
From: Peter Fisher [mailto:peterfisher@verizon.net]
Sent: Wednesday, May 19, 2010 7:27 AM
To: mpenner@NASTAD.org
Cc: Julie Scofield; Chris Taylor; Laura Hanen; Colin Schwartz; Martha Saly; info@hepcop.org; Church, Daniel (DPH), Dr. Richard Darling, FAIR CEO
Subject: NASTAD Mission Statement

Dear Mr. Penner,

I certainly appreciate the change in NASTAD's mission statement.

Now can you please change NASTAD's name to include viral hepatitis? Perhaps to NASTAVHD? A bit long and cumbersome, but having state and territorial AIDS Directors running VH is not acceptable.

There needs to be some recognition that HIV/AIDS disease interests are not simply taking over viral hepatitis. NASTAD cannot seem to accept that.

Please change the name to reflect disease equity.

Regards
Peter Fisher

From: FAIR Foundation [mailto:fair@dc.rr.com]
Sent: Wednesday, May 19, 2010 10:53 AM
To: 'Peter Fisher'
Cc: Murray Penner, NASTAD Dep. Executive Director, Domestic Pgms; Laura Hanen, NASTAD Director of Gov't Relations; 'Julie Scofield'; Ann Lefert, NASTAD Associate Director, Government Relations; 'Chris Taylor'; 'Laura Hanen'; Colin Schwartz, NASTAD Senior Associate, Viral Hepatitis; 'Martha Saly'; 'Church, Daniel (DPH)'; 'charles.gore@worldhepatitisalliance.org'; Julie Slater, NASTAD Director, Global Program; 'William Remak'; Kitty Candelaria (candelarianhci@hotmail.com); 'info@hepcop.org'
Subject: RE: NASTAD Mission Statement--insufficient, Elton John admission, etc.

Dear Peter,

Thank you for your ongoing and laudable advocacy for hepatitis patients. Regarding the communication to you by NASTAD's Deputy Executive Director of Domestic Programs, Murray Penner, the token addition of hepatitis to the Mission Statement at NASTAD is shown to have little meaning by the omission of hepatitis in the other pertinent sections of their ABOUT NASTAD web page at <http://www.nastad.org/About/About.aspx>. I include a just a sample of their omission of hepatitis in their literature below.

Who We Are:

The National Alliance of State and Territorial AIDS Directors (NASTAD) represents the nation's chief state health agency staff who have programmatic responsibility for administering HIV/AIDS healthcare, prevention, education, and supportive service programs funded by state and federal governments. NASTAD is dedicated to reducing the incidence of HIV/AIDS infection in the U.S. and its territories, providing comprehensive, compassionate, and high-quality care to all persons living with HIV/AIDS, and ensuring responsible public policies. NASTAD provides national

leadership to achieve these goals, and to educate about and advocate for the necessary federal funding to achieve them, as well as to promote communication between state and local health departments and HIV/AIDS care and treatment programs. NASTAD supports and encourages the use of applied scientific knowledge and input from affected communities to guide the development of effective policies and programs.

Membership

AIDS directors **No HCV directors, HCV org. CEO's, etc.?** in all 50 U.S. states, the District of Columbia , Puerto Rico, the U.S. Virgin Islands, and the U.S. Pacific Islands are represented by NASTAD, with an office in Washington , D.C. Programs administered by NASTAD members serve every population affected by and infected with HIV/AIDS. As such, NASTAD members offer considerable expertise in identifying community needs and responding to the challenges of the HIV/AIDS epidemic nationwide and throughout the world.

An organization that is clearly biased towards HIV/AIDS representing itself as the appropriate advocate for hepatitis patients is grossly unacceptable. Perhaps if they would adopt your suggested name change, include hepatitis in all representations as those above, and speak out on the outrageous disparity in bio-medical research funding that you see in the table below for hepatitis versus HIV/AIDS they would gain some credibility in the hepatitis community. There silence on the issue of disparity in bio-medical research funding is startling when it has been well-known for years that HCV is the leading cause of death in HIV/AIDS/HCV co-infected patients.

Even Elton John admitted publicly to 40 million viewers of the TV show, *Idol Gives Back*, that HIV is "not life-threatening anymore." (video link to his comments) Not even I would make that statement without qualifying "with one's use of the excellent HIV drugs that are now available"; however, how many HIV/AIDS patients need to die due to their HCV co-infected status before NASTAD will address this issue? Keep in mind that one of our Board's transplant surgeons, John Fung, MD, did the first high-profile liver transplant on an HIV/HBV co-infected patient, Larry Kramer, who now calls Dr. Fung "my great transplant surgeon." Our Board members of transplant surgeons, medical directors and doctors of pharmacy at FAIR work to save the lives of HIV patients when HBV and HCV end-stage liver disease are killing them, why doesn't NASTAD strongly advocate Congress and the NIH for more fair and equitable RESEARCH funding for a complete cure (sustained viral response) for hepatitis??

The existing treatment for HCV is ineffective in 50% of infected HCV patients (averaging all Genotypes) and even more ineffective in HIV/HCV co-infected patients. In addition, the side effects are brutal and, again, even more so in HIV/HCV co-infected patients. NASTAD's silence on the need for fair and equitable research funding is deafening, especially for their HIV/hepatitis co-infected brothers dying today. Now that NASTAD and all HIV organizations have been so successful in gaining excellent remedies for HIV with their largess of funds, we urge them to shift focus to the need for better treatment remedies for hepatitis patients. Indeed, I believe all hepatitis organizations, including FAIR, would partner with them should they opt to make such a strong change in their efforts and mission statements.

Dr. Richard Darling, DDS: National Public Citizen of the Year ([NASW](#))
 President & CEO: [FAIR Foundation](#), thousands working for equality in NIH research funding and to reverse the [organ-donor crisis](#)
 Founder: [Liver Disease & Transplant Support Group](#)
 Author: [Coma Life](#), memoir: survival over hepatitis C, liver cancer, 3 transplants, heart attack & diabetes
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Disease	2011 NIH Research \$	Deaths Per Disease	\$ Per Patient Death	\$ Per Patient
COPD	101 Million	126,128	811	7
Hepatitis C	102 Million	12,000	8,500	23
Cardiovascular	2.1 Billion	864,280	2,429	26
Hepatitis B	54 Million	5,000	10,800	43
Diabetes	1 Billion	72,449	13,803	42

Alzheimer's	480 Million	71,696	6,626	92
Parkinson's	171 Million	19,566	8,739	171
Prostate Cancer	329 Million	28,372	11,595	219
HIV/AIDS	3.2 Billion	14,110	225,656	3,032
All Cancers	6 Billion	559,888	10,716	4,152
Breast Cancer	765 Million	41,210	18,563	4,238
West Nile Virus	41 Million	28	1,464,285	64,364