



December 1996

SOME OBJECT TO RULE CHANGE ON WHO GETS SCARCE LIVERS

NEW YORK TIMES November 18, 1996 The decision to move people with chronic liver disease out of the most urgent category on the waiting list for transplants has alarmed patients and angered some doctors, highlighting longstanding disagreements in the field about the fairest way to dole out the nation's insufficient supply of donated livers.

The change of policy was announced Thursday by the United Network for Organ Sharing, a private nonprofit corporation in Richmond, Va., that has a contract with the federal government to control the distribution of donor organs.

Starting Jan. 20, patients on the waiting list who have chronic liver disease can never qualify for the category known as Status 1, the group that gets top priority for the next available organs because the patients in it are expected to die within a week or two.

Status 1 will include people with acute liver disease. Chronic diseases include hepatitis B and C, tumors and cirrhosis, which can be caused by alcoholism but also by other conditions unrelated to drinking.

Under the new system, patients with chronic disorders will still be eligible for transplants, but they may have to wait longer. They will not be moved to Status 1 even if death becomes imminent.

Status 1 will be reserved for patients facing death from sudden liver failure -- an acute condition caused by poisonous mushrooms, for instance, other toxins or certain severe infections. The group will also include people whose first liver transplants failed within a week of the surgery, as well as children in danger of brain damage as a consequence of liver failure. Many patients with chronic disease and their families are upset about the new rules, said Walter Graham, executive director of the organ network, but 95 percent of all liver transplants will still go to patients with chronic liver disease. Those patients will be in Status 2 or 3 groups, depending on whether they need to be hospitalized.

Doctors have been divided in their reaction to the new rules, with those at smaller transplant centers generally in favor and some doctors at larger urban centers opposed. The current debate has led to so much unrest that Health and Human Services Secretary Donna Shalala has scheduled public hearings on the issue next month and may usurp the network's authority to control the allocation of livers.

When the new rules were announced Thursday, some network members said the main reason for the change was to give top priority to the transplant patients with the best chance of surviving. But Graham gave a different explanation on Friday. He said the main reason

was that people with acute liver failure had the greatest need.

"These patients as a category are the sickest and have the most urgent need because they die very quickly, within hours or days," he said. "They need transplants right away."

The question of which patients were most likely to survive was a secondary consideration, Graham said. Although the network does not keep statistics comparing acute cases with chronic cases, he said, surgeons report that acutely ill patients who get livers quickly have better survival rates than the chronically ill. People with chronic conditions have been ill for a longer time and may have other health problems besides liver failure. Although the chronic category includes alcoholics, Graham said, the change in status is based on medical criteria, not moral judgments, and is not an effort to deny transplants to alcoholics.

On Friday, officials at the United Network for Organ Sharing were startled to get calls from about 100 patients, family members and advocacy groups, Graham said.

"There are a lot of patients who are extremely upset about what they've heard, and it's inaccurate and giving them the wrong impression," he said.

"What is being portrayed is that patients have been moved down on the list and feel they'll never move up to a place where they'll get a transplant. That's not true. A small group moved up to a higher category, as opposed to moving some people down. We didn't put people into a category where they'd never get a transplant."

In 1995, of 7,279 patients on waiting lists, 3,922 received livers, 552 died waiting, and the rest stayed on the list. Under the current system, people with acute liver failure receive 3.3 percent of all transplants. Under the new system, that figure is expected to rise to 4.4 percent.

Graham said the new policy would reduce the need for repeat transplants because people with acute liver failure were less likely to need a second donated liver. That is expected to free up about 200 livers for other patients in the next three years, he said. Among the most vocal critics of the new system are surgeons at some of the nation's largest transplant centers. Dr. Charles Miller, director of the organ transplant program at the Mount Sinai Medical Center in New York City, said that chronic patients sometimes "crash," or take a sudden turn for the worse, and need to enter Status 1. In a busy region like New York, he said, Status 2 requires too long a wait. "Essentially," he said, "we're going to watch them die." Miller said that some chronically ill patients who suddenly became very sick nonetheless had decent prospects for surviving a transplant. "I think it hasn't been demonstrated that acute patients do better than chronic," he said. "It depends on who and where you are. Only a physician can decide."

Dr. John Fung, a transplant surgeon at the University of Pittsburgh, said the new system "stacked the cards" against chronically ill patients. "I predict those patients will have an alarmingly high rate of dying on the waiting list," he said.

But the president of the United Network for Organ Sharing, Dr. James Burdick, a transplant surgeon at the Johns Hopkins Medical Center in Baltimore, said the new system would not keep severely ill patients with chronic disease from getting livers.

But he added, "It's a little less likely than it would have been before." If the new system turned out to work against such patients with reasonable odds for survival who needed to be Status 1, Burdick said, the rules might be adjusted.

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FROM THE INTERNET:

HCV-ACTIVIST

There is a newsgroup on the Internet to organize hepatitis C activism. Here is a quote from their webpage:

"In May 1996, HCV-Activist was established with a simple goal: To increase awareness in the media, and in government, about Hepatitis C, and the people who have it. People from all walks of life, and from several different countries, have since joined HCV-Activist. Most members either have HCV, or a loved one who does. Using the Internet, the fax, the phone, or postal service, we plan to reach out to those who can influence awareness levels (ie: the media), and those who control funding for research. Those of us with HCV *must* raise issues such as funding and drug research. Estimates are that over 3.5 million Americans and up to 400 million worldwide, have HCV, yet American government spending on HCV related research is a paltry \$4.5 million. Conversely, AIDS, with an estimated 300,000 people infected in the United States, receives over \$1.65 BILLION in government research dollars!

With a fatality rate of about 25% compared to 100% with AIDS, over 250% more people will die from HCV than AIDS, yet AIDS is an 'epidemic'. The only way to obtain comprehensive recognition for HCV, is if we join together to get that recognition.

We urge you to join us...To join the list, you must send a request to our server, "mailto:majordomo@statsrus.com"

In your message, simply type: subscribe hcv-activist

As organization is the key to an impactful and successful effort, when actions are assembled, the members of HCV-Activist will then be notified and asked to participate. It will be your choice as to whether or not you participate.

We will be conducting awareness campaigns targeted towards members of Congress, the NIH, the CDC, major new shows, the Canadian Parliament, and others. You will periodically be asked to send an e-mail, fax, letter, or perhaps place a call, to whomever will be lucky enough to be our "Target of The Week".

If you have general comments or questions about HCV-Activist, please contact Terry Bass, at: mailto:vikings777@aol.com or fax to (702) 853-2715

FAVORABLE EFFECT OF NEW ARTIFICIAL LIVER SUPPORT ON SURVIVAL OF PATIENTS WITH FULMINANT HEPATIC-FAILURE Abstract:

"The two most serious symptoms of fulminant hepatic failure are bleeding and hepatic coma. To overcome these problems, we developed an artificial liver support system comprising a combination of plasma exchange and hemodiafiltration using a high performance membrane. We treated 67 patients with fulminant hepatic failure. Of these, 65 patients (97.0%) regained normal consciousness, and 55 patients (80.9%) were kept alert as long as we continued to apply this system. All 7 patients (100%) with fulminant hepatitis caused by hepatitis A virus infection and 9 of 12 patients (75%) with fulminant hepatitis caused by acute hepatitis B (HB) virus infection survived. In addition, 7 of 15 HB virus carriers (46.7%) who developed fulminant hepatitis and 11 of 29 patients (37.9%) with fulminant hepatitis caused by non-A, non-B hepatitis viruses survived. The overall survival rate was 37 of 67 patients (55.2%).

Our artificial liver support system allows as high a survival rate as liver transplantation."

Author: YOSHIBA M, SHOWA UNIV, FUJIGAOKA HOSP, DIV GASTROENTEROL, AOBA KU, 1-30 FUJIGAOKA YOKOHAMA, KANAGAWA 227

Source: ARTIFICIAL ORGANS 1996 NOV;20(11):1169-1172

MEMBERSHIP DESK

The A.G.M. is now behind us. A great deal of progress was made particularly in deciding where and how the HeCSC should place its priorities. We still need you to consider becoming members as this gives us much more clout. Why not complete the Application Form today and mail it to the Toronto Address?

Reminder:- Any change of address, phone number, (area codes have been changed where necessary), or Postal Code please let me know at your earliest. Thanks.

Jim Lodge 386-8227

Co-chairperson.

Membership Chair.

DECEMBER SPEAKER by J.P.

Phyllis Kjellander, our December speaker, has a M.A. in Counseling Psychology and has done extensive research on the effects of meditation and visualization on the physical body.

She has recently traveled in Europe (Venice). She is quite busy and active here in Victoria with her practise, and she is involved in teaching additional seminars. She ran a weekend communication workshop at the Laurel Point early in November for federal employees. Her workplace office is in Oak Bay.

MEET A RESEARCHER

From: BornSthrn 7 Nov 1996

"I received the following response to an e-mail I sent to Dr. Fausto at U. of WA regarding a new research project he is heading that will be funded the National Institute of Allergies and Infectious Diseases:

'Sorry to disappoint you but our research project on Hepatitis C does not have a human therapy arm. The reason for that is that at the moment there are no special drugs available for the disease. Our research involves the development of a technique for gene therapy against hepatitis C virus in which we plan test what is called a "ribozyme" against the virus. These are nucleic acid molecules that might have the capacity to destroy the virus. Unfortunately the work is at its very start and there is a good many years of work before we can apply what we learn to human beings. The rest of the project deals with methods to study the replication of the virus in liver cells maintained in tissue culture as well as in mice. We are doing these type of studies because the major reason for the lack of effective drugs for HCV is that so far it has not been possible to grow the virus under laboratory conditions and study what it needs to replicate and to damage liver cells.

I recognize your frustration with the present state of affairs. My older brother is also a chronic carrier with very mild liver disease. After two courses of interferon. the recommendation is to stay away from alcohol and fatty foods and to periodically check liver enzyme levels. I hope that in his case as well as yours, the disease will not progress and you will be able to continue to enjoy a normal life.' "

STRUCTURE OF SCH-68631 - A NEW HEPATITIS C VIRUS PROTEINASE INHIBITOR FROM STREPTOMYCES SP ABSTRACT:

"A novel hepatitis C virus (HCV) proteinase inhibitor, Sch 68631 (1), was isolated from the fermentation culture broth of Streptomyces sp.

The structure of 1 was elucidated by analyses of spectro-scopic data and shown to be a new member of the phenanthrene-quinone family of compounds."

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NEXT MEETING:

Wednesday, December 18, 1996 1 - 3 PM, and again at 7-9 PM St. John the Divine Church Lounge 1611 Quadra St. (Entrance through the rear, marked Annex)
Our guest speaker will be Phyllis Kjellander. Note: Please see article in this issue of hepc.bull.

The deadline for any contributions to next issue of hepc.bull is December 23rd. Please contact Joan Diemecke at Tel. 479-5290.

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NOTE:

HeCSS cannot endorse any physician, product or treatment. The guests invited to our group to speak, do so to add to our information only. What they say should not necessarily be considered medical advice, unless they are medical doctors. The information you receive may help you make an informed decision. Please consult with your health practitioner before considering any therapy or therapy protocol.

RECIPE CORNER: SANTA'S SURPRISE XMAS DRINK

1 cup milk
1/2 banana
1 egg substitute (beware of raw eggs)
1/4 tsp. vanilla
1 tbsp. nuts or coconut (beware of peanuts)
nutmeg, wheat germ oil, honey, ice.

Blend and enjoy!

DAVE'S COLUMN
by David Smith

The AGM that took place on Nov. 8-9 was a success, considering it was the first time we had attempted to hold it away from Toronto.

It was a chance for people from all over Canada to mix and mingle, learn some new facts about Hep C, and gain some new ideas about how to spread the news about Hep C. Many thanks to Steven Kleinmann for his insightful and educational talk at lunch on

Friday, and also to David Lang and his wife Alice from the Hepatitis Educational Project (HEP) in Seattle. It is advantageous to have an international connection. Our networking can only improve from these joint efforts. David has had a liver transplant and he spoke about his personal travails as well as about the Project (HEP) at lunch on Saturday.

Most importantly, though, through our workshops that were held both afternoons, we identified what were our most pressing problems as a national organization and how to solve those problems. Perhaps our most persistent problem that everybody seemed to bring forth was the issue of fundraising. More on that later.

Other issues that we identified were the need for an executive director who can be paid for raising money on a national level and raise our profile in the country, membership, chapter development and lobbying, and most importantly, delivering support and education to our members.

Membership and chapter development will come on its own, as we become more solvent, locally and nationally.

Lobbying is an art form. I had it explained to me at length in one of our workshops by Alan Powell, who has been lobbying before the Krever Commission for the past two years and continues to lobby whenever the Krever Inquiry convenes. In essence, being a lobbyist means knowing your politicians: knowing their strengths, their weaknesses, what they stand for, what they believe in, what they don't believe in, their habits, how big or how narrow their margin of victory is, and writing to them and arranging to meet them in their offices. This was just a portion of what was discussed at our workshops, and of course these issues were fleshed out to include broader aspects of the topics discussed.

It was concluded, though, that our most pressing problem was that of supporting and educating our members, the public, and the medical community, as well as fundraising. Locally, that means grass roots fundraising, as well as going cap in hand to governments and agencies. If anybody has any ideas on fundraising, please call us. We would like to include everybody in this venture. With money, we can open up an office and centralize our communication. Our library would be more accessible because one could come down to the office and find the information one needs and photocopy it and take it away for one's own file. With an office, we could connect both as a group and on an individual basis more easily and more often. Volunteers could spend 2 or 3 hours of their time in the office to ensure that members' needs were met. It would also take pressure off working out of our homes. Dialogue and communications would also be improved. Now all this takes money. How are we going to raise funds for an office? We have an \$8000 grant coming in January from the Provincial Employees' Union Fund, but it is my understanding that none of this can be used for office rent, as it is specifically earmarked for education programs. I think it would be easier to initiate and develop these programs from a central location, where people can work together to launch them.

How about a ribbon day - a day or two specifically targeted to sell ribbons? How about a National Hep C week? These are big initiatives, requiring lots of organization and volunteerism. How about a benefit dance or walk-a-thon? Or a bottle-drive, with help from the Boy Scouts or some of the service clubs? Any more ideas? Let's see what we can do, then.

Aside from the workshops, we did a lot of schmoozing. The food was good, and perhaps the nicest element of our two days was the 4-piece classical quartet, of which Joan Diemecke is a member, which played at dinner on Saturday evening. All right, Joan! After dinner, the few remaining die-hards enjoyed a couple of hours of music and dancing, and it was great to see Jeremy Beaty, chairman, and Alan Powell, founder, getting up

to boogie and foxtrot, although let me add -- not together!

Apart from this, we took care of some business as well. Electing a new National Board of Directors, of which Leslie Gibbenhuck from Penticton, Herb Moeller from Richmond, and yours truly, are the BC representatives.

In closing, I would like to say that next year we hope to change the name of the event so more of you will feel part of the process. I know -- AGM sounds business-like, and perhaps a little antiseptic, but despite that, it was meant to be all-inclusive. How about "Hepstock Victoria 97. Ha ha! Just kidding.