

The FAIR  
Fair Allocations In Research  
FOUNDATION

www.FAIRFoundation.org

10/24/07

Elizabeth Furlong, RN, PhD, JD  
Associate Professor, Creighton University Medical Center School of Nursing  
Criss II 194C  
2500 California Plaza  
Omaha, NE 68178

Dear Dr. Furlong,

Congratulations on being named to serve as a member of the NIH Director's Council of Public Representatives (COPR). We are respectfully requesting that you consider the following information in formulating your recommendations to Director Zerhouni. The following text is our testimony to the Senate and House Appropriations Subcommittees overseeing NIH bio-medical research allocations.

On behalf of our thousands of members and supporters in all fifty states and the District of Columbia, we thank you very much for your consideration.

Sincerely yours,



Richard Darling, DDS  
President and CEO....and the 27-member FAIR Foundation Board of Directors listed below our testimony

-----  
RE: *Public Witness Testimony for the Record* – FY 2008 NIH Budget

Dear Subcommittee Members:

The death rate in our country from AIDS has plummeted as evidenced in 2006 by the 99 percent drop in California's newly infected AIDS patients[i] from just under 10,000 to 130 (as of 2/28/07) and the 93 percent drop to 100 deaths in all of Illinois's HIV/AIDS patients for 2004[ii]. In addition, we respectfully bring to Chairman Byrd's attention that this great success includes West Virginia where AIDS deaths have dropped to 23 for their latest reporting period (2005).[iii] This success against AIDS is being repeated throughout America, yet AIDS still receives ten percent of the entire National Institutes of Health (NIH) disease research budget.

Such exorbitant funding for AIDS has resulted in unfair allocations for all non-AIDS diseases, including the sixteen[iv] that kill a million more Americans than AIDS annually. For example,

cardiovascular disease kills almost a million Americans compared to 16,316 (2005)[v] for AIDS, yet the NIH is spending only \$40 on each CVD patient versus \$3,052 on each AIDS patient in research.[vi] Diabetes kills more citizens than AIDS and breast cancer combined, yet only \$50 is spent on each diabetic in research. More AIDS patients are now dying of hepatitis C than they are of AIDS,[vii] and hepatitis C (HCV) affects 4-5 times as many as AIDS yet only \$25 is allocated for each HCV patient.

Disease	2005 NIH Research \$	Deaths Per Disease	\$ Per Patient Death	\$ Per Patient
<b>HIV/AIDS</b>	<b>2.93 Billion</b>	<b>16,316</b>	<b>\$178,046</b>	<b>\$ 3,052</b>
Cardiovascular Dis.	2.3 Billion	930,000	\$ 2,523	\$ 40
Diabetes	1 Billion	73,965	\$ 14,236	\$ 50
Alzheimer's Dis.	642 Million	63,343	\$ 10,182	\$ 143
Prostate Cancer	373 Million	27,350	\$ 13,638	\$ 192
Parkinson's Dis.	205 Million	17,898	\$ 12,403	\$ 148
Hepatitis C	121 Million	12,000	\$ 10,166	\$ 25
Hepatitis B	36 Million	5,000	\$ 6,600	\$ 32
COPD**	66 Million	126,128	\$ 500	\$ 5
West Nile Virus	63 Million	161	\$390,304	\$14,932

Regardless if the funding comparison is measured utilizing “allocation per patient,” “allocation per death” or “total allocation” per disease, the great success of AIDS researchers has resulted in funding for AIDS now being disproportionate and inequitable.

In addition, hundreds of millions of dollars are raised for AIDS by celebrities and non-profit organizations (amfAR, etc.) while similar efforts do not exist for many other diseases. With the recent \$37 billion stock pledge by Warren Buffett to the \$29 billion Bill and Melinda Gates Foundation and Mr. Buffett’s support for the Gates’s bias in funding to combat HIV disease, the favoritism afforded this disease has reached excessive proportions. Indeed, Melinda Gates has stated that her fondest goal is a vaccine for HIV disease and to date the total funding by the Gates’s Foundation for all HIV programs is \$6.5 billion dollars. It is anticipated that much more of the Gates Foundation will go towards combating HIV disease in the future.

When one reflects that the total NIH bio-medical research budget for every disease known to man is only \$28.4 billion and ten percent of that also goes to HIV research, one can only be dismayed at the continual favoritism afforded this illness.

The NIH has responded to The FAIR Foundation’s requests to cease the favoritism afforded HIV/AIDS and to reallocate some of the present AIDS dollars to other diseases by referencing global AIDS and the fact that AIDS is communicable and destructive to the young.[viii]

What are the solutions for global AIDS—more research? No, the answers to global AIDS are the same that have dropped the death rate throughout America, and they have been expressed by Presidents Clinton, Bush and the Director of the NIAID, Dr. Fauci, namely: preventive

education, the drugs which converted AIDS from an acute illness into a chronic illness (HAART or Highly Active Anti-retroviral Therapy) and setting up health infrastructures.

Indeed, Dr. Fauci himself recently admitted the great success in HIV research when he stated on CNN, **“..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...”**

Regarding the “communicable” nature of AIDS, Congress must force realization upon the NIH that simply because an illness is “infectious” does not warrant disproportionate research funding. Patients suffering from non-communicable illnesses such as prostate disease, Alzheimer’s disease, etc. should not be discriminated against because they cannot transmit their disease to others or because its etiology is congenital or acquired by environmental causes.

In America’s youth, the CDC’s 2005 report states seven deaths in patients age <13, sixty-three under age of 19 and 677 deaths under age 30. The estimated deaths from SIDS (Sudden Infant Death Syndrome) each year is 3,000. Clearly, HIV disease is not a major factor killing our youth.

An unrecognized factor negatively impacting all non-AIDS diseases is the “compounding effect” of present NIH policy. The present funding total of each disease may be viewed as their “principal balance” for this analogy. If the present effort by 100 members of the House to increase NIH funding by 6.7 percent is successful, the increase in AIDS funding will be approximately \$194 million whereas Alzheimer’s disease will receive only \$43 million and Chronic Obstructive Pulmonary Disease (COPD) \$4.4 million even though those two diseases kill, respectively, three and nine times more Americans than AIDS. Each year the additional increases in the “principle balance,” or total funding, results in the “compounding interest effect” that increases the disproportionate funding for AIDS. Consequently, the gap in funding between AIDS and all other diseases grows even larger. Supplying greater funding to the NIH without redistribution of present inequities is unfair for non-AIDS illnesses.

**The issue of AIDS favoritism is rapidly becoming a political issue.** Before billions more dollars are spent on yet another preventive measure (HIV vaccine), **we urge you to publicly call for a partial redistribution of the HIV excess funding to other illnesses that do not presently have effective treatments, including the sixteen maladies<sup>[iii]</sup> that are killing a million more Americans than HIV disease annually.**

Indeed, with the budgetary limitations resulting from our government’s commitments, including supporting the war in Iraq and restoring the areas ravaged by hurricanes Katrina and Rita, necessary increases for bio-medical research funding have been non-existent. As with the common citizen whose budget is pinched, it is appropriate to reallocate existing funds, in this case some of HIV/AIDS funding to other illnesses.

**61 million voters with cardiovascular disease, 21 million diabetics and millions of other constituents with non-AIDS illnesses will applaud your courageous declaration, while approximately one million with HIV/AIDS may be dismayed at such an announcement.**

The FAIR Foundation (FAIR is an acronym for “Fair Allocations In Research) is a national organization representing thousands of members and supporters—concerned citizens—who want the success of AIDS advocates and AIDS researchers recognized with a corresponding change in the allocation priorities of the NIH with our taxpayer dollars that fund bio-medical research. Gay members of our country are present on our Board, including Ray Hill, who used to be one of this country’s most strident HIV activists. Because of their great success, Ray, who has been named Houston’s gay hero by that community seven years in a row, now advocates for hepatitis C.

On behalf of our national membership we are respectfully requesting that a portion of AIDS research allocations be reevaluated and redistributed now that the existing medications and extensive prevention programs for this illness have significantly mitigated its threat.

With great respect for your efforts, we are,



**and the 28-member Board of Directors below**

Richard Darling, DDS, President & CEO  
National Public Citizen of the Year (NASW-'03)

---

[i] <http://www.dhs.ca.gov/aids/Statistics/pdf/Stats2007/Feb07AIDSMerged.pdf> Page two

CA Office of AIDS – patients infected in 2006 who died in 2006

[ii] [http://fairfoundation.org/states/illinois\\_AIDS\\_deaths.htm](http://fairfoundation.org/states/illinois_AIDS_deaths.htm)

[iii] WVA Dept of Health, Tom Light, 304-558-1748 or [http://fairfoundation.org/states/west\\_virginia.htm](http://fairfoundation.org/states/west_virginia.htm)

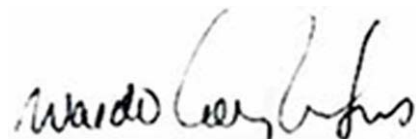
[iv] <http://www.fairfoundation.org/thesixteen.htm>

[v] [http://fairfoundation.org/CDC\\_AIDS\\_death\\_estimates\\_2001-2005.pdf](http://fairfoundation.org/CDC_AIDS_death_estimates_2001-2005.pdf)

[vi] <http://www.fairfoundation.org/factslinks.htm>

[vii] [http://fairfoundation.org/specter\\_letter\\_hcv\\_in\\_aids\\_pts.pdf](http://fairfoundation.org/specter_letter_hcv_in_aids_pts.pdf)

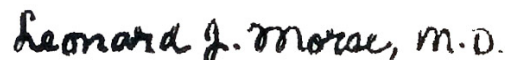
[viii] <http://www.fairfoundation.org/nihletter.htm>



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



John Fung, M.D.  
Chairman, Department of General Surgery  
Director, Transplant Center, Cleveland Clinic



Leonard J. Morse, M. D.  
Commissioner of Public Health, Worcester, MA  
Board of Directors: Worcester AIDS Project Workshop  
Recipient: AMA's "Pride in the Profession" award  
Chair Emeritus, AMA Council on Ethical &



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

Judicial Affairs (CEJA)

Past President, Mass. Medical Society & the Boston Medical Library

***Okechukwu N. Ojogho, MD.***

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



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

***Melba Moore, MS***

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

***Richard Swabb, MD***

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



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



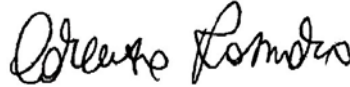
Jan Warner, Executive Director  
The Dennis James United Cerebral Palsy Center  
Cathedral City, CA



Bill Roberts, Patient Advocate

***Pedro Baron, MD***

Pedro Baron, MD  
Director of Pediatric and Adult Liver  
Loma Linda University Medical Center



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

***Charles Goodacre, DDS, MS***

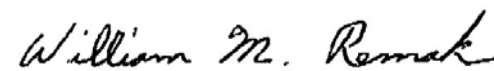
Charles Goodacre, DDS, MS  
Dean, School of Dentistry, Loma Linda U.  
Past President, American Board of Pros.

***Jill Weissman, Pharm. D.***

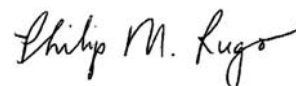
Jill Weissman, Pharm. D.  
Transplant Pharmacist; Assist. Professor  
Loma Linda University Medical Center

***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  
Director: Harrison House Substance &  
Abuse Rehabilitation Center  
Northampton, MA



Sandy Rodgers, Patient Advocate


Diabetes and Hepatitis C  
Hacienda Heights, California 91745



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

**Jim Ward**

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



Jan Warner, Executive Director  
The Dennis James United Cerebral Palsy Center  
Cathedral City, California

Parkinson's Disease and Stroke  
Kapalua, Maui, Hawaii



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



Kress Darling, Patient Advocate  
Chronic Obstructive Pulmonary Disease (COPD)  
Palm Desert, California



Patient Advocate: Breast Cancer  
Charlotte, NC