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Conference - 6/99 - Forum on Patient Outcomes

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FC | *Forum for Collaborative HIV Research*
HR | Center for Health Policy Research
George Washington University Medical Center

April 1, 1999

Todd Summers
Office of National AIDS Policy
736 Jackson Place
Washington, DC 20503

Dear Mr. Summers,

On behalf of the Planning Committee for the Forum for Collaborative HIV Research (FCHR) *Project to Develop a Research Agenda Regarding the Effect of the HIV Standard of Care on Patient Outcomes*, we are writing to invite you to participate in an important, two-day workshop in Washington, DC.

As you may know, current HIV clinical practice guidelines recommend regular diagnostic testing and aggressive use of antiretroviral drugs, which have been shown in clinical studies to prolong life and delay the onset of symptomatic HIV disease. Through this project, FCHR will investigate methods to determine:

- whether the practices recommended in HIV treatment guidelines have been incorporated into clinical care;
- if so, whether they are followed consistently and correctly;
- whether the incorporation of recommended practices has had a positive effect on the morbidity, mortality, and quality of lives of people with HIV;
- what effect the incorporation of guidelines for HIV care has had on the utilization of healthcare services.

The workshop will convene experts from many arenas, including evaluation research scientists, government healthcare plan sponsors, commercial managed care providers, clinicians, pharmaceutical industry representatives and patient advocates. The first day of the workshop will feature individual and panel presentations on a range of topics associated with patient outcomes research. (A tentative workshop agenda and Planning Committee roster are included for your review.) On the second day, participants will break into working groups to develop a preliminary research agenda. Based upon the working groups' deliberations, a final report and research agenda will be drafted and widely disseminated.

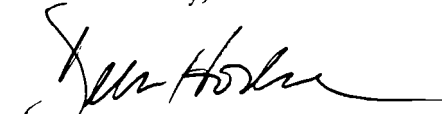
The Forum for Collaborative HIV Research (FCHR), a project of the Center for Health Policy Research at George Washington University, analyzes and develops policy in HIV clinical research and care by facilitating discussion between pharmaceutical companies,

patient advocacy groups, clinical researchers, government agencies, and health care providers.

The workshop will be held on June 3-4, 1999, at the American Geophysical Union, 2000 Florida Avenue NW, in Washington, D.C. Should you elect to participate, the FCHR will be pleased to cover your travel and accommodations expenses for the meeting. Should you have any questions, or should you wish to discuss any aspect of the meeting's program, please do not hesitate to contact either of us (Derek at 212.244.8555 or dh.daystar@ibm.net; David at 202.530.2307 or ihodxb@gwumc.edu).

We hope you will agree to participate in this important meeting. Thank you in advance for your favorable consideration.

Yours sincerely,



Derek Hodel
Project Coordinator

David Barr
FCHR Director

DH/DB/dh
Enclosures

*FCHR Project to Develop a Research Agenda Regarding
the Effect of the HIV Standard of Care on Patient Outcomes*

TENTATIVE AGENDA

Thursday, June 3, 1999

9:00 – 9:30 Continental Breakfast

9:30 – 10:00 Welcome and Introductions

10:00 – 10:30 HIV disease and patient outcomes research: a new opportunity to improve quality of care?

10:30 – 11:30 The growing importance of patient outcomes research in the management of chronic diseases

- how patient outcomes research is used in chronic disease
- how does patient outcomes research compare to other types of research?
- what types of endpoints are used in outcomes research? (process v. outcomes research)
- the value of patient outcomes research in the healthcare delivery system
 - pro: learning what works in the real world
 - con: overly generalized data that limit treatment options
- Outcomes research methods: How do you do it?
- What types of patient outcomes are most effectively measured? what types of process measures?
- Barriers/limitations of outcomes research

11:30 – 12:15 Diffusion of innovation: what do we know about how treatment guidelines are implemented in chronic diseases?

- The difference between “adopt” and “implement”
- How guidelines are implemented among various stakeholders: sponsors, providers, clinicians, social service providers, patients
- Effect of interest groups, advocacy groups, champions
- factors that may impede implementation
- evaluation methods: how is the implementation of guidelines evaluated?
 - process measures
 - outcome measures

12:15 – 1:15 Lunch

- 1:15 – 2:15 The challenges of evaluating the implementation of the HIV Clinical Practice Guidelines
- assumption: the guidelines (taken as a whole) are “effective”
 - guidelines comprised of multiple recommendations, supported by different kinds of evidence – from randomized, controlled clinical trials to expert opinion. Which components are well-established as efficacious? (What health outcomes are broadly accepted?)
 - evaluating the implementation of the HIV Clinical Practice guidelines
 - effect on healthcare utilization
 - patient outcomes
 - HIV-specific confounding (intervening) variables (comorbidities, adherence, healthcare coverage, health beliefs)
 - rapidly evolving standards of care
- 2:15 – 3:45 What is most important to know from patient outcomes HIV research?
- Government [HCFA/Medicaid] sponsor
 - Government [HRSA funded] provider
 - Commercial Managed Care Provider
 - Institutional Medical Director
 - Pharmaceutical Industry
 - Patient Advocate
- 3:45 – 4:00 Break
- 4:00 – 4:30 How does HIV patient outcomes research relate to other HIV research? (longitudinal cohort studies, observational data bases, comparative intervention studies, practice-based convenience samples, cross-sectional surveys)
- 4:30 – 5:30 Current Research Efforts
- 5:30 – 6:30 Reception

Friday, June 4, 1999:

- 8:30 – 9:00 Continental breakfast
- 9:00 – 9:30 Charge to Workgroups
- 9:30 – 12:00 Workgroup sessions
- 12:00 – 1:00 Working lunch
- 1:00 – 1:30 Workgroup sessions
- 1:30 – 3:00 Reports from the Workgroups/Close

*FCHR Project to Develop a Research Agenda Regarding
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Planning Committee

Bruce Agins, MD, MPH, *New York State Department of Health AIDS Institute*
Sam A. Bozzette, MD, PhD, *San Diego VA Medical Center*
Victoria Cargill, MD, *NIH Office of AIDS Research*
Donald Conway, MD, MBA, *Abbott Laboratories*
Lawrence Deyton, MD, MSPH, *Veterans Administration*
Susan Dooha, *Gay Men's Health Crisis*
William Duncan, PhD, *National Institute of Allergy and Infectious Diseases*
Mark S. Dworkin, MD, *Centers for Disease Control and Prevention*
Ruth Finkelstein, ScD, *New York Academy of Medicine*
Peter Fitzgerald, *American Association of Health Plans*
Randy Graydon, *HCFA Division of Advocacy and Special Issues*
Julia Hidalgo, ScD, MSW, MPH, *Center for Health Policy Research, GWU*
Richard Jeffreys, *AIDS Treatment Data Network*
Michael Johnson, MD, MPH, *Health Resources Services Administration*
John Ludden, MD
Leona Markson, ScD, *Merck & Co., Inc.*
Lynne Mofenson, MD, *National Institute of Child Health and Human Development*
Sissi Pham, PharmD, *Glaxo Wellcome, Inc.*
Penny Pine, *Health Care Financing Administration*
Sara Rosenbaum, *Center for Health Policy Research, GWU*
Catherine Wilfert, MD, *Duke University Medical Center*
Robert Zackin, ScD, *Harvard University*

Forum for Collaborative HIV Research
Project to Develop a Research Agenda Regarding
the Effect of the HIV Standard of Care on Patient Outcomes

June 3-4, 1999
American Geophysical Union
Washington, DC

☒ **Yes, I will attend the workshop.**

Name: Todd Summers
Title: Deputy Director
Address: Office of National AIDS Policy
736 Jackson Place
Washington DC 20503
Phone: 202-456-2437 Fax: 202-456-2438
E-Mail: tsummers@opd.eop.gov

☐ **I will need assistance with travel arrangements and accommodations.**
(The meeting organizers will contact you to make arrangements.)

☐ **I can't attend, but would suggest inviting the following person in my place:**

Name: _____
Address: _____

Phone: _____ Fax: _____
E-Mail: _____

☐ **No, I cannot attend.**

Please FAX this form back as soon as possible to:

Derek Hodel, Project Coordinator
The Daystar Group
PHONE: 212.244.8555
FAX: 212.244.9055
EMAIL: dh.daystar@ibm.net