



October 1996

NO COMPENSATION FOR CANADIANS INFECTED WITH HEPATITIS C, SAY MINISTERS

September 10, 1996 TORONTO (CP) -- Federal and provincial governments have flatly rejected a plan to compensate thousands of Canadians infected with hepatitis C through tainted blood.

"As a matter of policy, across all governments in Canada, we do not provide special assistance for medical mishaps," Ontario Health Minister Jim Wilson said Tuesday, the second day of a national health ministers' annual meeting.

More than 12,000 Canadians were infected with hepatitis C, a virus that can kill by attacking the liver, from bad blood in the 1980s -- 10 times the number who contracted the AIDS virus from contaminated blood.

Some victims of tainted blood got good news Tuesday, as the ministers agreed to extend the deadline of a provincial assistance package for those who contracted the AIDS virus through the blood supply.

Advocacy groups for hepatitis C victims, who have fought a bitter battle for compensation, said the ministers' announcement comes as a "tragic blow" as Canada struggles to resolve problems with its blood system.

"We are extremely disappointed and extremely concerned that the blood system will be turning its back on people who have been injured in the past," said Durhane Wong-Rieger, president of the Canadian Hemophilia Society, which has hundreds of members infected with hepatitis C.

The Red Cross is facing several lawsuits from people infected with hepatitis C. A class action suit has been launched in Quebec by a hepatitis C victim and two others are expected shortly in British Columbia and Ontario.

The Red Cross urged Federal Health Minister David Dingwall to discuss compensation when he sat down with his provincial counterparts this week.

The agency has warned claims from victims could cost a fortune -- as much as \$230 million, Red Cross president Janet Davidson wrote to a Manitoba deputy health minister in August.

But Wilson said governments weren't ready to cut deals with victims of hepatitis C by offering the kinds of compensation it did to those with HIV.

"Many people that suffer with hepatitis C, I know they have a difficult time, but we have pretty good treatments now to deal with that disease and also all the treatments and drugs are covered for people suffering with that disease," he said.

"People are free and there's no way ministers would ever interfere with their right to seek redress through our justice system and in the courts."

Meanwhile, the deadline extension for compensation claims is being offered to those infected with HIV by the blood system.

About 43 people in Canada would qualify and about 50 estates, but it won't be extended to victims' spouses and children, said Wilson.

Under the package, every province except Nova Scotia offered victims \$30,000 a year for life. Nova Scotia had more extensive deal which included compensation to spouses and children.

The original deadline for the assistance package expired March 15, 1994.

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.

IF YOU ARE TRACING YOUR MEDICAL RECORDS.....

Don't be discouraged if you are first told that your medical records have been destroyed. Since my April 96 diagnosis with Hep C it has unfortunately become increasingly important for me to become an advocate for my own health care. I had been transfused with two units of blood following the birth of my son in 1984. Now twelve years later, finding myself unable to work to the capacity that I knew I had once been capable of, and experiencing many troubling health symptoms, questions arose about the transfusion that I had received. Did my blood transfusion represent more than one donor? Was this a blood product that came from Canada or elsewhere? With a blood borne infection like Hep C was there any research in place that tracked donor/recipient variables in this illness?

I needed to know for my own peace of mind that my doctor and the Red Cross were concerned and responsive to this information. After all, on the day of my diagnosis, my name had been forwarded to the Capital Regional District Health Office where I, along with others who have received this unwanted life challenge, comprise the sad growing list of names that represent those diagnosed in British Columbia. Unfortunately this quest for my personal medical records wasn't an easy, straight forward matter. On June 4th, upon calling the hospital and requesting the procedure to retrieve medical records, I was simply told, "Sorry. 1984 records had been destroyed."

I remember my surprise and sense of disbelief - "Isn't a blood transfusion something that needs long standing documentation? How could medical records simply be destroyed?"

After discussing this with my husband, he was given the same response after his phone call. My family doctor was also told that my 1984 medical records no longer existed.

This somehow just didn't seem right and we were reluctant to give up. My husband decided to visit the hospital's Records department in person and speak to someone in charge. He stressed the seriousness of my diagnosis, and the importance of an accurate follow up. The matter was looked into further and after another couple of weeks I was asked to fill out and sign an 'AUTHORIZATION FOR THE RELEASE OF PATIENT INFORMATION' form.

On August 2nd I gladly drove into town to pick up my documentation. It was a small victory. I wasn't totally invisible. Within the 5 sheets that were handed to me was the cross-match file card. I could now forward this to my family doctor, who in turn would forward this to the Red Cross so that donor tracing could be initiated.

J.P.

MEMBERSHIP DESK

Jim Lodge

The year is moving right along. So, too, is your Support Group. I'm encouraged by the way our volunteers see to all the small details, which makes us tick, and have things to hand when needed. As the Group is growing, and so much is still needed to be done, it is becoming more evident for us to prepare much more in advance. This is being done by your Steering Committee right now, and details will be out shortly, but we will need your input, too, and any help you can see your way to giving. Just give a call to us three co-chairpersons anytime. Thank you in advance.

A note again about Membership in Hepatitis C Survivors' Society:

To become a member of HeCSS, a membership application form has to be completed, and with the minimum dues of \$15.00 per year, mail it to the National Office in Toronto.

Application forms are available at each meeting or on request. Benefits through the National Office are, an Income Tax Receipt, a membership card (good for twelve months), plus receiving the National News Letter. Your Victoria Chapter benefits too by a portion of the dues being returned, to help with our Chapter operating expenses.

Reminder:- Any change of address, phone number or Postal Code, please let me know at your earliest. Thanks.

Jim Lodge 386-8227
Co-chairperson, Membership Chair.

LIBRARY RULES

1. Anyone who checks out material from the library must be on the mailing list, must present a photo ID, and must fill out the back of the card that corresponds to the material.
2. Materials should be returned to the next meeting, with the exception of videos and some books. These items may be checked out for one week only. They may be renewed by phone if there has not been a request for them.
3. A maximum of 3 books or items may be checked out by each person. Items must be returned before more can be checked out.
4. A person in possession of overdue materials may not check out more until the item(s) is/are returned, the material(s) is/are replaced, or the library is reimbursed.

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

COORDINATING COMMITTEE -- VICTORIA CHAPTER

CO-CHAIRS:

JIM LODGE	TEL: 386-8227
DAVID SMITH	TEL: 658-4991
RYTA TRACY (on leave)	TEL: 475-1860

SECRETARY	RAE SUPEENE	TEL: 478-1974
TREASURER	FRANK NIELSEN	TEL: 727-7172
MEMBERSHIP	JIM LODGE	TEL: 386-8227
LIBRARY & BULLETIN	JOAN DIEMECKE	TEL: 479-5290 (TEL. & FAX)

CALENDAR OF EVENTS:

NEXT MEETING: Wednesday, October 16, 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)

HeCCS NATIONAL ANNUAL GENERAL MEETING

Victoria has the honor of hosting this important event. The dates are November 8th and 9th, at Royal Roads. Please mark your calendars now. There are plans for a dinner/dance the evening of November 9th. More information will be included in the next issue of hepc.bull, and in your next phone committee message.

TO KILL OR TO CURE - OPTIONS IN HOST-DEFENSE AGAINST VIRAL-INFECTION

Author: FV CHISARI,
SCRIPPS CLIN & RES INST,
DEPT MOL & EXPT MED,
10550 N TORREY PINES RD,
LA JOLLA, CA 92037

Publication: CURRENT OPINION IN IMMUNOLOGY 1996 AUG;8(4):478-483

It is generally thought that viral clearance is mediated primarily by antigen-specific T cell responses that destroy infected cells. This assumption may not be true for all viruses. Recent studies using a transgenic mouse model of hepatitis B virus infection have shown that adoptively transferred, virus-specific cytotoxic T cells can abolish hepatitis B virus gene expression and replication in the liver without killing the hepatocytes. This effect is mediated by interferon-gamma and tumor necrosis factor-alpha, which are secreted by the cytotoxic T lymphocytes following antigen recognition.

Similar noncytopathic cytokine-dependent 'curative' processes also occur in this model during an unrelated infection of the liver.

Intracellular viral inactivation mechanisms such as these could greatly amplify the protective effects of the immune response. Research has also been carried out to clarify the relevance of curative versus destructive mechanisms of viral clearance in other models of viral infection.

BIOGRAPHIES OF OUR MEMBERS

Our Monthly bulletin, hepc.bull, is looking for biographies of our members to print in the upcoming issues. How long have you had Hep C? How has it affected you? What do you do to stay well? Please contact Joan Diemecke at Tel. 479-5290, or send a fax to the same number. You may also send your story through email to her at 103125.1520@compuserve.com

We reserve the right to edit items submitted for publication in hepc.bull. All manuscripts will be kept by the editor, unless you include a stamped, self-addressed envelope, or make other mutually agreeable arrangements.

NOTES FROM DAVE

"Yesterday is a memory. Tomorrow is a mystery. Today is a gift and that's why it's called the present."

Just a little maxim that caught my eye on the wall of a public building today. Perhaps it's something that sounds like it could have been uttered by Stuart Smalley (you know, that guy that saves his family in the movie of the same name) but it did catch my attention for the reason that it fit so well with my own philosophy of time and what it means and always trying to live in the moment.

At first it takes a great amount of concentration to live your life in this fashion if you're not used to it. Mostly we agonize over the future and regret the past, if not sentimentalizing it.

All this pondering about the past and the future leaves little time to think about the present. John Lennon said it well with his line, "Life is what happens while you're busy making other plans."

Now, I know that the present doesn't look or feel that great to those of us living with Hep C. But in reality, it's all we have, so we might as well do our best with it. We can't control the future and we can't change the past, so if we can condition ourselves to make the most of "right now", all the rest of it will take care of itself. It's so simple and obvious, yet we have such a hard time abiding by it on a day to day basis.

We work for some mythical time in the future, when we retire or when the kids are all grown up, or some such fantasy. This is more like wishing your life away, and by this, we're missing the point of living. I'm not talking about giving up making plans for the future, or setting goals for yourself. I suppose being cursed with the ability to think has something to do with it, but that curse can also be a blessing. A little saying like this one conveys such direct meaning to one's brain. It smacks of truth and makes more sense because of its clarity and simplicity. It's a mantra for everyday living. Clip it out, stick it on your fridge door or your bathroom mirror. Meditate on it. Live by it. We can only benefit from it, and I honestly believe that living with Hep C will be made easier.

Being sick and going into my transplant forced me into thinking about the "here and now", because it was like "it's now or never" or "do or die", or something, and from the moment I woke up after the operation, the past ceased to have any meaning, and the future just opened up into a reality of infinite potential. The result of this was the creation of a whole new "now". One door closed and another one opened. This new realization stayed with me for quite a while, but dissipated with time.

Now I realized I'd have to work at it if it was going to remain my reality, and you know, when it doesn't come easy and you have to work at it to keep it actively in your mind, it takes on an even deeper meaning, and makes even more sense than when it first flashed into your consciousness.

The special meeting on the 21st of September was extremely education and enlightening. Coming straight from the horse's mouth, as it were, many of the myths about Hep C and interferon were dispelled. I would like to thank Dr. Anderson and Natalie Rock on behalf of everyone for taking time out of their busy schedules to come and talk to us.