Health & Human Services
Office of the Assistant Secretary
for Planning and Evaluation
200 Independence Ave., SW, Room 442E
Washington, DC 20201
lhardy@osaspe.dhhs.gov
Office: 202-260-5156
Fax: 202-690-6167

Julia Hidalgo, ScD, MSW, MPH
Senior Staff Scientist
Center for Health Policy Research
2021 K Street, NW
Suite 800
Washington, DC 20006
ihojxh@gwumc.edu
Office: 202-530-2375
Fax: 202-296-0025

Jonathan Kaplan, MD
Ass't for Opportunistic Diseases Branch
CDC&P
1 Mail Stop G-29
1600 Clifton Road, NE
Atlanta, GA 30333
jxl2@cdc.gov
Office: 404-639-2004
Fax: 404-639-2029

Deborah Katz, R.N.
Director, Office of Program Operations
& Scientific Information
National Institutes of Health
Solar Building, Room 2A20
9000 Rockville Pike
Rockville, MD 20892
dk30f@nih.gov
Office: 301-496-0545
Fax: 301-402-1505

Joseph F. Kelly
NASTAD
444 North Capitol Street, NW
Suite 339
Washington, DC 20001
nastad@aol.com
Office: 202-434-8091
Fax: 202-434-8042

John Ludden, MD
Senior Vice President
Medical Affairs
Harvard Pilgrim Health Care
10 Brookline Place, West
Brookline, MA 02146
john_ludden@hphc.org
Office: 617-730-7844
Fax: 617-730-7852

Joe O'Neill, MD., MS., MPH
Associate Administrator for AIDS
Department of Health & Human Services
HRSA AIDS Prog. Office, Room 14A-21
5600 Fishers Lane
Rockville, MD 20857
joneill@hrsa.dhhs.gov
Office: 301-443-4588
Fax: 301-443-9645

Marj Plumb
GLMA
459 Fulton Street
Suite 107
San Francisco, CA 94102
mplumb@glma.org
Office: 415-255-4547
Fax: 415-255-4784

Mike Saag, MD
Associate Professor of Medicine
University of Alabama
908 20th Street, South
Birmingham, AL 35294-2050
MSAAG@BYRD1917.his.uab.edu
Office: 205-934-7349
Fax: 205-975-6120

Catherine Wilfert, MD
Professor Emeritus
Duke University Medical Center
Room 1079
Duke South - Box 2951
Durham, NC 27710
wilfe001@mc.duke.edu
Office: 919-684-8772
Fax: 919-684-8514

Todd Summers
Office of National AIDS Policy
750 17th Street, NW, Suite 600
Washington, DC 20503
Office: 202-632-1090
Fax: 202-632-1096

Liz Wehr, JD
Senior Research Staff Scientist
Center for Health Policy Research
2021 K Street, NW, Suite 800
Washington, DC 20006
ihoexw@gwumc.edu
Office: 202-530-2306
Fax: 202-296-0025

Ellen C. Cooper, MD, MPH
Health Sciences Administrator
Office of AIDS Research, NIH
Building 31, Room 5C08
9000 Rockville Pike
Bethesda, MD 20892
ec65i@nih.gov
Office: 301-402-2932
Fax: 301-402-7769

Elaine M. Daniels, MD.,PhD
Associate Director for Science Policy
Office of HIV / AIDS Policy, OPHS, OS
Room 736-E, Humphrey Building
200 Independence Avenue, SW
Washington, DC 20201
edaniels@osophs.dhhs.gov
Office: 202-690-5560
Fax: 202-690-7560

Paul A. Gaist, Ph.D, MPH
Chair, Information Dissemination
Coordinating Committee
Office of AIDS Research, NIH
Building 31, Room 4C06
31 Center Drive
Bethesda, MD 20892
gaistp@nih.gov
Office: 301-402-3555
Fax: 301-496-4843

Jeff Jacobs
Director
Government Affairs
AIDS Action Council
1875 Connecticut Ave., NW, Suite 700
Washington, DC 20009
jjacobs@aidSACTION.org
Office: 202-986-1300
Fax: 202-986-1345

Robert S. Janssen, MD
Division of HIV/AIDS Prevention
Centers for Disease Control and
Prevention
1600 Clifton Road, NE
1 Mail Stop G29
Atlanta, GA 30333
rxj1@cdc.gov
Office: 404-639-0900
Fax: 404-639-0910

Donald A. Young, MD
Senior Vice President for Clinical Affairs
American Association of Health Plans
1129 20th Street, NW, Suite 600
Washington, DC 20036-3421
dyoung@aahp.org
Office: 202-861-1476
Fax: 202-331-7487

**FORUM FOR COLLABORATIVE HIV RESEARCH PROJECT ON THE DISSEMINATION
AND EVALUATION OF THE HIV CLINICAL PRACTICE GUIDELINES**

NAME, TITLE, & SSN*: _____

ORGANIZATION: _____

ORG. ADDRESS: _____

PHONE/FAX/E-MAIL: _____

PART II.

☐ YES, I WILL BE ATTENDING THE TWO-DAY MEETING IN WASHINGTON, DC.

☐ NO, I WILL NOT ATTEND THE TWO-DAY MEETING IN WASHINGTON, DC

PART III.

☐ YES, I WILL NEED HOTEL ACCOMMODATIONS.**

☐ NO, I WILL NOT NEED HOTEL ACCOMMODATIONS.

PART IV.

☐ YES, I WILL NEED AIRFARE ACCOMMODATIONS.***

☐ AND YES, I CAN RECEIVE GOVERNMENT RATES FOR MY TRAVEL.****

☐ AND NO, I CANNOT RECEIVE GOVERNMENT RATES FOR MY TRAVEL.

☐ NO, I WILL NOT NEED AIRFARE ACCOMMODATIONS. (NOTE, THE FORUM WILL NOT REIMBURSE YOUR AIRFARE).

PART V.

LEGEND:

*GW will need your SSN for identifying costs and reimbursements.

**Your hotel accommodations have been reserved at the Holiday Inn, Downtown (Washington, DC). You will need to call the Hotel (202-737-1200) no later then Wednesday April 29, 1998 to confirm your reservation and secure your room.

***You are responsible for arranging your airfare no later then Wednesday April 22, 1998 with our Travel Agent: Heritage World, Phone: 888-336-9187 or 202-518-5300 / fax 202-518-5333.

****If you are eligible to receive government rates for air-travel, we suggest that you purchase your airline ticket and submit the travel receipts to the *Forum* for reimbursement.

→Note, attached is a *Reimbursement Record* form. You will need to complete this form and attach it with receipts for reimbursable expenses.

☒ THIS NOTICE HAS TO BE FAXED ASAP TO: WILLIAM GIST AT 202-296-0025 ☒



FORUM FOR COLLABORATIVE HIV RESEARCH

February 23, 1998

Dear Colleague:

Thank you for your interest in serving as a Planning Committee member for the FCHR Project on the Development of an Agenda in HIV Patient Outcomes Research. We are looking forward to working with you on this endeavor. However, the FCHR Executive Committee has decided to spend additional time building support for the project and developing the appropriate background materials before we move forward with further planning. Therefore, we are going to postpone the Planning Committee meeting until early May.

At its recent meeting, the FCHR Executive Committee made two suggestions regarding this project. First, they felt that the project would be well-served by increasing the size of the Planning Committee to include greater expertise in outcomes research and broader participation from third-party payors. We will be holding several discussions during March to meet these goals. We would greatly appreciate your suggestions of individuals who could provide valuable experience and/or knowledge to this project. We will also compile a short report examining current research in HIV health care utilization. This report, to be completed in early April, will provide Planning Committee members with updated background information to assist in the planning process. It will be distributed to the Planning Committee members for their review prior to the initial planning meeting.

Upon the completion and dissemination of this report, the Forum will arrange the date and time for the Planning Committee meeting. At that time, the Forum will contact you for your availability. Should you have any ideas or comments you would like to suggest to the Forum for this report, feel free to contact either one of us.

Thank you for your time. We appreciate your continued interest in this project.

Sincerely,

A handwritten signature in black ink, appearing to read "David Barr".

David Barr
Director
(202) 530-2307
ihodxb@gwumc.edu

A handwritten signature in black ink, appearing to read "Tina Sogocio".

Tina Sogocio
Research Associate
(202) 530-2330
ihotms@gwumc.edu

Data Entry Form

Letter ID

10593

Writer First Name

David

Writer Last Name

Barr

Received Date

2/25/98

Subject

HIV Clinical Practice Guidelin

✓ Response Required?

Response Type

Response Date

Responder ID

Responder Name

Action Promised

Todd Summers

Action Completed

Action Date

Addressed To

Notes

Sender's Organization

GWU Med Cntr

Sender's Street1

Sender's Street2

Sender's City

Sender's State

Sender's Zip



FORUM FOR COLLABORATIVE HIV RESEARCH

February 24, 1998

Dear Planning Committee Member:

Attached you will find the final proposal for the FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice Guidelines. This final proposal incorporates the individual comments I received and the discussion from our teleconference.

As we discussed on the call, we want to move forward with the two-day workshop quickly. We are planning to hold the workshop on May 11th and 12th in Washington, DC. We are busy collecting background information for distribution at the workshop. You will receive information on travel and hotel arrangement later.

What is most important now is to compile a list of attendees and identify speakers for the various presentations and panels. In this, we very much need your assistance. I have attached a form for you to offer suggestions as to who to invite. Fill in those spaces on the forms where you know of an appropriate individual. Please offer what guidance you can and get it back to me as quickly as possible. We are seeking a diverse group of participants from academia, community advocacy, health care provision and management, and government.

Please fill out the attached forms and send them back to William Gist no later than Friday, March 6th. You can mail the forms to William at our address (FCHR, 2021 K St. NW, Suite 800, Washington, DC 20006 or fax them to 202-296-0025)

The recent Retrovirus Conference in Chicago confirmed the need for education and information in order to use the anti-viral treatment strategy successfully. The plan we are developing can do much to further this goal. Thank you for your assistance and cooperation.

Yours truly,

A handwritten signature in black ink, appearing to read 'David Barr'.

David Barr

**FCHR Project on Dissemination and Evaluation
of the HIV Clinical Practice Guidelines**

Speaker and Workshop Participant Proposals

Please re-read the project proposal and make suggestions for individuals who can present on Day One. Provide the information requested below:

Presentation: Overview of the HIV Clinical Practice Guidelines

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

**Presentation: The Need for Information Dissemination: the Effect on
Patient's Lives and on the Public Health**

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Presentation: How do you Disseminate Clinical Practice Guidelines?

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Panel: Target Audiences

Physicians:

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Patients:

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Social Service Providers:

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Health Care Providers/Payers:

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Panel: Current Dissemination Efforts

Federal Government:

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

State and Local Governments:

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Community Organizations:

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Pharmaceutical Industry:

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Health Care Providers/Managers:

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Presentation: Evaluating Dissemination and Utilization of Clinical Practice Guidelines

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Panel: Measurements - Evaluating Dissemination and Performance Efforts

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Panel: Challenges to successful dissemination and incorporation of the clinical practice guideline

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Workshop Participants

Research

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Workshop Participants

Federal Government

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Workshop Participants

State & Local Government

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Workshop Participants

Community Advocates/Educators

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____

e-mail: _____

Workshop Participants

Third-party Payors

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Workshop Participants

Pharmaceutical Industry

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Workshop Participants

Health Care Providers/Professional Organizations

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

Name: _____

Address: _____

Phone: _____ FAX: _____
e-mail: _____

FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice Guidelines

Project Proposal

Note: This project was originally described as one, which would jointly address issues of dissemination and evaluation of the HIV clinical practice guidelines. Given the outcome of the first meeting of the Project's Planning Committee, it is clear that this project should be split into two distinct processes. This proposal will address the dissemination of information and an evaluation of those efforts. A second proposal to develop a research agenda to evaluate the effectiveness of the Guidelines on patient outcomes and health care delivery will be developed separately.

Part I - Development of a Strategic Plan for the Dissemination of Information from the HIV Clinical Practice Guidelines

Goal: To develop a strategic plan for the dissemination of the information contained in the HIV Clinical Practice Guideline for health care providers, patients and caregivers. The Plan will include a determination of who needs the information and address the formats in which the information should be provided. The plan will provide strategies for both dissemination of information and the evaluation of the effectiveness of those dissemination efforts and whether the guidelines have been implemented in clinical practice. Finally, the plan will provide recommendations for the implementation of the proposals.

The project will consist of three components:

- (1) preparation for a two-day workshop to examine the needs and strategies for information dissemination, including the preparation of a bibliography and summary of current knowledge about information dissemination and evaluation techniques;
- (2) the two-day workshop, which will provide participants with information about current dissemination efforts, identify gaps in those efforts, and determine strategies for filling those gaps and evaluating those strategies;
- (3) the preparation of a written strategic plan based on the outcome of discussion from the workshop, along with recommendations for implementation of the plan.

Statement of Need

The development of new and more effective treatment strategies for HIV disease, including combination anti-viral therapy and viral load testing, create the possibility of turning HIV disease into a chronic, but manageable illness. When used properly, clinical studies have shown anti-viral therapy to be tolerable in most patients, and able to significantly reduce viral replication; thus halting immune system dysfunction, preventing AIDS-related opportunistic infections and death. However, these treatment regimens are

complicated to take, difficult to adhere to, and must be taken for a lifetime. If not taken properly, the virus is able to develop resistance to the drugs, which then lose efficacy. Resistance to one drug can often mean the development of resistance to an entire class of drugs. Determining how best to use these drugs and the development of long-term strategies for successful treatment is a challenge for even the most experienced physician and patient. It is hard to determine the optimal time to begin therapy, which combination to use, and how to treat patients for whom therapy is failing. Information about how to best utilize these therapies changes rapidly as new information from clinical studies emerges. Because of the emergence of drug resistance, improper use of anti-viral medication will significantly reduce the benefit to patients and could cause the development of transmission of drug -resistant strains of HIV, which would vitiate much of the progress made to date.

Recently released clinical practice guidelines offer health care provider and patients up-to-date information about anti-viral therapy and a framework for decision-making in the use of these drugs. These guidelines, developed by the federal government, through a process co-sponsored by the Henry J. Kaiser Family Foundation, are updated regularly and offer an opportunity to ensure that people with HIV get the safest and most effective outcome from these therapies. Because the information contained in the guidelines will help to avoid the widespread development of drug-resistant HIV, the guidelines are an important tool to protect the public health. The guidelines provide information about how to monitor HIV viral levels and immune system function, offer a framework to assess when to begin therapy and how to choose a combination that will best suit a patient's needs and ability to comply with the regimen, how to monitor side effects, and provide suggestions for switching therapies for patients who are not responding to treatment. There is an additional set of guidelines for pediatric patients, as well as a guideline for use of anti-viral therapy during pregnancy. The information contained in these guidelines should be seen as important as the drugs themselves, for without the necessary information, the use of the drugs is, at best, diminished, and will most likely cause more harm than good.

It is essential that the information contained in these guidelines is disseminated to health care providers, patients and caregivers to ensure the optimal use of these promising, but complicated therapeutic regimens. While there is a group of physicians who are able to keep up with the ever-changing status of HIV treatment information, most physicians are unfamiliar with the latest approaches in the use of anti-viral therapy. Patients need information to make informed treatment decisions and assist with adherence efforts. Additionally, social service providers and educators need treatment information in order to provide a high quality of service to their clients. Public and private third-party payors are another important target for this information as they manage health care delivery, including the development of drug formularies. Educational efforts must be tailored to meet the needs of diverse populations with HIV, taking into account differences in language, literacy skills, cultural and economic differences. Educational efforts need to be on-going in order to provide support for adherence strategies and to effectively manage toxicities and drug interactions. Such efforts also need to be able to incorporate new

information as it develops. The translation and dissemination of the HIV clinical practice guidelines will require a joint effort of multiple parties, including federal, state and local governments, pharmaceutical companies, pharmacists, clinical research programs, community-based organizations, health care providers and third-party payors.

Any strategy for dissemination of HIV medical information must include plans for the evaluation of such efforts. The evaluation must look at both the success of the dissemination efforts themselves, e.g. did the information get to targeted populations, and at whether the information has been incorporated into clinical practice. Past experience shows that without an evaluation component, guidelines are not utilized by providers. Clinical managers of population health care delivery systems want a simple set of management strategies that couple whatever the technical, science-based guidelines are to a clinical performance measure, which must be available in a timeframe that allows for quality improvement. Measured performance will determine if the guidelines are incorporated into care, not if the guideline is effective. It needs to be determined how to carry out the evaluations, which measures are best, and at which points within health care delivery to implement the evaluation.

The FCHR project will identify the target audiences for the dissemination of the guidelines, and determine the needs of those populations in understanding and incorporating the information. The project will include all three clinical practice guidelines - adults, children and pregnancy. The project will also provide an overview of research into information comprehension, dissemination, and evaluation techniques that will guide the discussion about how best to develop strategies for the transfer of information to the identified populations. The FCHR project will bring together representatives from each of these sectors to discuss their respective roles in the dissemination effort. The project will report to participants about current efforts to disseminate the information and will gather background information about information dissemination techniques to guide participant's in their discussion. The participants will then develop strategies for the dissemination of information and make recommendations as to how to carry out those strategies, articulating roles for government, community, industry and health-care providers. The participants will also discuss and recommend methods for evaluation of the dissemination strategies.

Preparation for Two-day Workshop

The preparation for the workshop will consist of drafting the agenda for the workshop with the Project Planning Committee, compiling a list of speakers and attendees, and preparing materials for distribution. The materials, prepared by FCHR staff, would provide overviews of: (1) current efforts to distribute HIV-related medical information to physicians, service providers and patients; (2) the literature describing methods for the dissemination of clinical practice guidelines; (3) the literature describing how patients and practitioners comprehend, retain and utilize medical information; (4) literature regarding methods to evaluate guideline dissemination to health care practitioners; and (5) information about how patients are receiving health care. A draft of the meeting agenda

will be developed by FCHR staff, circulated to the members of the Project Planning Committee and then discussed by the Committee via teleconference. Committee members will provide names for speakers and attendees for the workshop. FCHR staff will manage the logistics for meeting, including obtaining meeting space, making travel arrangements for participants, arranging for recording of the meeting, etc.

Workshop

The two-day workshop would bring together experts from academia, community, government, industry and health-care delivery. The first day would be a series of presentations and panel discussions. The second day, participants would be divided into work groups to strategize how to disseminate the clinical practice guidelines and how to evaluate those efforts.

Day One

Presentation: Overview of the HIV Clinical Practice Guidelines

- The purpose of this overview would be to provide a foundation for our discussion about how to disseminate the information. It would provide a brief overview of the Principles of Therapy and the three Clinical Practice Guidelines (copies would pre-distributed to all participants). The presentation should provide some background information about the current state of HIV disease and treatment, including background on the numbers of people on anti-viral therapy and those who will consider anti-viral therapy in the near future, background information about drug resistance, adherence, and monitoring of viral levels and immune system functions, choosing treatment regimens and addressing treatment toxicities and failures.

Presentation: The Need for Information Dissemination: The Effect on Patient's Lives and on the Public Health

- will provide a framework for our discussion by raising relevant issues about why the guidelines are important, including the impact that sub-optimal standards of care have on both individual patients and the public health; the role that information dissemination plays in choosing therapy, assisting adherence efforts, managing toxicities, controlling health care costs, and aiding prevention efforts

Presentation: How do you disseminate clinical practice guidelines?

- will provide an overview of how clinical practice guidelines have been translated and disseminated to different audiences, using examples from other diseases. The presentation should cover the results of research on information dissemination to doctors, patients and the incorporation of standards of care into health care delivery systems. This would include information on methods for distribution of information, how people comprehend and retain medical information and how to incorporate that information into practice.

Panel: Target Audiences - will identify the populations that need information, why they need it, how to reach them, identify special needs

- Health care providers
- Patients
- Social Service Providers
- Third-party payors

- the panel will consist of representatives from each of these sectors, discussing why they need this information, what their informational needs are, the formats in which information is best received, and what special considerations will exist for different populations within each group

Panel: Current Dissemination Efforts

- federal government
- state and local governments
- community organizations
- pharmaceutical industry
- health care providers/professional organizations

- the panel will consist of representatives from each of these sectors, each describing the current efforts to translate and disseminate treatment information to physicians, patients, health care providers and others

Presentation: Evaluating Dissemination and Utilization of Clinical Practice Guidelines

- the presentation will provide an overview of methods used to evaluate the dissemination and utilization of clinical practice guidelines in health care delivery, including a discussion about why the evaluation of such efforts is essential to the incorporation of guidelines into practice.

Panel: Measurements for Evaluating Dissemination Efforts

- What do we want from a measurement?
- What types of measurements are feasible?
- Where can measures be taken? - Medicaid programs, managed care organizations, pharmacies, etc.

Panel: Challenges to successful dissemination and incorporation of the clinical practice guideline

- rapidly changing information
- lack of long-term data
- complexity of the treatment strategy
- diverse methods of health-care delivery

- this panel will help to set the stage for the second day of discussion by outlining some of the challenges we face in implementing these clinical practice guidelines. Three speakers

- representing health care delivery, patient advocacy, and academia - will present their viewpoints.

Day Two

On the second day of the workshop, participants will be divided into work groups. Each group will be asked to focus on a particular target population. A designated facilitator would lead the group in discussion about the topic. A rapporteur would record the discussion and report back to the full group. The work groups will be able to discuss in greater depth: (1) the needs of the assigned population in the dissemination of information, (2) strategize as to how best to meet those needs, and (3) how to evaluate whether those efforts have led to the incorporation of the guidelines into clinical practice.

There will be four work groups:

- Patients
- Physicians and health care providers
- Health care managers
- Social service workers

Each group will be asked to identify the following:

- the needs for information within their target group, including special needs for sub-groups;
- what additional data may be required to better understand how their population comprehends and retains medical information;
- the formats in which information be provided to their population group;
- the proposed role of government, community, health care deliverers, pharmaceutical industry and professional organizations in the dissemination of information;
- proposed methods for evaluation of the dissemination strategies;
- proposed methods for evaluation of how the guidelines have been incorporated into care, including possible markers to use as performance measures.

Report back from Work Groups

Post-Workshop

Following the workshop, a report will be prepared by FCHR staff from the minutes of the workshop presentations and work group discussions. The report will include the background information developed before the workshop, summaries of the presentations and a strategic plan for dissemination of the Guidelines. The draft of the strategic plan will be distributed to the members of the Project Planning Committee for review and comment. Those comments will be incorporated into the document and the report will be released publicly. The Project Planning Committee will then meet again to discuss

recommendations for implementation of the plan. At this meeting, Committee members will report on how their respective agencies, companies and organizations are moving toward implementation of the ideas expressed in the Report.

A final evaluation of the project will be prepared by FCHR staff that will provide information as to how and to whom the Report was distributed, and what progress has been made to implement the strategies delineated in the Report.



FORUM FOR COLLABORATIVE HIV RESEARCH

To: Planning Committee of the FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice Guidelines

From: FCHR 

Re: Conference Call information & materials

Date: February 03, 1998

Attached you will find a copy of a draft "project proposal" for the Guidelines Dissemination Project. Also, listed is the conference call information you will need to access the teleconference:

- ✓ Date and time: Monday, February 09, 1998 at 4:00pm Eastern time
- ✓ Dial-in number: 1-888-232-0361
- ✓ Participant access code: 778-141



FORUM FOR COLLABORATIVE HIV RESEARCH

Forum for Collaborative HIV Research

Project on the Dissemination of the HIV Clinical Practice Guidelines

Planning Committee Teleconference

Monday, February 9, 1998 at 4:00 p.m. (EST)

Agenda

1. Review of Project
 - Collection and distribution of background information
 - Two-day workshop
 - Development of strategic plan
 - Planning Committee meeting to review implementation efforts
 - Timeline
2. Review of Project proposal:
 - Goals of project
 - Collection of background information
 - Structure for two-day workshop
 - Scope of presentations/panels for Day One
 - Topics for work groups for Day Two
3. Attendees
 - Panelists/presenters
 - Workshop participants

DRAFT

FCHR Project on Dissemination and Evaluation of the HIV Clinical Practice Guidelines

Project Proposal

Note: This project was originally described as one, which would jointly address issues of dissemination and evaluation of the HIV clinical practice guidelines. Given the outcome of the first meeting of the Project's Planning Committee, it is clear that this project should be split into two distinct processes. This proposal will address the dissemination of information and an evaluation of those efforts. A second proposal to develop a research agenda to evaluate the effectiveness of the Guidelines on patient outcomes and health care delivery will be developed separately.

Part I - Development of a Strategic Plan for the Dissemination of Information from the HIV Clinical Practice Guidelines

Goal: To develop a strategic plan for the dissemination of the information contained in the HIV Clinical Practice Guideline for physicians, patients and caregivers. The Plan will include a determination of who needs the information and address the formats in which the information should be provided. The plan will provide strategies for both dissemination of information and the evaluation of the effectiveness of those dissemination efforts. Finally, the plan will provide recommendations for the implementation of the proposals.

The project will consist of three components:

- (1) preparation for a two-day workshop to examine the needs and strategies for information dissemination, including the preparation of a bibliography and summary of current knowledge about information dissemination techniques;
- (2) the two-day workshop, which will provide participants with information about current dissemination efforts, identify gaps in those efforts, and determine strategies for filling those gaps and evaluating those strategies;
- (3) the preparation of a written strategic plan based on the outcome of discussion from the workshop, along with recommendations for implementation of the plan.

Statement of Need

The development of new and more effective treatment strategies for HIV disease, including combination anti-viral therapy and viral load testing, create the possibility of turning HIV disease into a chronic, but manageable illness. When used properly, clinical studies have shown anti-viral therapy to be tolerable in most patients, and able to

significantly reduce viral replication; thus halting immune system dysfunction, preventing AIDS-related opportunistic infections and death. However, these treatment regimens are complicated to take, difficult to adhere to, and must be taken for a lifetime. If not taken properly, the virus is able to develop resistance to the drugs, which then lose efficacy. Resistance to one drug can often mean the development of resistance to an entire class of drugs. Determining how best to use these drugs and the development of long-term strategies for successful treatment is a challenge for even the most experienced physician and patient. It is hard to determine the optimal time to begin therapy, which combination to use, and how to treat patients for whom therapy is failing. Information about how to best utilize these therapies changes rapidly as new information from clinical studies emerges. Because of the emergence of drug resistance, improper use of anti-viral medication will significantly reduce the benefit to patients and could cause the development of transmission of drug -resistant strains of HIV, which would vitiate much of the progress made to date.

Recently released clinical practice guidelines attempt to provide physicians and patients with up-to-date information about anti-viral therapy and a framework for decision-making in the use of these drugs. These guidelines, developed by the federal government, are updated regularly and offer an opportunity to ensure that people with HIV get the safest and most effective outcome from these therapies. Because the information contained in the guidelines will help to avoid the widespread development of drug-resistant HIV, the guidelines are an important tool to protect the public health. The guidelines provide information about how to monitor HIV viral levels and immune system function, offer a framework to assess when to begin therapy and how to choose a combination that will best suit a patient's needs and ability to comply with the regimen, how to monitor side effects, and provide suggestions for switching therapies for patients who are not responding to treatment. There is an additional set of guidelines for pediatric patients, as well as a guideline for use of anti-viral therapy during pregnancy. The information contained in these guidelines should be seen as important as the drugs themselves, for without the necessary information, the use of the drugs is, at best, diminished, and will most likely cause more harm than good.

It is essential that the information contained in these guidelines is disseminated to doctors, patients and caregivers to ensure the optimal use of these promising, but complicated therapeutic regimens. While there is a group of physicians who are able to keep up with the ever-changing status of HIV treatment information, most physicians are unfamiliar with the latest approaches in the use of anti-viral therapy. Patients need information to make informed treatment decisions and assist with adherence efforts. Additionally, social service providers and educators need treatment information in order to provide a high quality of service to their clients. Public and private third-party payors are another important target for this information as they manage health care delivery, including the development of drug formularies. Educational efforts must be tailored to meet the needs of diverse populations with HIV, taking into account differences in language, literacy skills, cultural and economic differences. Educational efforts need to be on-going in order to provide support for adherence strategies and to effectively manage

toxicities and drug interactions. Such efforts also need to be able to incorporate new information as it develops. The translation and dissemination of the HIV clinical practice guidelines will require a joint effort of multiple parties, including federal, state and local governments, pharmaceutical companies, pharmacists, clinical research programs, community-based organizations, health care providers and third-party payors.

Any strategy for dissemination of HIV medical information must include plans for the evaluation of such efforts to determine if the information has been incorporated into medical practice. Past experience shows that without an evaluation component, guidelines are not utilized by providers. Clinical managers of population health care delivery systems want a simple set of management strategies that couple whatever the technical, science-based guidelines are to a clinical performance measure, which must be available in a timeframe that allows for quality improvement. Measured performance will determine if the guidelines are incorporated into care, not if the guideline is effective. It needs to be determined how to carry out the evaluations, which measures are best, and at which points within health care delivery to implement the evaluation.

The FCHR project will identify the target audiences for the dissemination of the guidelines, and determine the needs of those populations in understanding and incorporating the information. The project will also provide an overview of research into information dissemination techniques that will guide the discussion about how best to develop strategies for the transfer of information to the identified populations. The FCHR project will bring together representatives from each of these sectors to discuss their respective roles in the dissemination effort. The project will report to participants about current efforts to disseminate the information and will gather background information about information dissemination techniques to guide participant's in their discussion. The participants will then develop strategies for the dissemination of information and make recommendations as to how to carry out those strategies, articulating roles for government, community, industry and health-care providers. The participants will also discuss and recommend methods for evaluation of the dissemination strategies.

Preparation for Two-day Workshop

The preparation for the workshop will consist of drafting the agenda for the workshop with the Project Planning Committee, compiling a list of speakers and attendees, and preparing materials for distribution. The materials, prepared by FCHR staff, would provide overviews of: (1) current efforts to distribute HIV-related medical information to physicians, service providers and patients; (2) the literature describing methods for the dissemination of clinical practice guidelines; (3) the literature describing how patients comprehend, retain and utilize medical information; (4) literature regarding methods to evaluate guideline dissemination to health care practitioners. A draft of the meeting agenda will be developed by FCHR staff, circulated to the members of the Project Planning Committee and then discussed by the Committee via teleconference. Committee members will provide names for speakers and attendees for the workshop. FCHR staff

will manage the logistics for meeting, including obtaining meeting space, making travel arrangements for participants, arranging for recording of the meeting, etc.

Workshop

The two-day workshop would bring together experts from academia, community, government, industry and health-care delivery. The first day would be a series of presentations and panel discussions. The second day, participants would be divided into work groups to strategize how to disseminate the clinical practice guidelines and how to evaluate those efforts.

Day One

Presentation: Overview of the HIV Clinical Practice Guidelines

- The purpose of this overview would be to provide a foundation for our discussion about how to disseminate the information. It would provide a brief overview of the Principles of Therapy and the Clinical Practice Guidelines (copies would pre-distributed to all participants). The presentation should provide some background information about the current state of HIV disease and treatment, including background on the numbers of people on anti-viral therapy and those who will consider anti-viral therapy in the near future, background information about drug resistance, adherence, and monitoring of viral levels and immune system functions, choosing treatment regimens and addressing treatment toxicities and failures.

Presentation: The Need for Information Dissemination: The Effect on Patient's Lives and on the Public Health

- will provide a framework for our discussion by raising relevant issues about why the guidelines are important, including the impact that sub-optimal standards of care have on both individual patients and the public health; the role that information dissemination plays in choosing therapy, assisting adherence efforts, managing toxicities, controlling health care costs, and aiding prevention efforts

Presentation: How do you disseminate clinical practice guidelines?

- will provide an overview of how clinical practice guidelines have been translated and disseminated to different audiences, using examples from other diseases. The presentation should cover the results of research on information dissemination to doctors, patients and the incorporation of standards of care into health care delivery systems. This would include information on methods for distribution of information, how people comprehend and retain medical information and how to incorporate that information into practice.

Panel: Target Audiences - will identify the populations that need information, why they need it, how to reach them, identify special needs

- Physicians

- Patients
- Social Service Providers
- Health care providers/payors
- Policy makers

- the panel will consist of representatives from each of these sectors, discussing why they need this information, what their informational needs are, the formats in which information is best received, and what special considerations will exist for different populations

Panel: Current Dissemination Efforts

- federal government
- state and local governments
- community organizations
- pharmaceutical industry
- health care providers

- the panel will consist of representatives from each of these sectors, each describing the current efforts to translate and disseminate treatment information to physicians, patients, health care providers and others

Presentation: Evaluating Dissemination and Utilization of Clinical Practice Guidelines

- the presentation will provide an overview of methods used to evaluate the dissemination and utilization of clinical practice guidelines in health care delivery, including a discussion about why the evaluation of such efforts is essential to the incorporation of guidelines into practice.

Panel: Measurements for Evaluating Dissemination Efforts

- What do we want from a measurement?
- What types of measurements are feasible?
- Where can measures be taken? - Medicaid programs, managed care organizations, pharmacies, etc.

Panel: Issues to Consider in Developing Collaborative Strategies for Dissemination of Information:

- Why is a collaborative effort valuable?
- Insuring the quality of materials
- Pharmaceutical industry marketing efforts
- Intra-government coordination

Day Two

On the second day of the workshop, participants will be divided into work groups. Each group will be assigned a topic. A designated facilitator would lead the group in discussion about the topic. A rapporteur would record the discussion and report back to the full group. The work groups will be able to discuss in greater depth: (1) the needs of different populations in the dissemination of information, (2) strategize as to how best to meet those needs, and (3) how to evaluate whether those efforts have led to the incorporation of the guidelines into clinical practice.

Charge to the work groups

- Identifying Target Audiences and their needs:
 - Patients
 - Physicians and health care providers
 - Health care managers
 - Social service workers
- Who Disseminates What to Whom?
 - Role of federal government
 - Role of state and local governments
 - Role of community-based organizations
 - Role of health care providers/deliverers
 - Role of pharmaceutical industry
 - Collaborative efforts
- Evaluating Dissemination Efforts
 - methodology for evaluation
 - evaluating health care providers
 - evaluating patient education efforts
 - possible markers to determine the use of clinical practice guidelines
 - implementing evaluation strategies

Report back from Work Groups

Post-Workshop

Following the workshop, a report will be prepared by FCHR staff from the minutes of the workshop presentations and work group discussions. The report will include the background information developed before the workshop, summaries of the presentations and a strategic plan for dissemination of the Guidelines. The draft of the strategic plan will be distributed to the members of the Project Planning Committee for review and comment. Those comments will be incorporated into the document and the report will be released publicly. The Project Planning Committee will then meet again to discuss recommendations for implementation of the plan. At this meeting, Committee members

will report on how their respective agencies, companies and organizations are moving toward implementation of the ideas expressed in the Report.

A final evaluation of the project will be prepared by FCHR staff that will provide information as to how and to whom the Report was distributed, and what progress has been made to implement the strategies delineated in the Report.



FORUM FOR COLLABORATIVE HIV RESEARCH

January 28, 1998

Todd Summers
Office of National AIDS Policy
750 17th Street, NW
Suite 600
Washington, DC 20503

Dear Mr. Summers:

Thank you for your recent participation in the Forum's first planning committee meeting for the *Dissemination & Evaluation of the HIV Clinical Practice Guidelines* multi-part project. You should have already received a copy of the project proposal outlining the goals for the information-dissemination portion of the project; if not, please contact the Forum, and a copy will be sent to you promptly.

As you will recall from the meeting, the second part of this project is to develop a research agenda to examine the effects that the clinical practice guidelines for HIV care have on patient outcomes and clinical practices. As proposed at the meeting, a two-day workshop would be held to review collected information in this area, to identify the issues for further discussion and analysis, and to develop a research agenda to address those issues. Experts from the fields of patient outcomes and health care quality research, and representatives from pharmaceutical companies, state Medicaid programs, managed care organizations, federal government agencies (i.e. CDC, AHCPR, HRSA, HCFA, NIH), patient advocates, and clinical researchers, would be convened at this workshop to accomplish the above tasks. The results of this workshop will be compiled into a report and broadly disseminated. Specifically, the patient outcomes project would provide: 1) an overview of current efforts to measure the scope of HIV medical care provided in diverse health care delivery settings and the effect of that care on patient outcomes; 2) an overview of research methodology in patient outcomes; 3) identification of issues relevant to studying patient outcomes in HIV disease; and 4) recommendations as to how those issues should be addressed by both the public and private sectors of research establishments.

After our previous meeting, it was decided that a second planning committee meeting to focus specifically on the evaluation of the guidelines on patient outcomes and clinical practices should take place with the inclusion of additional experts from the field. You are invited to participate as members of both Planning Committees, and we hope you are able to do so. Your participation in the Patient Outcomes Research Project would assist in the determination of issues

preliminary review of the literature for relevant data and background information that will aid planning committee members in these responsibilities. *In addition, if you have not already done so, please suggest names of experts in the field who could add valuable contributions at this planning meeting.*

Enclosed you will find an information sheet requesting your interest and availability for this planning committee meeting. Please fill out this form and fax it to the Forum as soon as possible. Confirmation of the date, time, and place of the meeting will be forwarded to you as soon as we have them arranged, as will travel and hotel information. If you have any questions regarding the planning committee meeting, please feel free to call or email us at any time.

Thank you in advance for your interest and participation in this new project. We look forward to working with you.

Sincerely,



David Barr
Director
(202) 530-2307
ihodxb@gwumc.edu



Tina Sogocio
Research Associate
(202) 530-2330
ihotms@gwumc.edu

Enclosure

FORUM FOR COLLABORATIVE HIV RESEARCH

**THE DEVELOPMENT OF A RESEARCH AGENDA REGARDING THE EFFECT OF THE HIV CLINICAL
PRACTICE GUIDELINES ON CLINICAL PRACTICES AND PATIENT OUTCOMES PROJECT:
PATIENT OUTCOMES RESEARCH PLANNING COMMITTEE**

Name: _____

Title: _____

Address: _____

Phone #: _____ Fax #: _____

Email address: _____

- ☐ Yes, I can participate on Planning Committee for Patient Outcomes Research project
☐ No, I cannot participate at this time.

• Suggestions of other participants: _____

Availability: the meeting will be a day-long meeting in Washington D.C.; please mark all that apply:

- | | |
|---|--|
| ☐ Monday, March 2, 1998 | ☐ Tuesday, March 10, 1998 |
| ☐ Tuesday, March 3, 1998 | ☐ Wednesday, March 11, 1998 |
| ☐ Wednesday, March 4, 1998 | ☐ Thursday, March 12, 1998 |
| ☐ Monday, March 9, 1998 | ☐ Friday, March 13, 1998 |

Please indicate your preferences below.

- ☐ Yes, I will need FCHR to cover travel expenses.
☐ No, I will not need FCHR to cover travel expenses.
- ☐ Yes, I will need hotel accommodations.
☐ No, I will not need hotel accommodations.

Are there any special considerations regarding your travel, accommodations, or attendance at the meeting? If so, please indicate: _____

Please fax this form to William Gist at: (202) 296-0025 by February 5, 1998.