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From: FAIR Foundation [mailto:fair@dc.rr.com]
Sent: Sunday, May 31, 2009 3:10 PM
To: Jonathan Rochkind (jrochkind@publicagenda.org)
Subject: RE: Impressions of HIV/AIDS in America

Jonathan Rochkind
VP-Research Director, Education Insights
[Public Agenda](#)

Cc by postal mail: Ruth Wooden, President; Will Friedman, Ph.D., CEO; Daniel Yankelovich, Chairman and Co-Founder; Amber Ott, Research Manager; Samantha DuPont, Research Assistant and your Board of Directors

RE: "Impressions of HIV/AIDS in America" <http://www.publicagenda.org/files/pdf/HIV-AIDS-May-2009.pdf>

Dear Mr. Rochkind,

Your findings, as reported by Kaiser Daily HIV/AIDS Report, that "Many Americans Support Increased Domestic Funding to Address HIV/AIDS," are in stark contrast to our experiences at numerous exhibits throughout America at American Diabetes Association (ADA) Conventions. At these Expos where thousands of diabetics, cardiovascular disease and renal patients attend, we have a patient join our organization, on average, every 2-3 minutes for six hours and each one is upset and angry at the favoritism and exorbitant funding for HIV disease. In Phoenix recently, we had a new member join, on average, every 56 seconds for 6.5 hours while expressing resentment over this issue of HIV preferential treatment in governmental funding as evidenced in the chart below.

Feel free to view the many pictures of the new members who, at such conventions, join the many thousands who are already members of our organization.

Phoenix: http://fairfoundation.org/news_letter/2009/02june/Phoenix_expo_pics2009.htm

Los Angeles Expo in Long Beach:

http://fairfoundation.org/news_letter/2009/02june/LA_expo_pics2009.htm

Detroit: [http://fairfoundation.org/news_letter/2008/04dec/FAIR_in_Detroit\(Novi\).htm](http://fairfoundation.org/news_letter/2008/04dec/FAIR_in_Detroit(Novi).htm) plus we received the same welcome in Tampa, Portland, Seattle, Pittsburgh, etc. etc.

I note in your intro statistics to HIV disease on page 6 that you provide no balance to your research project by providing facts of the laudable success against HIV disease [as stated on CNN](#) by Anthony Fauci, MD, the Director of the NIAID and America's top HIV researcher: "...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...".

"Balance" would have required the report by you, Samantha DuPont and Amber Ott to disclose Dr. Fauci's comments and to discuss this success that is evidenced by deaths from AIDS

[plummeting throughout America](#), including a [98 percent decline](#) in the rate of newly infected HIV patients in California from 9,797 to 157 in 2008.

On page 6 of your report you reference the drop from 44 percent to six percent of those who think HIV was/is the most urgent health problem facing the nation. You also reference the Kaiser Family Foundation stats that show a decrease in HIV/AIDS awareness among Americans from 34 percent to 14 percent. You then reference President Obama's quote of HIV disease being a "crisis" and the need to provide millions more for an awareness campaign.

We submit that HIV disease is, quite simply, not a crisis in the USA and Americans understand that. Indeed, if HIV, which is affecting just over one million and killing 14,110, is a "crisis" then what adjective do we use to describe cardiovascular disease that is affecting 80 million with 871,000 deaths annually or diabetes with its 25 million patients and more deaths than HIV disease and breast cancer combined? (CDC estimates)

It should also be considered by epidemiologists that in any subset of the population there will be a percentage of individuals who are fully informed but choose to act without proper protection against infection, be it to protect against the flu, HIV or HCV. 56,000 new HIV patients annually is 5.3 percent of the 1,050,000 estimated by the CDC—a reasonable figure representing those who will refuse to protect themselves and spending \$45 million more, as the President plans, in addition to the billions already spent, is unnecessary and a further waste of taxpayer dollars. Evidence of this is your own statement that "... most people were aware of the primary ways HIV is transmitted..." The fact that some mistakenly think HIV can be transmitted by casual contact contributes to misimpressions about HIV, but those misimpressions do not add to the infection rate; the fact is, virtually all Americans know the primary means of transmission and how to protect against infection.

The statement, "For many experts, there has never been a serious effort to combat the disease" is false and a clear insult to Dr. Fauci's superb work at the NIAID and a gross disregard of the [\\$300 billion](#) spent by our government to battle HIV since its onset in 1981. Furthermore, of the \$7.4 billion of stimulus funds going to the NIH Institutes, a large portion will likely go to HIV since the allocation is pro-rata per past year's funding. HIV has received ten percent of the NIH budget for many years.

Your "Finding Four" is faulty. It is not a "stigma" when citizens you interview reference that HIV is transmitted by those in high-risk groups (MSM, IV drug users and high risk heterosexual relations as defined by the CDC as having sex with someone who has HIV or is a significant risk of having HIV) who are having unprotected, risky sexual relations—it is a simple, undeniable fact. Indeed, our Board member, Leonard Morse, MD, Commissioner of Public Health, Worcester, Massachusetts and a Past Member, Board of Directors, Worcester AIDS Project Workshop, has continually informed the citizens of his community in billboards and other media outreach that HIV infection is preventable. Your "Finding Four" would suggest he is stigmatizing HIV patients when, of course, he is working hard to educate the public and save lives of those at risk.

Your study was funded by an AIDS group, was prepared for an AIDS organization (the NASCC) and "several experts in HIV/AIDS also contributed to the report," according to *Reuters*. We also note you "conducted 13 telephone interviews were conducted with people who work on various HIV/AIDS issues." This gives the impression of a clear bias on your part, especially since opposing views are not presented and you obtained the results they wanted to see in order to justify further exorbitant funding for HIV/AIDS.

We respectfully request that you retract your study and redo it with more balance to your report by providing the table below for review by your participants as well as statistics on the overall funding by our government since 1981 on HIV disease in comparison to the funding for all other maladies. A sample question: "Do you think the government should continue funding

HIV as in the past when it is spending \$29 for research on each of the estimated 80 million patients with cardiovascular disease which is killing 850,000+ annually in comparison to its present allotment of \$2,774 on behalf of each HIV/AIDS patient when their deaths have fallen to 14,110? Or another question that would have provided balance: Are you aware that the Dept. of Health and Human Services (HHS) has a program, [HOPWA](#) (Housing Opportunities for Persons with AIDS) that has spent billions of dollars helping AIDS patients with housing expenses and that HHS has no such program from other maladies? Etc.

Since their email addresses are not listed on your organization's web site, please forward this email to your co-researchers Samantha DuPont and Amber Ott for their review. We will also submit this letter by postal mail to your President, Ruth Wooden, your CEO, Will Friedman, Ph.D., your Chairman and Co-Founder, Daniel Yankelovich, and your Board of Directors. We are respectfully requesting that since their email addresses are also not available on the Public Agenda website that you forward this to Ms. Wooden, Mr. Friedman, Mr. Yankelovich and your Board of Directors so they can immediately be aware of our concerns.

Thank you.

Dr. Richard Darling, DDS: [Past National Public Citizen of the Year \(NASW\)](#) and our Board of Directors listed below

President and CEO: [The FAIR Foundation](#), a national organization with thousands of members and supporters whose goal is to reverse inequities in NIH research funding and to institute [new organ-donor policies](#) to reverse America's organ-donor crisis

Founder: [The FAIR Foundation Liver Disease & Transplant Support Group](#)

Author: [Coma Life](#), an autobiographical memoir of life "within" coma and survival over hepatitis C induced liver cancer, coma, 3 liver transplants, heart attack, diabetes & Muscular Dystrophy (Myasthenia Gravis)

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

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
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	39 Million	37	\$1,054,054	\$28,467

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.

* COPD is Chronic Obstructive Pulmonary Disease

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Bill Remak, B.Sc.MT, BA PHA Chairman, California Hepatitis C Task Force, Founder: National Association of Hepatitis Task Forces

Richard Darling, DDS, FAIR Foundation President & CEO, Past National Public Citizen of the Year (NASW), Founder: FAIR Liver Disease Support Group; author of *Coma Life*

Lorenzo Rossaro, M.D., Medical Director, Chief, Division of Gastroenterology and Hepatology, University of California, Davis Medical Center

Ray Hill, Ray Hill, Patient Advocate: HIV/AIDS & HCV; AIDS activist labeled "Citizen Provocateur" by United States Supreme Court Justice William Brennan (U.S. Supreme Court—Houston v. Hill, 482 U.S. 451); American Civil Liberties Union (ACLU) Lifetime Achievement Award for advancing the rights of gay, lesbian and transgender citizens, voted "gay hero" seven years in a row by the gay community of Houston, Texas

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