

The **FAIR**  
Fair Allocations In Research  
FOUNDATION

www.FAIRFoundation.org

FAIR Foundation member and hepatitis C advocate, Peter Fisher, asked Dr. Darling if FAIR was going to continue as a member of the National Virus Hepatitis Roundtable. Dr. Darling emailed the Director of the NVHR and the following discussions ensued.

**From:** FAIR Foundation [mailto:fair@dc.rr.com]  
**Sent:** Tuesday, January 12, 2010 1:49 PM  
**To:** 'Martha Saly'; 'Peter Fisher'  
**Subject:** RE: NVHR mailing list

Dear Martha,

Peter asked if I wanted FAIR to continue with the NVHR. Before I can answer that question, I'd be grateful for a bit of information from you.

Does the NVHR have any intention of communicating directly with the NIH and Congress regarding the embarrassing disparity in bio-medical research funding for HCV vs. HIV/AIDS as reported by the NIH and as seen in the chart below? Not only is this disparity insulting to HCV patients, but illogical since HCV is killing more AIDS patients than the opportunistic infections that used to kill them, a fact recognized by many dozens of HIV orgs years ago. The disparity is also troubling when the NIAID director has publicly admitted that the success against HIV is "breathtaking" with patients who "..look and feel well, living gratifying lives."

I say "as reported by the NIH" above to reference the NIH's listing of HCV funding estimate of \$96 million on their reporting site because the dollar figure is actually fiction. I unearthed the details of that \$96 million and found a large percentage of that \$96 million was being spent on HIV related studies. I then joined with physicians on our Board of Directors and Ray Hill and registered a complaint with the OGE and the acting NIH director. The director informed us the startling news that not only is there no Congressional research allocation for hepatitis C, but there is no NIH budget allocation for hepatitis C either.

When I initially went to the first NVHR meetings in DC, I took the microphone to respectfully bring this disparity to the NVHR membership audience. AIDS activists hollered at me then and confronted me later with verbal abuse so strong their spit was flying on me; I received no support from the NVHR. I have assumed since that time that the presence of individuals with HIV as their primary focus within the NVHR had negated any chance of the NVHR speaking out on this disparity in funding. Hopefully, I am wrong.

Repeating my first question, do you as the Director have any plans to communicating directly with the NIH and Congress regarding the embarrassing disparity in bio-medical research funding for HCV vs. HIV/AIDS?

Thank you.

*Richard*

Dr. Richard Darling, DDS: Past National Public Citizen of the Year (NASW)  
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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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 Dis.	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 Dis.	480 Million	71,696	\$ 6,626	\$ 92
Parkinson's Dis.	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

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**From:** Martha Saly [mailto:mbsaly@nvhr.org]

**Sent:** Tuesday, January 12, 2010 2:29 PM

**To:** 'FAIR Foundation'; 'Peter Fisher'

**Subject:** RE: NVHR mailing list

Dear Richard:

Please visit the NVHR website ([www.nvhr.org](http://www.nvhr.org)) and follow the link to the Viral Hepatitis and Liver Cancer Prevention Act (HR 3974). NVHR was instrumental in developing that bill and finding congressional sponsors. The bill includes language around the need for more research, along with other issues vital to viral hepatitis prevention and control. Just last week I made hill visits to advocate for funding, both through the passage of this bill and through the appropriations process. NVHR members make hill visits very often and we recently sent out a notice of the AASLD's hill day and invited our members to join the AASLD doctors on their planned visits on the Hill.

Regarding HIV/AIDS funding, the newly published IOM report, that NVHR cosponsored, includes strong language pointing out the disparities in funding to the CDC Division of Viral Hepatitis. It points out that hepatitis gets only 2% of the overall funding to the Center for HIV, STD, Viral Hepatitis, and Tuberculosis. NVHR has and will continue to advocate for increased funding for viral hepatitis, not only at the CDC, but at NIH and HHS. NVHR will *not* advocate for funding to be reallocated from HIV, STD, TB to Viral Hepatitis. We believe that while those programs are significantly better funded than ours, we cannot advocate to take vital funding away from other disease states, but rather to advocate for parity in funding to viral hepatitis.

Since we did not have influence over the what IOM report committee considered to be important issues, we were pleased that they pointed out the need for increased research for a hepatitis C vaccine. You can download the IOM report at [www.iom.edu](http://www.iom.edu). Further, there have been numerous stories in the media over the past couple of days quoting the IOM report regarding the stark comparisons between AIDS infection rates and deaths and those caused by viral hepatitis, as you mentioned in your email. NVHR has been pointing this out for years, but it is gratifying to have the esteemed Institute of Medicine say the same. NVHR focuses on liver cancer in much of our advocacy work because it is one way to bring together our commitment to both hepatitis B and hepatitis C.

I hope this answers your questions regarding NVHR's priorities and helps you to make a decision about whether to continue your membership.

Thank you  
Martha

Martha Saly  
Director  
National Viral Hepatitis Roundtable (NVHR)  
phone: 707-480-0596  
www.nvhr.org

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**From:** FAIR Foundation [mailto:fair@dc.rr.com]  
**Sent:** Monday, January 18, 2010 2:40 PM  
**To:** 'Martha Saly'; 'Peter Fisher'  
**Subject:** RE: NVHR mailing list

**Dear Martha,**

**Thank you for your response. As a hepatitis C patient and secondly as President of FAIR Foundation which advocates for fair bio-medical research funding for all illnesses, not just HCV research, I continue to be very disappointed in the NVHR's approach to our (hepatitis C patients') plight.**

**HR3974's section on research is stated below with my comments:**

“(1) conduct epidemiologic and community based research to develop, implement, and evaluate best practices for hepatitis B and hepatitis C prevention especially in the ethnic populations with high rates of chronic hepatitis B and chronic hepatitis C and other high-risk groups; **My God, more epidemiologic and best practices research???** And for whom are we going to do this? Who gets HCV these days? IV drug users, primarily. We need to “research” this? No, provide clean syringes and continue existing educational efforts for them.

(2) conduct research on hepatitis B and hepatitis C natural history, **Natural history?? What nonsense. Who wrote this?? Some health aide working for some Senator?? Who is so ignorant by now that they don't know the history of HCV?? Pathophysiology means “The functional changes associated with or resulting from disease or injury.” Any of us with HCV can answer this question; to study it is absurd and a waste of time., improved treatments..improved treatments—excellent, the entire paragraph should be focused on this goal and why is there not a specific dollar amount requested We have zero allocation now.** and prevention (such as the hepatitis C vaccine) **hepatitis C vaccine?? For who?? IV drug users? Are we going to vaccinate the country like HIV advocates want us to do to prevent a few people from getting HCV by IV drug use, tattooing or shared razors??** , and noninvasive tests that help to predict the risk of progression to liver cirrhosis and liver cancer; **Why should we study such risk? If one has cirrhosis one may get HCC, plain and simple. Advocate for new organ-donor policies and get the cirrhotic patient transplanted before he/she develops to HCC.**

(3) conduct research that will lead to better noninvasive or blood tests to screen for liver cancer, **unnecessary, the present use of MRI's works well and that is non-invasive and more effective treatments of liver cancer – good.** caused by chronic hepatitis B and chronic hepatitis C; and

(4) conduct research comparing the effectiveness of screening, diagnostic, management, **. Been there, done that, how is it working for us who failed to clear??** and treatment approaches **yes, let's focus on treatment and better meds** for chronic hepatitis B, chronic hepatitis C, and liver cancer in the affected communities

**(5) Where are studies on HCV co-infection and HBV co-infection and I'm not referring to HCV/HIV or HBV/HIV co-infection which is minor compared to those patients with HCV and diabetes or HCV and cardiovascular disease? The effects of Peg + Riba on those HCV/diabetic patients, etc?**

**Bottom line, we all know what it is, what it does to us, who has it or will show up as having it soon due to drug use decades ago, so all this “epidemiological,” “natural history,” etc. focus is not in the best interest of those of us with HCV. You can identify and talk to millions with HCV, then what are**

**you going to do? Treat them with the existing poor meds that not only are not effective on 50% (avg.) of patients, but that cause such severe side effects that people are devastated for months and years? Martha, we need better drugs to treat HCV and if even a reasonable fraction of the resources that have been spent on HIV had been spent on HCV drug development, we'd have tolerable and much more effective meds.**

More of my notes are below within your email, Martha, for your consideration...

Dear Richard:

Please visit the NVHR website ([www.nvhr.org](http://www.nvhr.org)) and follow the link to the Viral Hepatitis and Liver Cancer Prevention Act (HR 3974). NVHR was instrumental in developing that bill and finding congressional sponsors. The bill includes language around the need for more research, along with other issues vital to viral hepatitis prevention and control. Just last week I made hill visits to advocate for funding, both through the passage of this bill and through the appropriations process. NVHR members make hill visits very often and we recently sent out a notice of the AASLD's hill day and invited our members to join the AASLD doctors on their planned visits on the Hill.

Regarding HIV/AIDS funding, the newly published IOM report, that NVHR cosponsored, includes strong language pointing out the disparities in funding to the CDC Division of Viral Hepatitis. **For the CDC and its epidemiological studies, etc. No mention in IOM of poor NIH research or that there is NO NIH or Congressional HCV allocation for research!** It points out that hepatitis gets only 2% of the overall funding to the Center for HIV, STD, Viral Hepatitis, and Tuberculosis. NVHR has and will continue to advocate for increased funding for viral hepatitis, not only at the CDC, but at NIH **Please provide copies of NVHR correspondences to the NIH Director regarding the poor NIH dollars going to HCV for bio-medical research or the fact that there is no NIH HCV budget allocation.** and HHS. NVHR will *not* advocate for funding to be reallocated from HIV, STD, TB to Viral Hepatitis. We believe that while those programs are significantly **Significantly?? \$20 versus \$2,774 per patient??** better funded than ours, we cannot advocate to take vital funding away from other disease states, but rather to advocate for parity in funding to viral hepatitis. **Parity? So you want HCV to get the same amount as HIV--10% of the NIH budget--to establish parity?? \$2.8 billion more for HCV? That will take money from other illnesses, which are also being negatively impacted by the favoritism for HIV. You can't have parity without an unrealistic expectation for HCV funding and there are no such funds available. When one disease is receiving exorbitant funding that it does not need any more, HIV, they should share with others, not hoard it and your position supports their selfish actions. In addition, what about the funding for HCV's co-morbid diseases, like HCV/diabetes or HCV/CVD, that are negatively impacted by the favoritism for HIV patients.**

Since we did not have influence over the what IOM report committee considered to be important issues, we were pleased that they pointed out the need for increased research for a hepatitis C vaccine. **Absurd, see my comments above on an HCV vaccine.** You can download the IOM report at [www.iom.edu](http://www.iom.edu). Further, there have been numerous stories in the media over the past couple of days quoting the IOM report regarding the stark comparisons between AIDS infection rates and deaths and those caused by viral hepatitis, as you mentioned in your email. NVHR has been pointing this out for years, but it is gratifying to have the esteemed Institute of Medicine say the same. **NVHR focuses on liver cancer in much of our advocacy work** because it is one way to bring together our commitment to both hepatitis B and hepatitis C. **So to placate the HBV researchers and advocates you focus on liver cancer when relatively few HBV...and HCV...patients have it compared to millions struggling with HCV? Keep in mind there are very effective, tolerable treatments for most HBV patients—we HCV patients don't have that luxury. The focus you state here is not in the best interests of the HCV patients. Although the NVHR represents all hepatitis patients, its focus should be on the patients most affected and those with the least effective and least tolerable treatment regimen. That, of course, means HCV patients.**

**In your signature below you state, "The National Viral Hepatitis Roundtable is dedicated to developing, implementing and maintaining a national strategy to eliminate viral hepatitis in the United States." How does one eliminate HCV? Not with yet more "epidemiological and history studies," but with effective and tolerable medicine and that requires more HCV bio-medical research for successful development.**

**I'm assuming that as Director of the NVHR you have hepatitis and most likely HCV. Please correct me if I'm wrong. I don't understand how anyone with HCV can support so many aspects of policy that are not dedicated to more bio-medical research to insure all of us HCV patients "clear" the virus and no longer are leading to ESLD status, throwing up blood, having foot long needles stuck in us draining**

10 liters of fluids, have encephalopathy so bad we don't know a remote control from a telephone so we have to take Lactulose that makes us excrete all day long, then frequently die due to the shortage of organs.

Which reminds me, does the NVHR have a policy on the need for new organ-donor policies because of the failure of altruism to meet the demand for organs. As you know, the major cause of liver transplant is HCV—it would seem most appropriate for you to support these much needed new policies. You can read about them and view many eminent supporters [here](#).

Thank you, in advance, for sending copies of your advocacy to the NIH as you mentioned above and for providing your policy on organ donation. This will help our Board determine if we will continue as members of the NVHR (we meet next weekend). I shared one of FAIR's many correspondences to the NIH director with you in my email and it is below, but many more over the years are available through in our newsletters [here](#).

### *Richard*

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

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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**From:** Martha Saly [mailto:mbsaly@nvhr.org]

**Sent:** Tuesday, January 19, 2010 6:48 AM

**To:** 'Peter Fisher'; 'FAIR Foundation'

**Subject:** RE: NVHR mailing list

Dear Peter and Dr. Darling:

Dr. Darling, regarding some of your points, which I agree hold some validity, there is a difference between a grassroots advocacy call to action and legislation. NVHR has been asking for an increase of 50 million dollars in appropriations every year for as long as I can remember. We are told over and over again that we are asking for too much at one time. Does this make me angry, hell yes it does. HR 3974 calls for 90 – 120 million. I have no expectation that we will get that either to be frank, but I do believe that the IOM report helps our case tremendously.

If by parity, you mean that NVHR should be demanding \$168 million, I am afraid that will not happen until thousands of hepatitis patients spill their blood on the capitol steps for all of congress to walk through. But I, and NVHR perseveres and continues to raise our voices. We see the IOM report as a good tool to further our cause. NVHR had no ability to affect the contents of the report or the issues that the esteemed body of scientists chose to address. Certainly, they could have added more to their already comprehensive report, but we are very pleased to have their weight behind our cries for more attention and more resources for viral hepatitis.

NVHR is a national organization. NVHR's policy priorities are clearly stated on our website. We are an independent body, but one that is led by an elected committee of people with the same interest that you have in eliminating hepatitis B and C in this country. NVHR will not change its way of advocating to the style that you would like, so I do agree that it is pointless for you to continue as a member of this organization. There are over 150 organizations in NVHR and I have

not received the type of emails that you have been sending me from others. In fact, I have received many correspondences thanking me and NVHR for our work and praising the IOM report.

On a personal note, do not presume to tell me to whom I must answer based on my hepatitis C status. I answer to myself. I have worked hard to help people with hepatitis C for ten years. I will continue to advocate, in my own way and without being bullied, for people in America who are affected by hepatitis B and hepatitis C. To say I ( or the organization that I head) am greedy is patently false. I, and the people who give freely their time to NVHR, do our work for the love of our communities.

Sincerely,  
Martha Saly

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**From:** FAIR Foundation [mailto:fair@dc.rr.com]  
**Sent:** Friday, January 22, 2010 11:42 AM  
**To:** 'Martha Saly'  
**Cc:** 'Peter Fisher'  
**Subject:** RE: NVHR mailing list

**I'm perplexed by your comments, Martha, many of which don't reflect what I wrote. Your tone dismays me; I would expect more respect be given from an HCV org. to one who has seen the depths of HCV suffering, both personally and in close to 2,000 hours of working in the liver transplant ICU here. Please note my responses below.**

Dear Peter and Dr. Darling:

Peter, I apologize for not responding sooner. Occasionally I indulge myself in a weekend off.

Dr. Darling, regarding some of your points, which I agree hold some validity, there is a difference between a grassroots advocacy call to action and legislation. NVHR has been asking for an increase of 50 million dollars in appropriations every year for as long as I can remember. We are told over and over again that we are asking for too much at one time. Does this make me angry, hell yes it does. **Your anger pleases me. If I were in such a position, I'd ask for \$500 million to \$1billion and let them respond to that, all the while expressing your deserved anger at any attempts to lessen the amount. It's the old "ask for a lot more than you think you can get, then compromise." Fauci is getting almost \$3 billion for HIV every year at the NIH, yet he went before Congress with the past CDC director and asked for \$5 billion more. The audacity one might say, but they know that if they ask for the moon, they'll get a lot more than if they ask for \$50 million.** HR 3974 calls for 90 – 120 million. I have no expectation that we will get that either to be frank, but I do believe that the IOM report helps our case tremendously. **I agree it helps in getting more money at the CDC, but no mention of funds for the NIH for research is a serious flaw.**

If by parity, you mean **It was your email that expressed a desire for parity. HIV gets \$2.9 billion for NIH allocations. Parity would then call for HCV to get \$2.9 billion and that, of course, is not realistic. Parity is not the solution or doable, HIV sharing their largess with other illnesses is needed.** that NVHR should be demanding \$168 million, I am afraid that will not happen until thousands of hepatitis patients spill their blood on the capitol steps for all of congress to walk through. But I, and NVHR perseveres and continues to raise our voices. We see the IOM report as a good tool to further our cause. NVHR had no ability to affect the contents of the report or the issues that the esteemed body of scientists chose to address. Certainly, they could have added more to their already comprehensive report, but we are very pleased to have their weight behind our cries for more attention and more resources for viral hepatitis.

NVHR is a national organization. NVHR's policy priorities are clearly stated on our website. We are an independent body, but one that is led by an elected committee of people with the same interest **As long as your officers and directors bristle at the thought of taking some of the excessive funding for HIV and allocating it to other diseases (including HCV) that have not had the same success that Dr. Fauci**

**speaks of (here) in his team's development of HIV meds, your interest is not at all the same as those of the suffering mono-infected HCV patient. The NVHR has an H in it for HCV, not HIV. Your organization is more concerned with not ruffling the feathers of HIV/AIDS members that it is in fighting for more NIH research funds for the MONO-infected HCV patient. that you have in eliminating hepatitis B and C in this country. NVHR will not change its way of advocating to the style that you would like, so I do agree that it is pointless for you to continue as a member of this organization. I didn't say FAIR was not continuing as a member. Every organization needs opposing opinions from its members or how is knowledge advanced with debate? If everyone agrees all the time, progress toward new approaches and solutions are stymied. There are over 150 organizations in NVHR and I have not received the type of emails that you have been sending me from others. What are you talking about? I don't even ever remember communicating with you before and I never sent you anything from anyone else. In fact, I have received many correspondences thanking me and NVHR for our work and praising the IOM report. And precious few are living with ESLD and know the real battles with HCV that severely ill patients experience. No one who has gone through the hell of ESLD would congratulate the NVHR at its impotent stance regarding the HIV-HCV disparity in funding, both at the NIH and the CDC.**

On a personal note, do not presume to tell me to whom I must answer based on my hepatitis C status. I answer to myself. **The NVHR director stating she answers to herself without including HCV patients is shocking. As Director of the National Virus Hepatitis Roundtable you answer to every one of us with HCV and although HIV/HCV co-infection and HBV are proper issues, the mono-infected patient should be your main focus because we are the main constituency representing this disease in the world.** I have worked hard to help people with hepatitis C for ten years. I will continue to advocate, in my own way and without being bullied, **I cannot express opinions and fact without such an inappropriate accusation of "bullying"??** for people in America who are affected by hepatitis B and hepatitis C. To say I ( or the organization that I head) am greedy **to my knowledge, neither Peter nor I used the word "greedy."** **When I spoke of those who hoard their funds I used the term "selfish" and I identified that I was referring to HIV, not the NVHR. Personally, I do think those representing HIV patients in the CDC, NIH and throughout America are greedy in not sharing their wealth now that they have had such great success that has not been attained by many other illnesses.** is patently false. I, and the people who give freely their time to NVHR, do our work for the love of our communities.

**You did not send copies of your communication with the NIH directors or your policy on organ donation so I can assume they don't exist. You did not identify your HCV status—we'd like to know someone representing us has experienced the hell of Peg + Riba and/or ESLD so they have some intimate understanding of the real suffering of HCV patients. Your not sharing that speaks volumes and partially explains the NVHR failure to achieve proper funding for HCV bio-medical research. Speaking of research...let us look at your Jan 11 Press Release entitled "NVHR: Landmark IOM Report on Chronic Viral Hepatitis & Liver Cancer Finds Inadequate Federal Funding Thwarting Education, Surveillance Efforts." In it Lorren states, "On behalf of more than 5 million Americans afflicted with chronic viral hepatitis B and C, NVHR applauds the Institute of Medicine for its comprehensive examination of the complex public-health issues related to education, surveillance, immunization, and treatment of chronic viral hepatitis." Where is "the lack of bio-medical research and NIH funding" in Lorren's sentence with a criticism of the IOM and corresponding statement of the need for these urgently needed dollars?**

**As I indicated above, I did not express a desire to have FAIR leave the NVHR and it is our organization's desire to remain as a member. I join with our Board's liver transplant surgeons, medical directors and other patients advocates in expressing our hope that you will consider reprioritizing the NVHR's efforts to insure that your main focus is on gaining more HCV bio-medical research funding from Congress and the NIH for the mono-infected HCV patient.**

**Richard**

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**From:** Martha Saly [mailto:mbsaly@nvhr.org]  
**Sent:** Friday, January 22, 2010 12:03 PM  
**To:** 'FAIR Foundation'

**Cc:** 'Peter Fisher'

**Subject:** RE: NVHR mailing list

Dear Dr. Darling;

You are a welcome member in NVHR. You are welcome to voice your opinion as to NVHR's mission, but at this time NVHR does not advocate for taking money from any other disease state to fund viral hepatitis. There are numerous other diseases that receive vastly greater sums than viral hepatitis. It is a terrible shame and one that I am dedicated to fixing, but not at the expense of people suffering from other diseases.

Regarding my personal statement, I was not representing NVHR in that statement. And in my statement that I answer to myself, my intention was that I answer to myself in terms of what I do to honor my dedication to people with viral hepatitis, to whom I answer every day in what I do. I sincerely believe that my work helps people, both in my role with NVHR and in the numerous other ways that I dedicate myself to those with HCV.

Regarding the tone, I do apologize to you, as you are perfectly correct, you have not been rude to me, nor have we ever communicated. I have however had some heated correspondences from Peter, and it was to him that my comments were directed, whether appropriate or not, they were not meant for you.

The word greed is Peter's and he used it in the email below the correspondence from me to you both.

I am finished with this conversation. Please continue to advocate for the causes that we both believe in; there is room for all opinions and actions and I will continue to operate NVHR according to the work plan outlined by the elected steering committee.

Thank you

Martha