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10/19/08

Julie Louise Gerberding, M.D., M.P.H, *Director*  
Centers for Disease Control and Prevention  
1600 Clifton Road, Atlanta, GA 30333

Cc: Lorenzo Rossaro, MD, Donald Hillebrand, MD, Susan Olender, MD and Pam Langford,  
Founder (HEALS of No. Georgia HCV Support Group)

RE: CDC web site error possibly contributory in UNOS waiting list deaths

Dear Dr. Gerberding,

On your web site under "FAQ's for the Public" at  
<http://www.cdc.gov/hepatitis/C/cFAQ.htm#cFAQ31> the CDC asks and answers the following  
question:

Question: [Can I donate blood, organs, or semen if I have hepatitis C?](#)

Answer: [No, if you ever tested positive for the hepatitis C virus \(or hepatitis B virus\), experts recommend never donating blood, organs, or semen because this can spread the infection to the recipient.](#)

This answer is partially true and partially false, and the recommendation against HCV patients donating may have already contributed to deaths on the UNOS waiting list by preventing a potential organ donor and/or his family from allowing use of the hepatitis infected cadaveric organs or tissues for transplant.

I enclose the following:

- A segment of an article by one of the members of our Board of Directors, Lorenzo Rossaro, MD, FACP; Director, Liver Transplant program and Professor and Chief, Division of Gastroenterology and Hepatology, University of California, Davis Medical Center. On page two Dr. Rossaro clarifies that transplant programs are accepting HCV infected organs for transplant.
- An article from About.com by Susan Olender, MD, instructor of clinical medicine at Columbia University College of Physicians and Surgeons in New York City where she also is on staff in the Division of Infectious Disease, specializing in HIV primary care. In her article she clarifies that not only organs from "hepatitis" patients can be utilized in transplant, but also tissues.

- A response to my question on this issue from UNOS's research specialist, Denise Tripp. She states there is no rule that forbids cadaveric donations by HCV patients. In my question to her, I should have generalized and said "hepatitis" but it is reasonable to believe that there is no rule that applies to HAV or HBV either.

The use of HCV infected organs is not new. In 2001, when I was dying from HCV related cirrhosis, my hepatologist, Donald Hillebrand, MD, Medical Director of Liver Transplant at LLUMC (now in same position at Scripps Green Transplant Center in La Jolla, CA and also a member of FAIR's Board of Directors) came to me in the ICU and said, "Dr. Darling, if we get a liver that is in good condition but from a person with HCV will you accept it?" Since I was close to death the answer was prompt: "Yes!" In such instances the patient must sign a form that gives consent and acknowledges that an organ infected with HCV may be used in the transplant and I did that.

The issue of "semen donation" is clearly "No" for HBV patients but more controversial for HCV patients. In my work with HCV patients for many years, there have been many who have been married for decades without transmission to a spouse. I believe when sexual transmission occurs between married partners it is because conditions (e.g. ulcers, tissue tears, etc.) are present that allow blood-to-blood transmission and the semen is not contributory. However, opinions are not substantive and you may prefer to continue your cautious stance and urge against the donation of semen from an HCV infected individual.

Therefore, I suggest replacing the one paragraph with a few and I offer some examples for your consideration:

[Can I donate blood if I have, or have had, a hepatitis virus?](#)

[No, if you ever tested positive for a hepatitis virus, experts recommend against donating blood.](#)

[Can I donate organs or tissues if I have, or have had, a hepatitis virus?](#)

[Yes, healthy organs and tissues infected with hepatitis viruses can be used for transplant with proper notification and acknowledgment by the patient.](#)

[Can I donate semen if I have a hepatitis virus?](#)

[The CDC recommends against the donation of semen by patients infected with a hepatitis virus.](#)

In appreciation of your responses to letters from me and our Board of Directors, please accept a separately mailed copy of my book, *Coma Life*. I hope you enjoy it and after you have read it, that you share it with someone who has ESLD. Indeed, it has given hope to thousands of such hepatic patients throughout the USA and they have given it the mantra, "My God, if Dr. Darling made it through three transplants, I (or my son, daughter, mom, etc.) can make through one."

With great respect for your efforts, I am,

*Richard Darling, DDS*

Richard Darling, DDS, Past National Public Citizen of the Year

President & CEO, FAIR Foundation

Founder: The FAIR Foundation Liver Disease & Transplant Support Group

Author: Coma Life

[http://www.hcvadvocate.org:80/hcsp/articles/Multiple\\_listing.html](http://www.hcvadvocate.org:80/hcsp/articles/Multiple_listing.html)

## Increasing the Chance of Receiving Liver Transplantation by Multiple Listing

**Lorenzo Rossaro, M.D., F.A.C.P. Professor of Medicine  
and Connie Wylie, R.N., M.S.N., F.N.P**

**Hepatology and Liver Transplant University of California Davis Medical Center  
Sacramento, California**

[PDF \(download\)](#)

### SUMMARY

- **Multiple listing (registering at two or more transplant centers) increases the chance of receiving liver transplant since candidates at centers local to the donor hospital are usually considered ahead of those who are more distant.**
- **Multiple listing can also shorten the average waiting time of liver transplant candidates by several months, although it does not guarantee that every multiple-listed patient will have a shorter waiting time.**
- **Other waiting time factors include how urgently the patient needs a transplant (i.e., MELD score) and how closely the donor and candidate match on body size and blood type.**
- **There is a shortage of donors nationwide with about 20,000 patients waiting for liver transplant, and only about 5,000 donors per year. Everyone should share the goal of increasing organ donation to save more lives.**

### Organ Allocation and Liver Transplantation (LT)

When organs become available, the United Network for Organ Sharing (UNOS), the agency under contract with the federal government to oversee all organ recovery and transplant activities in the United States, will run a match list based on a point system to identify recipients. **The point system, called MELD (Model for End-Stage Liver Disease) score, is the numerical scale used for liver allocation, ranging from 6 (less sick) to 40 (very sick) (Figure 1).**

**Figure 1: MELD score. It predicts mortality in End-stage Liver Disease: 10-12 is when patients should be evaluated for liver transplant, 15 is generally required in order to be considered to receive a transplant.**

**Patients waiting for an LT are ranked in order of their disease severity. The sickest patients are the highest on the list.**

The median MELD score for when transplants occur varies in different regions of the country, due to a variety of factors. The national average MELD score is 22, the same as in Sacramento in 2007, while the San Francisco Bay area's median MELD score is 29 or greater (**Figure 2**).

**Figure 2: MELD score at time of Liver Transplant in California. In Sacramento (Sac) and in San Diego (SD) the MELD score at the time of Liver Transplant is lower than in the larger cities of San Francisco (SF) and Los Angeles (LA). This usually translates to shorter waiting times for patients listed in the former center.**

**In accordance with UNOS policies (OPTN 3.2.3) transplant centers are required to provide patients listed for LT with written information about multiple listing. They should also keep a form, signed by the patient, on their files that document compliance with this policy. Listed patients who did not receive the "Questions and Answers for Transplant Candidates about Multiple Listing and Waiting Time Transfer" should contact their transplant center immediately.**

### **Hepatitis C, liver cirrhosis and transplantation**

Complications of Chronic hepatitis C virus (HCV) are the most common indication for LT, accounting for more than 40% of transplants performed in the United States. Most patients with HCV do not require LT, and many even with liver cirrhosis may have a nearly normal life span and quality of life. It is when the liver fails, in advanced stages of cirrhosis, or when liver cancer occurs, that LT becomes the only option for long term survival. At that point, patients are referred by their physicians to a transplant center. Dual listing or multiple listing may increase patients' chances of receiving an LT by registering at two or more transplant centers in different areas. It can shorten the wait time of LT candidates by several months, can decrease the suffering, or even save lives, given the shortage of organ donors. Many centers offer their patients with HCV the possibility of receiving organs which are infected with HCV (expanded donor pool), as long as the liver graft does not have significant damage or scarring and the patient accepts by signing an informed consent.



**Richard Darling, DDS**

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**From:** PeachStatePam [figment@nettally.com]  
**Sent:** Wednesday, September 17, 2008 11:33 PM  
**To:** figment@nettally.com  
**Subject:** Can I be an organ donor, even if I have hepatitis?

**Can I be an organ donor, even if I have hepatitis?**

By [Charles Daniel](#), About.com

Updated: August 21, 2008

About.com Health's Disease and Condition content is reviewed by [Susan Olender, MD](#)

**Question:** Can I be an organ donor, even if I have hepatitis?

**Answer:** Yes, you can! Some people think that having hepatitis means that they can't be an organ donor. This is a myth. People can still be an organ donor and have acute or even chronic hepatitis.

Organ donation is a tremendous act of kindness, and there is a great need for organ donors of all ages. In fact, there is no age limit. Even if your liver isn't in good enough shape for donation, perhaps other organs and tissues could be used by someone else.

Here are examples of organs, in addition to the liver, that can be used: heart, intestines, kidneys, lungs and pancreas. In addition, certain tissues can also be used: bones, corneas, sclerae, tendons and certain veins.

There are, however, diseases that will prevent organ donation. Examples of two relatively common diseases include being HIV positive and having actively spreading cancer.

Sources:

Donate Life America. Retrieved August 18, 2008. Understanding Donation. [http://hepatitis.about.com/gi/dynamic/offsite.htm?zi=1/XJ&sdn=hepatitis&cdn=health&tm=71&gps=238\\_486\\_788\\_462&f=21&tt=12&bt=1&bts=1&zu=http%3A/www.donatelife.net/UnderstandingDonation/](http://hepatitis.about.com/gi/dynamic/offsite.htm?zi=1/XJ&sdn=hepatitis&cdn=health&tm=71&gps=238_486_788_462&f=21&tt=12&bt=1&bts=1&zu=http%3A/www.donatelife.net/UnderstandingDonation/)

<http://hepatitis.about.com/od/questions/f/OrganDonor.htm>

No virus found in this incoming message.

Checked by AVG - <http://www.avg.com>

Version: 8.0.169 / Virus Database: 270.6.21/1677 - Release Date: 9/17/2008 5:07 PM

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

From: Datarequest [mailto:datarequest@unos.org] Denise Tripp, UNOS Research  
Sent: Tuesday, September 09, 2008 7:18 AM  
To: fair@dc.rr.com  
Subject: RE: Request Data

Dear Dr. Darling,

There is no rule that forbids it; therefore it is up to the centers.

Let me know if you need anything else.

Best,  
Denise Tripp  
UNOS/Research

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

From: fair@dc.rr.com [mailto:fair@dc.rr.com]  
Sent: Sunday, September 07, 2008 1:42 PM  
To: Datarequest  
Subject: Request Data

REQUEST DATA MESSAGE FROM UNOS WEB SITE

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FIRST NAME: Dr. Richard  
LAST NAME: Darling  
ORGANIZATION: FAIR Foundation  
ADDRESS: 78629 Bougainvillea Drive  
ADDRESS TYPE: 501c3  
CITY: Palm Desert  
STATE: CA  
ZIP CODE: 92211  
COUNTRY: USA  
PHONE: 760 200-2766  
EMAIL: fair@dc.rr.com  
PROFESSION: Other  
Title: Dr  
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DATA REQUEST:

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Transplants: Selected  
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Description: Please provide a link to, or a pdf of, the specific section in your rules governing transplant teams that allows cadaveric donations from hepatitis C patients to be used for transplant. It would be helpful if the bylaw provided could specify what organs and/or tissues can be used for transplant when coming from a hepatitis C patient. Thank you.  
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