

11/16/08

Institute of Medicine
Keck Center-8th floor
Board on Population Health-Viral Hepatitis Study
500 Fifth St., NW, Washington, DC 20001

RE: Submission of testimony for Public Meeting, Thursday, December 4, 2008: Institute of Medicine Committee on Prevention and Control of Viral Hepatitis Infections in the United States

Dear Members of the Committee,

In your announcement of this meeting you stated “The committee will assess current prevention and control activities and identify priorities for research, policy, and action.”

We would like to present the following testimony regarding the “priorities for research.”

- Hepatitis C has been recognized for years by many dozens of HIV/AIDS groups in testimony before Congress as being more responsible for deaths in HIV/AIDS patients than the opportunistic infections that used to kill them.ⁱ
- The CDC estimates the number of chronically ill HCV patients at 3.1 million versus 1.1 million for HIV/AIDS.ⁱⁱ
- The CDC estimates the number of deaths from HIV/AIDS at 14,016 versus 8,000 to 10,000 for hepatitis C.^{iii iv} We have contacted the departments of health in each state and they report to us 10,778 deaths from HIV/AIDS with many states experiencing over ninety percent reduction in HIV/AIDS deaths.^v
- The amount of funding on HIV disease by our government since the inception of HIV in our country is now approximately \$275 billion dollars.^{vi} The 2009 HIV/AIDS budget request is \$24.1 billion.^{vii} The NIH NIAID budget for HIV/AIDS bio-medical research is \$2.9 billion, which is a full ten percent of the entire bio-medical research budget. The amount of NIH funding for hepatitis C research is \$107 million, a decline of seven million dollars since 1994.^{viii}
- Such favoritism for HIV/AIDS has resulted in the NIH spending \$20 and \$34 on each HCV & HBV patient, respectively, versus \$2,774 on each HIV/AIDS patient in bio-medical research.
- \$48 billion has been budgeted this year for PEPFAR and global HIV/AIDS, TB and Malaria. Consider: the amount of NIH bio-medical research on every disease know to man is only \$29 billion yet we budget \$48 billion, a preponderance of which will go toward one disease in one

country: HIV in Africa.^{ix}

- The Bill & Melinda Gates Foundation has spent approximately \$7 billion on global HIV efforts to date and is approaching \$1 billion in expenditures for HIV vaccine research.^x Expenditures by the Gates Foundation for hepatitis B or C, if any, are not published on their website.
- Warren Buffet has pledged most of his \$40 billion in wealth to the Gates Foundation and Buffet is supportive of Gates bias in favor of HIV/AIDS funding.^{xi}
- Our country's top HIV/AIDS researcher and Director of the NIAID, Anthony Fauci, M.D., has said, "'...the scientific advancements that have been made in HIV [research] are breathtaking [with] highly effective drugs to suppress HIV to the point where what was a death sentence in the early eighties to now having patients who look and feel well, who are leading very productive, very gratifying lives..."^{xii}

When our organization exhibits at large conventions and the attendees see our banner that includes the table below, a new member joins, on average, every 2 minutes all day long while expressing great anger and disgust at the favoritism that continues to be afforded HIV disease in research funding by our government.

| Disease | 2009 NIH Research \$\$ | Deaths Per Disease | \$\$ Per Patient Death | \$\$ Per Patient |
|---------------------|------------------------|--------------------|------------------------|------------------|
| COPD | 90 Million | 126,128 | \$ 714 | \$ 7 |
| Hepatitis C | 107 Million | 12,000 | \$ 8,916 | \$ 20 |
| Cardiovascular Dis. | 2.3 Billion | 871,500 | \$ 2,714 | \$ 29 |
| Hepatitis B | 42 Million | 5,000 | \$ 8,400 | \$ 34 |
| Diabetes | 1 Billion | 74,817 | \$13,365 | \$ 39 |
| Parkinson's Dis. | 186 Million | 19,547 | \$ 9,516 | \$ 124 |
| Alzheimer's Dis. | 644 Million | 71,696 | \$ 8,928 | \$ 124 |
| Prostate Cancer | 344 Million | 27,050 | \$ 12,717 | \$ 181 |
| HIV/AIDS | 2.9 Billion | 14,016 | \$ 206,906 | \$ 2,774 |

We are respectfully requesting that the Institute of Medicine Committee on Prevention and Control of Viral Hepatitis Infections in the United States and the National Viral Hepatitis Roundtable enact policy statements calling for a cessation of the bias for HIV/AIDS research funding and that consideration be given to increasing the funding for HCV & HBV research.

Indeed, with budgetary limitations now in place due to our government's financial crisis that prevent overall increases in NIH funding, we recommend adding the following request: a reallocation of a portion of HIV/AIDS research funding to other illnesses that have not had the same success that Dr. Fauci has laudably achieved and describes so well in the quote above, including HCV and HBV.

Thank you for your consideration of this request and with great respect for your efforts we are,

Richard Darling, DDS

and our 25-member Board of Directors listed below

Richard Darling, DDS, Past National Public Citizen of the Year

President & CEO, FAIR Foundation

Founder: The FAIR Foundation Liver Disease & Transplant Support Group

Author: Coma Life, an autobiographical memoir of life "within" coma and survival over hepatitis C, liver cancer, 3 liver transplants, heart attack, diabetes & muscular dystrophy

ⁱ http://fairfoundation.org/specter_letter_hcv_in_aids_pts.pdf

ⁱⁱ <http://www.cdc.gov/hepatitis/Statistics.htm>

ⁱⁱⁱ <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2006report/table7.htm>

^{iv} <http://www.cdc.gov/hiv/topics/surveillance/resources/reports/2006report/table7.htm>

^v http://fairfoundation.org/states/hiv-aids_deaths_by_state.htm

^{vi} Henry J. Kaiser Foundation reports \$150 billion HIV funding up to 2004. Every year thereafter the amount budgeted has been \$20+ billion including \$24.1 billion for 2009. In addition, one must note the \$48 billion PEPFAR funding, of which approx \$30 billion is for global AIDS.

^{vii} <http://www.kff.org/hivaids/upload/7029-041.pdf>

^{viii} <http://www.nih.gov/news/fundingresearchareas.htm>

^{ix} http://kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=53609

^x http://fairfoundation.org/news_letter/2006/04sept/newsletter.htm

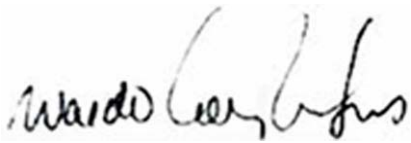
^{xi} http://fairfoundation.org/news_letter/2006/04sept/newsletter.htm

^{xii} <http://fairfoundation.org/fauci.wmv>

The FAIR
Fair Allocations In Research
FOUNDATION

www.FAIRFoundation.org

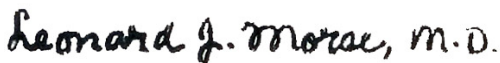
The FAIR Foundation Board of Directors as co-signers of this letter to the Institute of Medicine
Committee on Prevention and Control of Viral Hepatitis Infections in the United States



Waldo Concepcion, MD, FACS
Associate Chief, Div. of Transplantation
Stanford University School of Medicine



John Fung, MD
Chairman, Department of General Surgery
Director, Transplant Ctr, Cleveland Clinic



Leonard J. Morse, M. D.
Commissioner of Public Health, Worcester, MA
Chair Emeritus, AMA Council on Ethical &
Judicial Affairs (CEJA)
Past President, Mass Medical Society &
the Boston Medical Library



Donald J. Hillebrand, MD
Medical Director, Liver Transplant
Scripps Green Hospital
La Jolla, CA

Okechukwu N. Ojogho, MD.

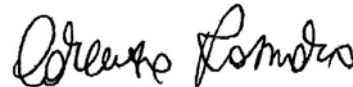
Okechukwu N. Ojogho, MD
Director, Transplantation Institute
Loma Linda University Medical Center

Pedro Baron, MD

Pedro Baron, MD
Director: Pediatric/Adult Liver Transplant
Loma Linda Univ. Medical Center



Phil Berry, MD
Founder/Past President: Texas Medical Assoc.
President, Texas Medical Assoc. Foundation
Past member, UNOS Board & Finance, Dallas, TX



Lorenzo Rossaro, MD, FACP
Medical Director/Chief of Hepatology
Liver Transplant Department
UC Davis School of Medicine

Melba Moore, MS

Melba Moore, MS
Commissioner of Public Health
St. Louis Department of Public Health

Charles Goodacre, DDS, MS

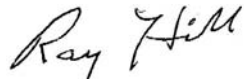
Charles Goodacre, DDS, MS
Dean, School of Dentistry, Loma Linda U.
Past President, American Board of Pros.

Leigh Aveling, D.Min.

Chaplain & Associate Professor
Director: Shands Jacksonville Transplant Center
School of Religion
Loma Linda University



Dave Courtney, Patient Advocate
Alpha-1-Antitrypsin disease
VP: The Presumed Consent Foundation
President: Texas Panhandle Chapter, TRIO



Ray Hill, Patient Advocate, HIV/AIDS and Hep C
ACLU Lifetime Achievement Award
Houston's Gay Male Hero Award-7 years

Jim Ward

Jim Ward, Captain, SC, USNR (Ret.)
Patient Advocate: Cardiovascular Disease
San Diego, CA

Jill Weissman, Pharm. D.

Jill Weissman, Pharm. D.
Transplant Pharmacist; Assistant Professor
Loma Linda University Medical Center



Arthur Curley, Attorney-at-Law
President, Bradley Curley Asiano, PC
Larkspur, California

Kress Darling

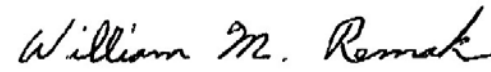
Patient Advocate, Chronic Obstructive
Pulmonary Disease
Palm Desert, CA

Robert Gish, MD


Robert Gish, MD
Med. Director: Liver Dis. & Transplant
California Pacific Medical Center
San Francisco, CA

Jacqueline Marcell

Patient Advocate: Alzheimer's disease,
Caregivers and Elder Awareness
Author/Publisher: *Elder Rage* & Radio Host
Irvine, California



Bill Remak, B.Sc.MT, BA PHA
Chairman, California Hep. C Task Force
Founder, Nat. Assoc. of Hep. Task Forces



Philip Rugo, Patient Advocate: ALD
Past Director: Harrison House Substance &
Abuse Rehab. Center, Northampton, MA



Sandy Rodgers, Patient Advocate
Parkinson's Disease and Stroke
Kapalua, Maui, Hawaii



Norman Kay, Patient Advocate:
Prostate Cancer
Lahaina, Maui, Hawaii

Richard Swabb, MD

Richard Swabb, MD
Board Certified in Nephrology & Int. Med
Loma Linda University Medical Ctr.