



www.FAIRFoundation.org

2/23/09

Phillip T. and Susan M. Ragon  
InterSystems  
1 Memorial Dr # 6  
Cambridge, MA 02142

RE: HIV/AIDS Philanthropy

Dear Mr. and Mrs. Ragon,

Our organization now has thousands of members and supporters in all fifty states. In representing them, I join with our 26-member Board of Directors of surgeons, medical directors, and patient advocates in applauding you and your husband for your concern for HIV patients and for your generous philanthropy.

However, we are respectfully requesting reconsideration of your \$100 million gifting with a significant portion to be allocated to non-AIDS illnesses, including thoughtfulness of the numerous patients with rare illnesses, which receive very minimal funding from our government.

We offer the following thoughts to give credence to our request:

- The success of NIH research efforts are stunning: HIV/AIDS deaths have plummeted wherever the HAART therapy has been instituted, including in the USA where HIV deaths have decreased over 90 percent<sup>i</sup> in many states including a 98 percent decline in newly-infected patient deaths in California from 9,764 in 1992 to 229 (as of 8/31/08).<sup>ii</sup>
- Confirming this success, [our country's top HIV/AIDS researcher and the Director of the NIH's NIAID which oversees all HIV research funding, Anthony Fauci, MD has said 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..."](#)<sup>iii</sup>
- Would a vaccine for HIV be helpful for global AIDS? Yes, but before we continue to spend billions on that effort to benefit patients who have successful drugs as described by Dr. Fauci above, let us re-direct a large portion of those funds to non-AIDS illnesses that do not have effective remedies (drugs), including the sixteen that kill a million more annually than HIV now.<sup>iv</sup>

- A full ten percent of our government’s budget for bio-medical research (\$2.9 billion) goes to only one disease: HIV/AIDS.<sup>v</sup>
- TARP will provide \$8.2 billion to the Office of the Director for research priorities, of which \$7.4 billion will be transferred to the individual Institutes and Centers and the Common Fund, based on their current proportion in the FY 2009 appropriations bill. Since HIV disease is now receiving ten percent of the NIH budget it is likely it will receive a very large portion of that pro rata TARP distribution to the NIAID.
- The amount of funding on HIV disease by our government since the inception of HIV in our country is now approximately \$300 billion dollars.<sup>vi</sup>
- \$48 billion has been budgeted this year for PEPFAR and global HIV/AIDS, TB and Malaria and most of this will go towards battling HIV. Consider: the amount of NIH bio-medical research on every other disease know to man is only \$26.1 billion.<sup>vii</sup>
- HIV disease has also received great funding from sources in addition to the US government’s largess:
  - 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,<sup>viii</sup>
  - Warren Buffet has pledged most of his wealth to the Gates Foundation and Buffet is supportive of Gates bias in favor of HIV/AIDS funding.<sup>ix</sup>
  - The television shows “Survivor,” “American Idol” and “The Apprentice” have given the proceeds of their auctions to HIV/AIDS beneficiaries for years.
  - Numerous private individuals in Hollywood and elsewhere, such as Elizabeth Taylor and Sharon Stone, and major organizations like amfAR have raised billions of dollars for HIV programs for decades.
  - Pharmaceutical companies have spent billions of dollars in research & development to develop effective remedies for HIV
  - And now, your generous philanthropy.
- Many research efforts by universities, etc. that rely on philanthropic donations by individuals and non-profits are suffering severe decreases in contributions due to our country’s and the Madoff financial crises. HIV/AIDS, due to its exorbitant federal and private funding sources like your gift, is not experiencing the same degree of shortages.
- According to the United Nations and several of the world’s most eminent health scientists and organizations who published a landmark global consensus in *Nature*, Chronic Non-communicable Diseases (CNCD), such as cardiovascular disease, type 2 diabetes and many cancers kill twice as many globally as the combined total of HIV/AIDS, malaria, TB, maternal & peri-natal conditions, and nutritional deficiencies.<sup>x xi</sup>

- The 2009 HIV/AIDS budget request is already significant at \$24.1 billion.<sup>xii</sup> This includes a program that has distributed billions of dollars to fund HIV/AIDS patients' housing/mortgage, etc. expenses. It is called HOPWA (Housing Opportunities for Patients with AIDS)<sup>xiii</sup> and our government (HUD) has no such program for non-AIDS illnesses like Alzheimer's, Parkinson's disease, etc.

When our organization exhibits at large conventions and the attendees see our banner below that displays our government's research bias in favor of HIV disease, a new member joins FAIR, on average, every two minutes all day long while expressing great anger and disgust at the favoritism that continues to be afforded HIV disease in funding.

### **Our Government's Bio-Medical Research Allocations by the National Institutes of Health**

<b>Disease</b>	<b><u>2009 NIH Research \$\$</u></b>	<b>Deaths Per Disease</b>	<b>\$\$ Per Patient Death</b>	<b>\$\$ Per Patient</b>
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
<b>HIV/AIDS</b>	<b>2.9 Billion</b>	<b>14,016</b>	<b>\$ 206,906</b>	<b>\$ 2,774</b>
All Cancers Total	5.5 Billion	559,650	\$ 9,888	\$ 3,830
Breast Cancer	716 Million	40,910	\$ 17,501	\$ 3,967
<b>West Nile Virus</b>	39 Million	<b>37</b>	<b>\$1,054,054</b>	<b>\$28,467</b>

The NIH funding for 6000 Orphan (rare) diseases was reported to be \$1.2 billion until 2007. It is now reported to be only \$645 million which equals only \$107,500 for each disease's entire bio-medical research effort.

We respectfully restate our request that a significant portion of your HIV philanthropy be re-directed to bio-medical research on non-HIV/AIDS illnesses.

Thank you for your consideration of our request.

Sincerely yours,



Dr. Richard Darling, DDS, Past National Public Citizen of the Year  
 President & CEO, FAIR Foundation, a volunteer 501(c)(3) organization with no paid employees  
 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

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- i [http://fairfoundation.org/states/hiv-aids\\_deaths\\_by\\_state.htm](http://fairfoundation.org/states/hiv-aids_deaths_by_state.htm)
- ii <http://fairfoundation.org/quiz/quizanswer.htm>
- iii <http://fairfoundation.org/fauci.wmv>
- iv <http://www.fairfoundation.org/thesixteen.htm>
- v <http://www.nih.gov/news/fundingresearchareas.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://kaisernetwork.org/daily\\_reports/rep\\_index.cfm?DR\\_ID=53609](http://kaisernetwork.org/daily_reports/rep_index.cfm?DR_ID=53609)
- viii [http://fairfoundation.org/news\\_letter/2006/04sept/newsletter.htm](http://fairfoundation.org/news_letter/2006/04sept/newsletter.htm)
- ix [http://fairfoundation.org/news\\_letter/2006/04sept/newsletter.htm](http://fairfoundation.org/news_letter/2006/04sept/newsletter.htm)
- x [http://fairfoundation.org/news\\_letter/2008/01march/nature\\_magazine.pdf](http://fairfoundation.org/news_letter/2008/01march/nature_magazine.pdf)
- xi <http://www.peterrussell.com/Odds/WorldClock.php>
- xii <http://www.kff.org/hivaids/upload/7029-041.pdf>
- xiii <http://www.hud.gov/offices/cpd/aidshousing/programs/>

Recordable • 52X • 700MB • 80min

Dr Anthony Fauci's Powerful  
30 sec quote on CNN  
From FAIR Foundation 760-2002766

**Memorex**<sup>®</sup>

**CD-R**

COMPACT  
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When you were in high school, if your father had slipped you \$29 in crisp dollar bills, you would've been elated. But what if he then turned to your sister and handed her \$2,774? Would you have shouted...

**“That’s not fair!”**

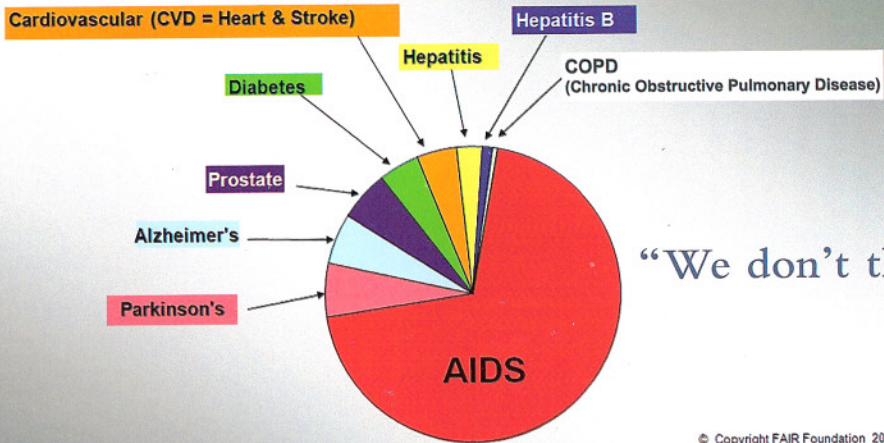
Without a doubt.

**The FAIR**  
Fair Allocations In Research  
**FOUNDATION**

“Is this fair?”



### NIH Research Money Budgeted per Death



“We don't think so!”

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The Issue →

Cardiovascular disease kills 870,000 per year vs. 14,016 for AIDS  
Cardiovascular disease: \$2,714 per death vs. \$206,906 for AIDS



A 501(c)(3) NON-PROFIT ORGANIZATION

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## Are these Fair Allocations In Research?

Disease	2009 NIH Research \$	Deaths Per Disease	\$ Per Patient Death	\$ Per Patient
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All Cancers Total	5.5 Billion	559,650	\$ 9,888	\$ 3,830
Breast Cancer	716 Million	40,910	\$ 17,501	\$ 3,967
West Nile Virus	56 Million	124	\$ 451,613	\$ 15,427

6,000 orphan (rare) diseases receive, on average, only \$200,000 per illness.

Visit our website to view our 27-member Board of Directors of surgeons, medical directors, dentists, pharmacists and patient advocates.



# THE TRUTH

Believe it or not, if you or a loved one suffer from cardiovascular disease (CVD) or any other disease except cancer, our government has handed you that \$29 dollars for bio-medical research or a similar small amount, while unfairly giving each of your sisters and brothers – a.k.a. patients suffering from AIDS – a whopping \$2,774.

The lion's share of the Federal research budget is spent on AIDS – a disease that is killing a fraction of Americans each year when compared with diseases like diabetes and Alzheimer's. Even the flu kills twice as many people as AIDS.

CVD kills 870,000 every year, which is 62 times more than AIDS. Diabetes kills more Americans than AIDS and breast cancer combined, yet the government is spending only \$39 on each diabetic compared to that \$2,774 on each HIV patient. The shocking truth is that CVD receives over 1/2 billion less than AIDS, and the increase in AIDS funding since 1999—just the increase— is greater than the entire budget for every other disease except cancer. Billions for AIDS also comes from pharmaceutical companies, the 50 states, celebrities and well-intentioned citizens like Bill Gates.

## FAIR IS FAIR

The FAIR (Fair Allocations In Research) Foundation is dedicated to equitable research funds for all diseases, including the 16 that kill a million more Americans than AIDS annually. Our secondary factors insure diseases that cause great suffering with low mortality (6,000 rare illnesses) will also receive increased funding.

AIDS activists should be commended for reducing AIDS deaths 98 percent in California's newly infected patients and over 90% in many other States. But now it is time to start giving other diseases their fair share of research dollars so that they, too, can experience better health.

But the need for change isn't just about AIDS. The amount spent on research for the "Health Effects of Climate Change" is greater than the funding for brain cancer, Down Syndrome, cystic fibrosis, autism, cerebral palsy, cervical cancer, hepatitis B & C, multiple sclerosis, muscular dystrophy, uterine cancer and 6,000 other maladies. That's not fair either.

Choose today to join the thousands of FAIR Foundation members and supporters in all fifty states who are calling for change.

Cut along line

**WE NEED YOUR HELP** The FAIR Foundation is determined to increase research funding for your disease of interest. Please tear off this page and send your donation today. We thank you for your support!

**YES, I WANT TO HELP! PLEASE ACCEPT MY DONATION OF \$ \_\_\_\_\_**

\_\_\_\_\_  
Name

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Email Address

Please mail to: FAIR, 78-629 Bougainvillea Drive, Palm Desert, CA 92211

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