
From: FAIR Foundation [mailto:fair@dc.rr.com]
Sent: Thursday, May 20, 2010 10:52 AM
To: 'charles.gore@worldhepatitisalliance.org'
Cc: 'Harry'; 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'; Colin Schwartz, NASTAD Senior Associate, Viral Hepatitis; 'Martha Saly'; 'Church, Daniel (DPH)'; Julie Slater, NASTAD Director, Global Program; 'William Remak'; Kitty Candelaria (candelarianhci@hotmail.com); 'Silvia Hinojosa-Price'; 'peterfisher@verizon.net'; 'Tricia Lupole'
Subject: RE: World Hepatitis Day and inappropriate hepatitis representation in the USA

Dear Mr. Gore,

Please allow me to follow up on the comments below by you and Mr. Hooks.

The national organization of which I am President and CEO was never contacted regarding your election of Taylor and we have thousands of members, a very large number with HCV and HBV. I know of only one organization in the USA that was contacted for the election of Gore and I do know of many who were not. Taylor was definitely not chosen by a well represented sample of "our community" as you state below.

Speaking personally as an HCV patient and for my 26-member Board of Directors of liver transplant surgeons, medical directors, et al, we don't want someone representing hepatitis patients in the USA who is from an organization whose major focus is HIV/AIDS. We want someone whose sole focus, whose organization's major focus is HCV—that person does not have to have HCV although that would be preferable since they would truly understand our plight. As I wrote yesterday with facts from their website, NASTAD is clearly focused on HIV/AIDS, not HCV and Taylor has admitted publically that he does not have HCV.

I say HCV and not HBV without bias against HBV patients whom our organization also helps with support and transplant, but because of the greater morbidity and mortality of HCV here in the USA and globally, the excellent drugs available for HBV patients now and the fact that the major cause of ESLD and liver transplant is HCV.

Taylor has brazenly refused to respond to our concerns and this complete lack of respect for the many hepatitis C patients contesting his position is unacceptable. If he were sincere in his desire to help heal the HCV community and promote its agenda, he would act honorably act and resign immediately, which would enable you to hold an emergency election to fill his vacancy with an HCV advocate from an HCV organization.

I applaud your goals; however until such change is made, our organization and many others like ours in the USA, including HepCop, the California HCV Task Force, et al, will not support your organization and we will continue to make our concerns and objections known to the public and to all potential financial sponsors. It is obvious from the attached pictures of World Hepatitis Day in the USA that there is little support here for the present leadership—4-5 million

HCV patients and only 50 or so attend? Such a small attendance is very embarrassing to all; change is urgently needed.

Sincerely,

Richard

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
Contact: 78629 Bougainvillea Drive, Palm Desert, CA 92211 (760) 200-2766

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

-----Original Message-----

From: Harry [mailto:hooks1@mindspring.com]

Sent: Wednesday, May 19, 2010 7:13 PM

To: Charles.Gore @WorldHepatitisAlliance.org; Silvia Hinojosa-Price; peterfisher@verizon.net; ctaylor@nastad.org

Cc: jscofield@nastad.org; Ihanen@nastad.org; cschwartz@nastad.org; info@hepcop.org

Subject: Re: World Hepatitis Day

"Public dissent like yours undercuts everything and therefore is directly counter to the interests of 500 million people. It is also extraordinarily misplaced"

Mr. Gore,

Let me explain what it looks like from my side of the mirror.

All I've seen over the past ten years, is HCV being pushed to the back burner. The known risks have been altered to the point of being unreal, this is why, I believe we are starting to see clusters of new infections here in the US. The watered down version isn't keeping medical professionals alert and practicing the proper precautions.

The constant push from the HIV community has buried HCV with STDs which as you know it is not.

The majority of the folks I deal with are Veterans and their families. They have no reason to go to a STD clinic to be tested or find answers.

The misinformation spread by groups that have the ear of officials has been devastating and frankly I'm tired of seeing good people die because of it. The VA follows the CDC and WHO's lead on the reason for a person is infected. Through this process, we have seen legitimate risks discarded, combat is no longer a listed risk, vaccinations are contested, even though it is known to be so, medical procedures before what is now standard precautions are not considered risks and on and on.

So on this I don't feel that my dissent is extraordinarily misplaced. I think it is right on target and intend to continue until things look better on this side of the mirror.

Harry Hooks
Director, HCVets.com
Educational Website & Support Forum
HCVets@aol.com
856-340-0269
<http://HCVets.com>

I have a favour to ask. Please read what I have to say and then respond to me

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Public dissent like yours undercuts everything and therefore is directly counter to the interests of 500 million people. It is also extraordinarily misplaced. I shall (now for the third time) give you the history. I'm sorry that it's lengthy but you need to know this.

I was diagnosed with HCV in 1995 and cirrhosis in 1997. I do not have HIV. At the time, there was no NGO for people with HCV in the UK (although more than 500 for HIV!!) so I set up The Hepatitis C Trust with 3 other HCV+ friends in 2000. I have run it since then, only ever employing HCV+ staff until a month ago when the need to expand forced me to take on someone whose partner is HCV+. That includes all staff, paid and volunteers. In addition almost everyone of my Board is HCV+. In the UK, like elsewhere, we have had issues with HIV organisations wanting to move into HCV. I have made it very clear that it is the Trust that speaks for people with HCV. We work with HIV organisations where our interests intersect, for example in HCV/HIV co-infection and advocating for BBV testing in prisons.

In 2002 I was involved with an initiative to get HCV NGOs from around Europe together to share best practice. From that emerged a decision to hold a European HCV awareness day on October 1st and also to establish a European

NGO umbrella organisation. Because some of the groups involved had a wider remit than just HCV (e.g. all liver disease), this organisation became the European Liver Patients Association and I was elected the first president in 2004. The HCV awareness day became a viral hepatitis awareness day because many of the groups covered both HBV and HCV. A number of other groups decided to join the initiative (e.g. from Australia) and the awareness rather misleadingly got called World Hepatitis Awareness Day (WHAD). I attended AASLD in 2005 and asked all the US groups I met there if they would like to take part (to try to make it a world day). I was told very clearly that was not possible because October 1st is the start of Breast Cancer Awareness month (which was much bigger in the US than Europe). I went back to the groups participating in WHAD and over the next year talked them into accepting that we might have to change the date of the awareness day. Following AASLD 2006 I asked all the North American HCV and HBV NGOs I knew or had heard of to get together and choose someone to represent the continent for a meeting at EASL in April 2007. Clearly, that wasn't everyone but it was the best I could do, given the constraints of time and money.

The groups got together, had a formal election process and chose Chris Taylor - that is to say the people in your hepatitis community did that. Chris may work at NASTAD but his work is hepatitis. I did the same thing with other parts of the world, getting the groups I knew about to choose a representative. I then got sponsorship and held the meeting in April 2007 at which the representatives from the groups around the world decided to establish a World Hepatitis Day on May 19th. I then set up the World Hepatitis Alliance as the NGO to run World Hepatitis Day with the representatives of each region as the Board. I was simply acting as facilitator and not intending to be on the Board but it quickly became apparent that no-one else had the time to run it so the Board chose me as president. The idea has always been to get everything up and running and then formalise the membership process and hold proper elections for the Board. This has taken much longer than expected, because membership has turned out to be immensely complicated. We have over 280 patient groups from more than 60 countries participating in WHD and what constitutes a 'patient group' differs markedly from country to country (I'm happy to explain the complications in a later email if you like because this is the reason for the delay and the fact that you have not yet had the opportunity to express your views through elections). Our membership criteria is set out on the website but there has been a lot of dissatisfaction with it (generally with it being too restrictive) so we are revisiting it in the next 4 weeks immediately after WHD. We hope to have it all sorted very shortly.

That is the history. The real history. Anything else you have heard is just gossip.

When you attack Chris then, you are attacking someone chosen by your community. Yes, it wasn't the perfect mechanism but it has only ever been a temporary solution until we can hold proper elections. Furthermore, Chris has been a BRILLIANT hepatitis advocate. I say that as a hepatitis patient totally committed to the cause you also say you share.

Given what you have just read, please would you each tell me why you are not prepared to wait until elections are held and why you continue to vilify someone chosen by your community who has done nothing but advance your cause?

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I'm very much looking forward to hearing from you

Charles

Charles Gore
President,
World Hepatitis Alliance
Rue du Marché 7, 4th Floor
1204 Geneva
Switzerland
Tel: +44 20 7089 6220
Mob: +44 7920 20 21 22
www.worldhepatitisalliance.org

-----Original Message-----

From: Silvia Hinojosa-Price [mailto:shprice326@yahoo.com]
Sent: 15 May 2010 02:29
To: peterfisher@verizon.net; ctaylor@nastad.org
Cc: jscofield@nastad.org; Ihanen@nastad.org; cschwartz@nastad.org; info@hepcop.org; Charles.Gore @WorldHepatitisAlliance.org
Subject: Re: World Hepatitis Day

Did you send it already?

Peter, are you feeling okay? This is a mild letter. I don't like it. It's too nice. The part about one of you finding out he's coinfecting. It sounded like like gossip. I think you should have said ..we have been informed by a reliable source that he had identified himself as coinfecting when he joined the WHA. That information is not secret so I doubt Carlos would mind

They should be afraid of Carlos. He's planning to tell all in June.

On Fri May 14th, 2010 11:19 AM PDT Peter Fisher wrote:

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>demanding your resignation. We hope you will look at some of the comments
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To: "Silvia Hinojosa-Price" <shprice326@yahoo.com>;
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<info@hepcop.org>
Sent: Wednesday, May 19, 2010 10:54 AM
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