

**From:** [The FAIR Foundation](#)  
**To:** [Daniel S. Levine \(dlevine@bizjournals.com\)](mailto:dlevine@bizjournals.com);  
**CC:**  
**Subject:** "Scientists feel deflated as NIH research bubble starts to pop"  
**Date:** Thursday, May 18, 2006 12:07:00 PM  
**Attachments:**

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Re: <http://sanfrancisco.bizjournals.com/sanfrancisco/stories/2006/05/08/newscolumn2.html>

Dear Mr. Levine,

Thank you for your above referenced article. I am respectfully requesting permission to reprint your article in our next national Newsletter.

Please note that as President and CEO of The FAIR Foundation I have given over 100 presentations across the country and seventy-five to the Senate and House Legislative Health Aides, including to most working for the members of the Senate and House Appropriations Subcommittees, calling for more fair and equitable distribution of NIH funds with a corresponding re-distribution of a significant portion of present HIV/AIDS funding to other illnesses (see [here](#) ). I join with my 27-member [Board of Directors](#) consisting of eminent physicians, dentists, pharmacist and disease advocates in pointing out that although the death rate from AIDS has [fallen 98 percent in California's](#) newly infected patients, which is representative of what is happening [nationally](#), HIV/AIDS still receives ten percent of the entire NIH research budget. That is not fair, nor is it equitable.

We disagree with ex-NIH Director, Harold Varmus, MD, who was at the helm of the NIH and ordered the relaxation of ethics requirements which caused ethical conflicts that necessitated the present Director, Elias Zerhouni, MD, to issue a reversal of Varmus's policies and sweeping changes that eliminated hundreds of financial conflicts of interest between researchers and pharmaceutical companies (Paragraph 6 [here](#)). The NIH clearly deserves criticism for not recognizing the great success of AIDS researchers and advocates with a corresponding re-distribution of a portion of HIV/AIDS funding. You state in your article and we have stated for years in [our communications](#) with Congress that budgetary constraints eliminate increases in overall funding, therefore it is our contention that existing allocations must now be redistributed to where they are most needed.

The FAIR Foundation now consists of thousands of members and supporters in all fifty states and the District of Columbia who are calling for change in Congress and the NIH regarding the distribution of research funding. We also are very involved in helping transplant patients. Indeed, members of our Board are saving the lives of HIV patients with transplant and one, [John Fung, MD](#), was the first surgeon to transplant an HIV patient, Larry Kramer, who is arguably the most strident HIV activist this country has ever

witnessed although our gay Board member, Ray Hill of Houston, may also qualify for that award. Ray recognizes the disproportion NIH funding and has switched his focus to hepatitis C, which [dozens of HIV organizations](#), in their communications to Congress, recognize as now being responsible for more AIDS related liver deaths than AIDS is, yet hepatitis C receives only \$25 per patient in funding versus \$3,040 for an HIV/AIDS patient. While helping to insure the lives of HIV patients (for which Kramer [states great gratitude](#) to Dr. Fung) FAIR is also calling for an end to HIV/AIDS favoritism in NIH and Congressional funding. We only want that which is fair and equitable for each illness, no more and no less.

We hope you will bring this issue to the public's attention with a follow-up story that references FAIR's national effort in order to bring balance to Dr. Varmus comments and to reinforce the need for change at the NIH and in Congress on this issue to insure proper funding for all non-AIDS illnesses, including the [sixteen](#) that kill a million more Americans than HIV disease annually.

Thank you for your consideration.

Most Sincerely,

**Richard**

**PS: For your review, the paragraph in our Newsletter that will describe your report will link to it [here](#).**

Dr. Richard Darling, DDS: [National Public Citizen of the Year](#) (NASW-03)

President and CEO: [The FAIR Foundation](#), a national movement to reverse inequities in research

funding distributions by the National Institutes of Health

Founder: [The Coachella Valley Hepatitis C, Liver Disease & Transplant Support Group](#)

Board of Directors: United Organ Transplant Association

Ambassador: OneLegacy, a transplant donor network

Author: [Coma Life](#), an autobiographical memoir of life "within" coma and survival over hepatitis C induced liver cancer, three liver transplants, heart attack, diabetes

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Disease	2007 NIH Research \$\$	Deaths Per Disease 2004	\$\$ Per Patient Death	\$\$ Per Patient
<b>AIDS</b>	<b>2.9 Billion</b>	<b>15,798</b> (a)	<b>\$ 182,807</b>	<b>\$ 3,040</b>
Parkinson's Dis.	232 Million	17,898 (f)	\$ 12,403	\$ 148
Alzheimer's Dis.	645 Million	63,343 (d)	\$ 10,182	\$ 143
Prostate Cancer	373 Million	29,578 (e)	\$ 12,474	\$ 133
Diabetes	1.05 Billion	73,965 (c)	\$ 14,236	\$ 50
Cardiovascular Dis.	2.35 Billion	930,000 (b)	\$ 2,523	\$ 37

Hepatitis B	33 Million	5,000 (h)	\$ 6,600	\$ 32
Hepatitis C	122 Million	12,000 (g)	\$ 10,166	\$ 25
COPD *	63 Million	126,128 (i)	\$ 499	\$ 5
West Nile Virus	42 Million	116 (j)	\$362,068	\$ 14,242

\*\* COPD = Chronic Obstructive Pulmonary Disease

Statistics based on information from the CDC & NIH See: <http://www.fairfoundation.org/update.htm> for verifying links

Join the FAIR Foundation today: <http://www.fairfoundation.org/join.htm> (free)

[NIH Orphan Drug Allocation of \\$1.2 Billion](#) for 6000 diseases equals only \$200,000, on average, for research on each disease.