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BC CHAPTERS NEWS BULLETIN

HEPATITIS C SOCIETY OF CANADA MAY 1998

Issue No. 12

Hundreds turn up for National Rallies

Another watermark in HeCSC history was achieved on Monday April 20, 1998, when two national rallies were held in Ottawa and Victoria. HeCSC members came together united and told our politicians that we will not be divided. Media coverage was excellent at both rallies. Many members are now telling their stories to the media with bravery and dignity, if not a little bit of discomfort. I feel honoured and privileged to be a supportive witness to the struggle, to see a community come together and fight for their lives.

Here are the remarks of our President Jeremy Beaty at the Ottawa press conference:

"We waited patiently for Krever to write his report; we waited patiently for the governments of Canada to tell us how they would help us. We have publicly been witnesses to our heartaches from within very private families. As sick people we have been patient and reasonable in believing we would be cared for to ease our suffering through social justice and compassion. The wait is over. Today, we express our anger, frustration and outrage that decisions have been made to divide us when we will not be divided. That money is being held out as a salve to our needs without anyone caring about what are these needs.

April 20, 1998, will be a day long remembered for the coming together undivided of all Hepatitis C victims who were harmed through no fault of their own.

We are gathering together on Parliament Hill as one voice from across Canada to say publicly that we will not be divided. Those who cannot be here today have told us we will not be divided.

Today we are taking the following actions:

I will be hand carrying a letter to our Prime Minister asking him to personally intervene to ensure a just and fair resolution of the issues arising from the Krever Report that directly affect Hepatitis C victims who have been harmed through no fault of their own.

I will be hand carrying a letter to our Health Minister, Allan Rock asking for independent legal representation, funded by the Government, for the Hepatitis C Society of Canada to access professional advice on behalf of all Hepatitis C transfused victims.

We are asking for a full Parliamentary debate so that the victims and the people of Canada can hear the Government justify why it proposes to artificially and arbitrarily divide and create barriers among people who have the same

(Continued on page 3)

Positive Action, Ireland

Positive Action is the support group for Irish women infected with Hepatitis C through the contaminated Blood Product Anti-D. This was a product given to Rhesus Negative women who were carrying or giving birth to a Rhesus Positive child. It was a routinely administered blood product and accepted as safe by around 60,000 women who received the product made by the Irish State Blood Bank from 1970 to 1994.

In 1994 it emerged that certain batches of Anti-D were contaminated with Hepatitis C but it took nearly three years for infected women, through Positive Action, to learn the full truth about this contamination with a Tribunal of Inquiry into the Blood Transfusion Service Board conducted by a former Irish Chief Justice, Mr. Tom Finlay. Positive Action members were represented by the group's legal team at this Inquiry.

It was a member of Positive Action, Mrs. Brigid McCole whose brave fight through the courts was to uncover the first hidden information about the contamination. She died of Hepatitis C in October 1996 just days before her court case was due to be heard but the courage and struggle of this mother of 12 was to awaken huge public interest in the scandal and turn the political and moral tide to support Positive Action in its search for justice and the truth. A hidden scandal had now become a matter of public outrage.

This report highlighted that this contamination need never have happened if basic donor selection procedures had been adhered to by the BTSB. Instead the BTSB knowingly took plasma in 1976 from a pregnant woman who had naturally occurring high levels of Anti-D and who was undergoing plasma exchange treatment while she was clinically diagnosed as having infective hepatitis. Hepatitis C had not been identified at this time, but Hepatitis non-A, non-B, was well documented in medical literature. It also emerged when the first jaundice reactions from women who received Anti-D were notified to the Blood Bank in 1979 they were not followed through.

In 1991 Hepatitis C testing became available and a London Hospital showed the clear link between Hepatitis C and the archived blood samples from women who were jaundiced in 1977. Despite having clear evidence the Irish Blood Bank did nothing.

(Continued on page 3)

COMING UP:

Victoria Chapter Meetings: Last Wednesday of each month 1 - 3 PM, and again at 7-9 PM, St. John the Divine Church Lounge, 1611 Quadra St. (Entrance through the rear, marked Annex) NEXT MEETING: May 27th.

Penticton Chapter Meetings: Third Thursday of every month, 7-9 PM, Penticton Health Unit - Board rooms. NEXT MEETING: May 21st.

Kelowna Chapter Meetings: Last Saturday of every month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: May 30th.

Nanaimo Chapter Meetings: Second Thursday of every month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: May 14th.

Vancouver CLF Support Group Meetings: Second Thursday of every month, 7:30 PM, Nurses' Residence of VGH. (12th and Heather). There should be signs directing you to the right room. Next Meeting May 14th. Contact the CLF for more info at 681-4588 or Herb at 241-7766.

Sunshine Coast Support Group Meetings: First Thursday of each month, 7:30 PM, Coast Garibaldi Health Unit in Gibsons. NEXT MEETING: May 7th. Contact Carol for more information: 886-4298 or email her at <ryker@cheerful.com>

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SUBSCRIPTION FORM

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(A limited number of newsletters will be available free of charge at the meetings, as well.)

DISCLAIMER: HeCSS cannot endorse any physician, product or treatment. Any 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. The opinions expressed in this newsletter are not necessarily those of the organization.

THANK YOU!

Victoria Chapter HeCSC acknowledges the personal donations, donations in kind and memorial donations received to date, and the following for discounts, donations of services, or equipment: Monk Office Supply, CFAX 1070 Radio, Apple Canada, Pacific Coast Net and Island Internet, Inc.

The deadline for any contributions of *hepcBC.bull* is the 22nd of each month. Please contact: Joan Diemecke at Tel (250) 388-4311, <pdiemecke@compuserve.com>, Darlene Morrow at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3, <hepcbc@sprint.ca> or C.D. Mazoff at <squeeky@pacificcoast.net> The editors reserve the right to edit and cut articles in the interest of space.

ADVERTISING: The deadline for placing advertisements in the *hepcBC.bull* is the 15th of each month. Rates are as follows:

Newsletter Ads:

\$10 for 1/6th page, per issue

\$100 for 1/6th page, 12 issues (in advance)

\$20 for 1/3rd page, per issue (vertical or horizontal)

\$200 for 1/6th page, 12 issues (in advance) whole page:

\$60 per issue

\$600 for 12 issues

1/2 page:

\$30 per issue

\$300 for 12 issues

Dear Editor:

I've just been talking to the Capital Health Office - Kate Darling - at 388-2225 about Hep B and Hep A vaccines - Immunization Program for Hep A will start after April 1st - call their office after that date. Can you arrange to have this info put in our Victoria Bulletin and on the web site? The Hep A vaccine (series of two shots over 6 months and lasts 20 yrs.) will be given free to any/all people with Hep C. For uninfected people who are living in a house with a Hep B carrier they can have the series of 3 shots free also but have to call Kate Darling at the Health Office to make arrangements.

Lisa in Victoria



FROM THE OKANAGAN

Ahhh, spring in Washington, D.C. It truly was a remarkable experience and an opportunity I will not soon forget.

The three day conference was held at Georgetown University - the home of the Hoyas. I was greeted by many I had spoken with only via email. It was great to meet these wonderful people face to face. I met Thelma King Thiel, founder Hepatitis Foundation International, Ron Duffy founder HCV Global Foundation, Trish Parnell, founder of PKIDS, Alan Franciscus, founder Hepatitis C Support Project, Cynthia Hoff VP, Hepatitis Education Project, Carol Craig and many others who post to the HEPV-L.

Saturday, all participants were invited to share what they do best. What a room full of motivated talent, representing almost every state! Hearing everyone's secrets was truly inspirational! We created a Patient Advocacy Panel whose goal will be patient empowerment. We identified 6 priorities of this panel. We will be meeting regularly to accomplish the goals we set for ourselves and our groups.

Despite the border it became very evident we have the same issues, problems and needs. As we can not individually do much to advance research, it was decided prevention through education and awareness be our main goal.

Sunday we got to hear the leading US doctors and researchers tell us what is new. They were an inspirational group. The panel included (all doctors) John Lamontagne - NIH, Harold Margolis - CDC, Leonard Seeff - Veterans Administration, Blaine Hollinger - Baylor College of Medicine, and Jay Hoofnagle - NIH. Probably the loudest messages these gentlemen brought to the delegates were: 1) we must push for doctors and health care workers to be better educated about Hepatitis C and 2) yes, Hepatitis C carriers DO experience liver pain - it is very real!

The highlight of the weekend was listening to Dr. C. Everett Koop speak at the Awards dinner and to actually meet the four researchers who discovered the Hepatitis C genome.

Dr. Koop has been working on a process, hyper thermal therapy, for 8 years, a process where he extracts the infected person's blood, heats it, then replaces it. This effectively kills the virus. It sounds very promising and I hope to be able to share more with you at a later date.

We spent our last day learning how to approach politicians and practising our newly learned skills. We also made an impromptu visit to the Canadian embassy where we were not made to feel very welcome. I suppose we should have made an appointment!

I am looking forward to attending again next year...God willing.

Until next month, take good care of yourselves.

Love,

Leslie

Vancouver Support Group

On May 14th the Liver Support Group will have a guest from the Self Help Resource Association attend and facilitate the support group. The goal is to establish group norms and objectives for a cohesive support group. A second support group for the Fraser Valley/Delta area will also be discussed. Meeting time is 7:30pm. All interested participants are invited to attend.

CANADIAN LIVER FOUNDATION

Evening in the Clouds: A Gospel Dinner for Charity Experience the music of the Cloud Nine Gospel singers at Mango's Restaurant in the Pacific Inn White Rock on Monday, June 8th at 7 PM. Tickets are \$45.00 and can be purchased at the CLF office or any Hagan's Travel. Proceeds benefit liver disease research.

CLF Second Annual Charity Golf Classic Westwood Plateau Golf and Country Club. Tuesday June 2nd with a 6:30 AM tee off. Join avid golfers for a full round of golf and raise funds for liver disease research> This is a pledge event and registration packages can be obtained by calling the CLF.

Reminder: Any change of address, phone number or postal code, please let your phone contact (in Victoria) or your chapter secretary know ASAP
HeCSC Victoria Tel. (250) 388-4311
hepcvic@pacificcoast.net

(Continued from page 1)

viral illness through no fault of their own.

We are asking for open discussions with the provincial Ministers of Health to provide for health guarantees that allow priority access to treatment and therapies for persons infected with Hepatitis C through blood and blood products.

Since the compensation plan was announced last month we have heard how any additional dollars will damage our health care system. The maintenance of the health care system has no more to do with Hepatitis C than it does with foreign aid, flood and ice storm relief, or the purchase of submarines or helicopters.

We have also heard how the Government of Canada, in defending its Hepatitis C position, cannot compensate all those harmed through health care. We agree. That is the responsibility of those who deliver babies, set broken legs and provide anesthetics. However, the Government directly provides the blood that has harmed us and must take the responsibility for the harm caused.

We are simply average Canadians expressing our expectations with dignity. Our demands are precise. We expect a positive response--now."

We need everyone's involvement to help galvanize governments into action. Your future depends on it.

Until next month,
Tim McClelland
Executive Director

(Continued from page 1)

There was a second major contamination of Anti-D from 1991 to 1994. Then the B.T.S.B. ignored positive Hepatitis C tests on Anti-D samples and put the product into circulation.

The compensation scheme negotiated by Positive Action is now on a Statutory basis and therefore cannot be abolished without reference back to the Irish Parliament by any Government. Positive Action also negotiated a detailed health scheme, which includes home support services, for those infected. These schemes also apply in a similar fashion to persons who received Hepatitis C through transfusions, dialysis treatment or through blood products used to treat hemophiliacs. The group also coordinated contact between legal teams who represent individual women on compensation issues under a lead team which dealt with central issues.

Positive Action has been a multi-faceted organization for Anti-D Mothers. It has dealt with medical, legal and welfare issues and most importantly it has provided a forum for women to meet with each other and gain support and friendship from others in a similar situation. It is now developing a psychological service for members and operates from an office in Dublin staffed by a coordinator and Secretary.

Just over 1,000 women have now been screened positive for Hepatitis C antibodies and/or virus in Ireland to date.

hepcsc@island.net April 20, 1998



Background document on Irish Compensation

*Scheme for all Hepatitis C victims infected
through blood and blood products*

In Dublin, two panels of the Compensation Tribunal sit five days a week hearing compensation awards. Each claim is determined individually and in private. 1,792 claims for compensation under this statutory scheme have been lodged.

The scheme is open to all persons diagnosed with Hepatitis C from tainted blood or blood products. The children or spouses who become secondarily infected can claim. No time periods are specified.

Two national screening programs have taken place in Ireland inviting people who have received blood and blood products to come forward for Hepatitis C testing.

The Compensation Scheme is enshrined in law - meaning no future Irish Government can dissolve it by claiming hard economic times.

Only the legal team representing the victims asks questions at non-adversarial hearings.

Claimants can decide whether they wish a full and final payment or a provisional award - this allows an individual to return to the Compensation Tribunal in the event of a specified deterioration in health.

Loss of income and other associated costs can be claimed.

If an offer of compensation is unacceptable to an individual then a claimant can appeal all or part of that award in private to the Irish High Court.

All legal and other costs associated with a successful claim are met by the State.

The scheme does not prejudice the right of an individual to go directly to the High Court and claim compensation there instead of from the Tribunal. Background document on Irish Compensation Scheme for all Hepatitis C victims infected through blood and blood products

Hepatitis C Society of Canada (HeCSC), April 1998.

DAVE'S COLUMN

Someone a long time ago said that "Canada needs only to be known in order to be great." Once upon a time, Canadians were known for their compassion, therefore its standing in the world was a model for other countries to emulate.

Compassion: What does it mean exactly? According to *Collins' Thesaurus* it can mean clemency, commiseration, condolence, humanity, kindness, mercy, sorrow, sympathy, tender-heartedness, and tenderness; qualities sadly lacking in today's government and, by extension, throughout our whole society.

Our nation is becoming a country full of special interest groups competing for an ever decreasing slice of the economic pie. This is exactly what our governments want to see happen. It's the old divide and conquer routine. That way, the government can have an easier time controlling us, even though its more chaotic and everyone always seems to be in crisis mode.

Now, I don't want to believe this. It seems to offend my innate but very British sense of decency and decorum. Are we not placed here upon this earth ultimately to help each other, especially within the confines of our national borders? Sure, we'll help individuals wronged by the "system". We'll give aid to those whose economic and ecological systems have failed them. We'll provide for flood and ice victims. We will correct the injustices done to those in our society who've been wrongly convicted of crimes. We will give millions if not billions of dollars to other countries to give them a leg up when needed. But for some strange reason, our governments will throw a paltry few thousand dollars to some, only some, not all of those of us who have been poisoned by a medical system that gave us no reason to distrust or fear it. This is becoming a travesty of Canadian justice. How the scales of our political will can tip so far out of balance to favour the bottom line instead of compassion and human decency is beyond comprehension. How these people can actually get up in the morning and look at themselves in the mirror is mind-boggling to say the least.

Our esteemed leaders are so far out of touch with reality, they think that we will actually swallow their swill about dates and times of eligibility for compensation. Their insistence that 1986 was the benchmark year for admissibility of fault and a bonafide cut-off point for compensation is, to my mind, a conscious effort on their part to confuse the issue and mislead the public away from the truth, the truth being that both the Red Cross and the federal government AND the pharmaceutical companies engaged in a campaign to hoodwink the general public.

We know that the truth about the blood supply was well known as early as 1978 given that it was already being reported in the media. I ask the question at this time. Did it really take 12 years to build the infrastructure to implement the test that would have avoided this scandalous and avoidable sin against the Canadian public, or did those responsible just care less about the consequences of their actions and let the chips fall where they may, which has led us to the present horrible state of affairs?

David Smith, Chair

WARNING FOR PEOPLE TAKING CESAMET (Nabilone)

I spoke with Dr. Anderson this morning. He was very concerned about something that he had heard. It appears that some people with HCV are taking Cesamet (nabilone) for nausea. This drug is very toxic to the liver and should NOT be used by HCV patients.

Nabilone is used in the treatment of nausea associated with chemotherapy. Nabilone should be used in extreme caution in patients with severe liver dysfunction (HCV).

In addition, the side effects of Nabilone include depression, loss of appetite, confusion, fatigue and headache. These side effects are already common in HCV patients especially those taking interferon. A decrease in the white blood cells is also seen with both the nabilone and interferon.

If nausea is a problem, it is recommended that ginger be used. You can buy standardized, organic ginger in the health food store (\$10.00 for 100-500mg capsules). Take 3 capsules as needed. If this doesn't work, Graval would be the second choice.

Darlene Morrow

Hepatitis C Victims Define Their Expectations

Media Release

*Hepatitis C Society of Canada (HeCSC)
Ottawa, April 20.*

Prime Minister Jean Chrétien has, today, been requested by the Hepatitis C Society of Canada to personally intervene to ensure there is a just and fair resolution of issues arising from the Krever Report on the Blood System in Canada.

The Society has taken this action in its bid for compassion and justice for all Canadians infected, through no fault of their own, with Hepatitis C through blood and blood products. Members of the group will gather this morning from all parts of Canada on Parliament Hill to publicly show their anger and sense of outrage and how the Government proposes to resolve compensation issues.

On March 27, 1998, the Government excluded many sufferers of this Hepatitis C tragedy from its compensation plan. The Hepatitis C Society of Canada has also asked the Prime Minister and Federal Health Minister Allan Rock, as well as their Government colleagues, to re-open the compensation plan and ensure there is full consultation in advance of a negotiated settlement.

Joining the rally will be two representatives from the Irish Hepatitis C campaign group, Positive Action. Josephine Mahony and Jane O'Brien will tell Canadian victims how the

Irish plan includes health and compensation for all infected through blood and blood products. The Krever Report described the Irish solution as the world's most advanced system for righting wrongs perpetrated by the State.

The Hepatitis C Society of Canada is now stepping up its campaign to ensure there is an immediate political will to address current issues through consultation with victims. Prime Minister Chrétien was told by the Society President that "it is not adequate or acceptable to simply offer money to a selected group in an attempt to absolve your responsibilities".

In particular the group is now seeking:

Re-opening of the Compensation Plan to address the cruel offer and to ensure there is full consultation in advance of a negotiated settlement.

Independent legal representation for the Hepatitis C Society of Canada, funded by the Government, to enable it access professional advice on behalf of transfused victims. This is sought in a letter to Federal Health Minister Allan Rock. The Society has told the Minister that the solutions, with cruel and unjust exclusions, will not work and an immediate meeting is sought with Minister Rock.

A full parliamentary debate to allow Canadians to hear the Federal Government try and justify why it proposes to artificially divide and create barriers among people who have the same viral illness, through no fault of their own.

The Hepatitis C Society of Canada is now stepping up its actions to ensure politicians and our fellow citizens understand the anger, frustration and outrage victims feel at the inadequate plan put forward by the Governments.

Today we have written to all Provincial Health Ministers and all Cabinet Ministers in the Federal Government clearly stating our anger and outrage at what is proposed. Other actions planned include:

-A national recruitment campaign to give victims and their families a voice in reaching a just and fair resolution of this issue.

-Developing an intensive communications network to communicate with provincial, and Federal Government politicians to ensure they are fully aware of the our strong views and concerns.

-President of the Hepatitis C Society of Canada Jeremy Beaty said today victims have been patient too long. "As sick people we have been patient and reasonable in believing we would be cared for to ease our suffering through social justice and compassion. The wait is over. Today we express our anger, frustration and outrage that decisions have been made to divide us when we will not be divided". He described the April 20 Rally of Hepatitis C victims as a day that will be long remembered for the coming together of all Hepatitis C victims who were harmed through no fault of their own.

*Tim McClelland,
Executive Director*

AGE-RELATED RESPONSE TO INTERFERON-ALFA TREATMENT IN WOMEN VS MEN WITH CHRONIC HEPATITIS C VIRUS INFECTION

Background: Interferon alfa is used widely for patients with chronic hepatitis C virus (HCV) infection. Little is known, however, of the relationship between patients' sex and the effectiveness of interferon alfa treatment in these patients. **Methods:** We treated 311 patients (199 men and 112 women) with human lymphoblastoid interferon (6 million units subcutaneously every day for 2 weeks and 3 times a week for 22 weeks) and observed them for an additional 6 months. Serum HCV RNA levels and genotype were tested by polymerase chain reaction before treatment. A liver biopsy was also done. For the purposes of this study, a complete response was defined as the elimination of HCV RNA for at least 6 months after the termination of treatment. **Results:** The rate of complete response was 27.1% for men and 24.1% for women. With multiple logistic regression analysis, the HCV RNA level ($P < .001$), genotype ($P < .001$), patients' sex ($P < .05$), and the interaction between sex and age were associated with a complete response to interferon alfa. The rate of complete response was 33.3% in men aged 39 years and younger, 25.0% in men aged 40 years and older, 75.0% in women aged 39 years and younger, and 15.6% in women aged 40 years and older. The odds ratio by group was 1.00, 0.72, 4.38, and 0.21, respectively. **Conclusions:** Our finding that women aged 39 years and younger are responsive to interferon alfa treatment suggests that hormonal activity, in particular the level of estrogen, may be associated with the sustained elimination of HCV.

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*SOURCE: ARCHIVES OF INTERNAL MEDICINE
1998 JAN26;158(2):177-181*

Pharmacare Deductible to Increase

As of April 1998, the BC provincial government has increased the annual pharmacare deductible from \$600 to \$800. To keep this in perspective— Saskatchewan residents must pay \$850 every 6 months or \$1700 per year.

April 20, 1998

Delivered by Hand

The Honourable Jean Chrétien
Prime Minister
House of Commons
Ottawa, ON

Dear Prime Minister

We have come here today to Parliament Hill as Hepatitis C sufferers to ask you to personally intervene to ensure there is a just and fair resolution of this blood tragedy.

Compassion and justice are what we seek. The offer of compensation before us artificially divides us and creates barriers among people who have the same serious viral illness, through no fault of their own. The Government must now re-open the compensation plan offered in March, which excludes so many sufferers, and ensure there is full consultation in advance of a negotiated settlement. We stand united as victims of the Canadian blood tragedy.

Justice Krever in his Report spoke for us all when he concluded: "Compensating some needy sufferers and not others ... cannot be justified". He had your confidence when he was appointed by you to investigate the blood scandal in Canada. He uncovered a catalogue of decisions made poorly and in bad faith that have left us, the victims, bearing the consequences of this tragedy. We are sick, many of our friends have died and Hepatitis C will claim many more Canadian lives.

Today, people have traveled from all parts of Canada to show publicly to you, your Government colleagues, and all politicians their sense of outrage at how you propose to resolve this issue. Others had wished to join us but were too ill to travel. Compensation and other recommendations of the Krever Report must be addressed urgently by the Federal Government. Our voices are raised today for a just and fair resolution of the health and compensation issues. It is not adequate or acceptable to simply offer money to a selected group in an attempt to absolve your responsibilities.

We ask you to accept the responsibility, as Prime Minister, of seriously addressing the consequences of what is acknowledged as an "unprecedented public health disaster in Canada". This must be done through full consultation with representatives of the victims, without undue delay, and to the satisfaction of those infected. We now seek an immediate meeting with you so you can hear first hand of our concerns. We are available to meet with you at any time and our members throughout Canada eagerly await your response.

Yours sincerely,

Jeremy Beaty
Chairman and President

April 20, 1998

Delivered by Hand

The Honourable Allan Rock
Minister of Health
House of Commons
Ottawa

Dear Minister Rock

Hepatitis C sufferers, from all parts of Canada, are gathered on Parliament Hill, to ask you to provide us with a compensation plan for all victims that matches your words in dealing with this issue in a fair and humane way.

Our presence is a symbol of the anger and injustice members feel at the way this issue is being handled. We oppose the creation of artificial divisions among victims. Today we are also writing to Prime Minister Jean Chrétien, and other Government Ministers, to highlight the urgent need for a fair and just resolution of this blood tragedy. The Government must now re-open the compensation plan offered in March, which excludes so many sufferers, and ensure there is full consultation in advance of a negotiated settlement.

As representatives of the largest Hepatitis C through transfusion group in Canada, the Hepatitis C Society of Canada asks that you to provide funding for independent legal representation to enable our Society to access professional advice on behalf of Hepatitis C transfused victims. This is an issue you can immediately address, and show clear good faith, through a willingness to assist us in our efforts to reach a just resolution.

Health issues are also of serious concern to our members and in particular the need to provide priority access to drug treatment and therapies, that are not included in today's health care.

All victims suffer equally from the same debilitating and uncertain condition and attempts to provide simple solutions with cruel and unjust exclusions will not work.

Representatives of our group now seek an immediate meeting with you at any time to discuss our position and to personally hear your proposals on resolving this issue. We await your immediate response to matters raised in this letter.

Yours sincerely

Jeremy Beaty, Chairman and President.



SQUEEKY'S CORNER

“April 20, 1998: Making a difference”

When I first became really ill with hep, my horizons diminished accordingly. I began to see myself as increasingly incapable of any meaningful activity. Slowly, however, things began to change; and what changed me most was getting involved with an on-line hepatitis C information network and the Hepatitis C Society of Canada.

At first things were slow. About 2 years ago in Montreal, not much was happening. A few of us tried to organise, and we had some successes. Slowly it began to dawn on me that I could do some things. Become informed, for one—and pass it on, for two (I think that's Canuck-eh?). But I kept having this idea: since I was so tired most of the time, if somebody were to plop me down somewhere (like in front of some parliament buildings) with a sign in my hand (or around my neck) and the weather weren't TOO bad (we're not talking Miami here), then, well, I'm so tired I really wouldn't mind and *maybe*, just *maybe* somebody out there would begin to understand that what we were going through demanded **attention!**

On April 20, 1998, I got my chance. Boy did I ever. What a day in the life of a hepper! Thank you Tim. Thank you Jeremy. Thank you Leslie & thank you Dave for your leadership, and for getting the message out. And a special big thanks to Helen Hubbard and the others who spoke out from their hearts and moved many of us to tears. Thanks also to all of you whose names I don't know, or can't remember, for the letters (Ron Thiel, Peggy Daisley, Gary Joneson) and faxes that you have sent to politicians and the media, and for your encouragement. Thanks to all on various phoning committees for doing your job and getting the message out. Thanks to those of you who answered phones, printed out fliers, paid for photocopying and postage out of your own pockets.....etc. etc. etc.

I don't have the exact numbers--but we had well over one hundred people show up at the Rally in Victoria. We had media coverage from the beginning of our walk from the office all the way through the downtown core and on to the Provincial Legislature. We had politicians, people and the press. We had people stopping to take notice and cars honking their support for us as we marched for justice.

It's funny, but on April 20, 1998, I felt **proud** to be a hepper. Instead of feeling on the outside, I realised that I was part of a family of people just like me who were ill and who needed treatment, a cure—and justice. If we didn't succeed in driving that point home to all the politicians on April 20, I am positive that we *did succeed* in getting through to some of them.

The point is that the fight has just begun, and

we can't back down now. So, if you don't know what you can do, or if you feel too tired, I'm pretty sure that somebody can pick you up and plop you down right where you're needed. And, guess what? There's a pretty good chance that I'll be the guy next to you.

Keep fighting!

Squeeky

IVAN'S INPUT

A lot is being said about compensating ALL victims of Hep C tainted blood, which is fair enough, but I think its now time that we/you/someone come up with some facts and figures for that compensation.

In other words, its one thing to jump up and down about how unfair the present compensation package is, but something else again to actually quote monetary figures on what we/you/everyone would like to see for compensation, and to have the media also quote these monetary figures. I think the more specific we make our claim, the better chance we have of getting what we want.

To that end, the following is what I as someone who was unjustly infected by tainted blood would like to see as a compensation package....

Since the Government is quite adamant that '86 is the cut off date, which means they won't simply compensate everyone from the beginning of time, I think it is fair to ask for a two or three tiered package, those before a test was available ('80, '81, or '82) depending on who you believe on when a test was available, '81 to '90, (when they SHOULD have been testing) and after '90 when they actually did start testing.

I think some sort of package like that offered to the HIV victims is the kind of thing we should be pushing for, not a small one time lump sum.

Something like the following....

The Federal Government should compensate those that were infected from '81 or '82 to '90 with \$75,000.00 over 3 years (\$25,000.00 a year). Those infected before '82 should get something like \$25,000.00 or \$30,000.00 as a one time payment. (Even though we are talking about two different groups, we are STILL talking about compensating EVERYONE)

The Provincial Governments should be compensating those from '81 or '82 to '90 with AT LEAST \$12,000.00 a year (if not more) for as long as the person is infected with Hep C. Remember this is a life long debilitating progressive liver disease. Many people infected with Hep C are already on some form of Provincial Disability, and many more will be on some form of Disability in the near future.

Having the Province's put this up front as a compensation package means those infected would not have to go through the arduous task of claiming Disability. Those infected before '82 should get free access to drug therapy and medication, as well as ANYONE infected with Hep C, regardless of how they became infected (just as is done for HIV infected people). This still calls for compensation for everyone, but is a multi-level package.

There should ALSO be a SURVIVOR BENEFIT provision made for children and spouses of people who die due to being infected with HEP C. In other words, whatever compensation package is provided, should continue to go to the children or spouse after death for a certain time period, something like 10 years. (Provided either by Federal or Provincial Governments.)

The Federal and Provincial Governments should undertake to fund research for a cure for HEP C.

For those that have been infected AFTER 1990, these will have to be dealt with as individual legal action suits, the blood supply is not safe even today, but many people now know the risks of blood transfusions.

Something like the above plan, LIKE THAT OFFERED TO HIV VICTIMS, is in my humble opinion, a FAIR one. It DOES NOT bankrupt any of the Governments nor OVER BURDENS the Healthcare System, but shows SUPPORT and COMPASSION for those that were UNFAIRLY INFECTED with Hepatitis C.

Again, as I stated, simply calling the present offered package a joke, I believe will get us nowhere, but actually asking for specific amounts of money, and specific compensation for specific groups shows that we actually KNOW what we are talking about, and shows that we KNOW WHAT WE WANT, and that we will not except anything less.

*Ivan Good
Victoria Chapter*



IT'S TIME TO STEP INTO THE RING

I've been putting this off for sometime now; always successful in finding some valid excuse to offer the inquiring minds who want to know if I've been writing lately. But being a writer with an imagination makes my offered excuses (because that's exactly what they are) totally plausible - even to myself. So I'm a great one for believing my own reasons for not writing, which makes me a fantastic procrastinator. And procrastination is a wonderful luxury to bask around in, if you have the time.

But as the years since 1983 go by, and all of a sudden reach 15 years with a potentially fatal disease called hepatitis C, I am realizing that, like a lot of "luxuries" slowly exiting my life, time is becoming less and less of a commodity. So it seems, this would be the time I have had enough. It's now my time to step up and join with the crowds who are becoming instrumental in taking away the "silent" in what's called "The Silent Killer."

Upon sitting down to write this, I realize a lot of you aren't ready, for one reason or another, to stand up and be counted, to be loud and proud, vocal or seen. I understand this because I also realize that I have had a lot more time than some of you to get over the anger and helplessness. No, let me rephrase that. To deal with the anger and helplessness. No longer can I literally take this lying down.

I am, of course, talking about the (lack of) compensation in the package offered down from Allan Rock that excludes and separates a group of innocent victims who could have also had this infection prevented.

To the many of you who have been brave enough to allow their status be publicized, "Right on!" Definitely, this is the way to go. I believe it is no coincidence that as I write, the demonstration in Victoria has just appeared on the noon news as a headliner. Cool. I have to thank-you all for being there. Most well done. I am proud of you, and wish I could be there; but I'm doing what I can, here.

Which brings me to this call to the people: You do not have to get publicized to do something about this - if you don't want to. Write letters. Make phone calls. Do it horn the privacy of your own home. Get your friends and family to write letters and make those annoying phone calls with demands for answers to your question of "What is going to be done?" Never underestimate the power of the people. And that would be us -because there's no cavalry charging up the hill to the rescue. Are we all quite mad enough yet?

So, with anger being such a great motivator and all ... Have we all written our letters to Prime Minister Chretien? And how about flat Allan Rock? Well, okay. But there's still Premier Glen Clark? And Penny Priddy? And of course, you've contacted your MLA? Your MP? Hhhmmmm... all right... No letters. Well, what about some phone calls?

Have you asked your friends and family to write and call?

(Continued on page 8)

We would like you to meet Hopsy the HepC bunny.



My husband and I decided that I would paint this bunny for his quilt square. The original Hopsy is painted on a 12"x12" square of yellow broadcloth. It was sent to Hawthorne, California and is now part of Marie Stern's Hepatitis C quilt project. The message from Hopsy #1 is: Have you been tested? / "Hop to it!" / KEN / Saint John, N.B.

Our second Hopsy arrived in Penticton, British Columbia on December 14th, 1997. Leslie said her smiling young son was thrilled to realize that a stranger would paint something just for him. So, this Hopsy is being framed and will hang on the bedroom wall of a nine year-old boy who has Hepatitis C. The message from Hopsy #2 is: "Hi Jarad".

The third Hopsy was painted as a poster which could promote awareness about Hepatitis C and would urge people to be tested for this virus if they have any of the risk factors. On February 3, 1998, I telephoned our local Public Health Nurse and told her about Hopsy the HepC bunny. I told her that this poster was suitable for doctors' offices or bulletin boards. Within the hour, I had a meeting at the Public Health office. So, this Hopsy poster was on display at an Information Meeting, on March 5, 1998. This Hopsy is painted on a 14"x13" piece of yellow broadcloth. The message from Hopsy #3 is: Have you been tested? / "Hop to it!" / Hepatitis C.

I offered to paint another Hopsy poster for the upcoming meeting and my suggestion was approved. The fourth Hopsy poster was displayed at the entrance area for the Information Meeting about Hepatitis C. This meeting was held on March 5, 1998 at the Public Library, Market Square, Saint John, New Brunswick. This

Hopsy is painted on a 14"x22" piece of white Bristol board. The message from Hopsy #4 is: "Anybunny can have Hepatitis C".

Ken & Audrey Knight
kknight@nbnet.nb.ca
<http://www.geocities.com/yosemite/6419>

For more information about the Hep C quilts,
please contact:

Marie Stern <stern@flash.net>
Leslie Gibbenhuck <bchepec@bc.sympatico.ca>

New Technique for Designing Antivirals to Help HIV Patients May Also Help Hepatitis Patients

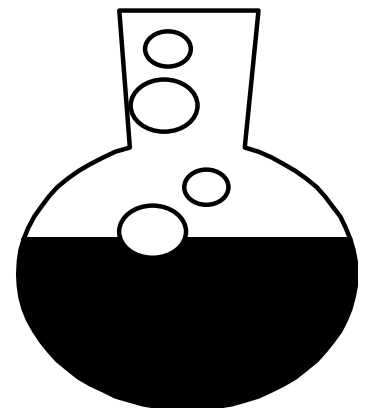
SOURCE: AIDS TREATMENT NEWS
New Antiviral Technology in Human Testing; Article Available From AIDS TREATMENT NEWS

SAN FRANCISCO, April 15 / PRNewswire/ -- A new technology for designing antiviral drugs, developed by Trimeris, Inc., a biotech company in Durham, NC, and largely "off the radar" of the media and Wall Street, is explained in the April 17 AIDS TREATMENT NEWS, a twice-monthly newsletter on HIV treatment research. T-20, the first such drug and the only one now in human testing, reduced HIV viral levels as well as the approved protease inhibitors, in a proof-of-principle trial in patients; no side effects were seen. The technology is not limited to HIV, but may also produce drugs against other enveloped viruses -- a group including influenza, hepatitis B, hepatitis C, and Ebola.

Because it targets a different viral mechanism than any drug now in use, T-20 may work equally well even for the patients who are hardest to treat those who have already become resistant to all available HIV treatments.

T-20 was discovered unexpectedly at Duke University during HIV vaccine research. This drug must be given by injection, and will probably be delivered by MiniMed portable infusion pumps like those now used with diabetes, allowing precise control of blood levels. Later, orally available equivalent drugs may be developed.

An in-depth description of this antiviral technology is available without charge from AIDS TREATMENT NEWS; ask for a preprint of "T-20 and Trimeris." Contact AIDS TREATMENT NEWS at 800-TREAT-1-2 or 415-255-0588, fax 415-255-4659, or email aidsnews@aidsnews.org. Back issues of AIDS TREATMENT NEWS -- which has been published continuously for over 10 years -- are available at <http://www.immunet.org/atn>.



(Continued from page 7)

Hey, don't feel bad. I'm just starting to do it now myself.

I only recently sent my one-page letter to all the above MP's, etc. I would think one page - for now~. We should follow up our letters with more phone calls and then send copies of previous letters along with any new ones. Also, the Hep C Society of Canada (and your lawyer, if you have one) would like copies of your letters as well. Just for your convenience, and so you no longer have a excuse, the addresses are included at the end of this column. No stamps needed MP's -just your local MLA.

As for phone calls, try these 1-800 numbers out... very interesting. Yes, it's really quite amazing how deftly those government agencies can pass you around so quickly that, in just under 15 seconds, you have talked to all three secretaries of our Premier, Provincial Minister of Health and local MP, and not learned a thing. Call back. They have mastered the art of passing-the-buck rather well with our tax dollars. So don't stand for it. Make these secretaries take a message with your name and your concerns BEFORE they transfer you down the line - and be prepared for a "We need something in writing."

With action, we become involved in our own destiny. We therefore become instrumental and effective. We cannot wallow in self-pity, sadness or anger - well, not all the time anyway... So, in rising above the negatives, by doing something positive, we can feel better about ourselves spiritually, which is just as important as looking after ourselves physically by eating properly, avoiding alcohol and beings as active as possible - which we will get into later, amongst other things. Until then, "Take special care of yourselves - and keep up the good fight."

The Right Honourable Jean Chretien
Prime Minister of Canada
Langevin Block
80 Wellington Street
Ottawa, Ontario, KIA OA2

Thu Honourable Glen Clark
Premier of B.C.
Parliament Buildings
Victoria, B.C., V8V 1X4

The Honourable Allan Rock
Minister of Health
Brooke Claxton Building
Postal Locator 0916A
Ottawa, Ontario, K1A 0K9

The Honourable Penny Priddy, MP
Minister of Health
Parliament Buildings
Victoria, B.C., VSV 1X4

For the name and address of your MLA and Prov. MP offices call #1-800-661-8683.
For the name and address of your MP call #1-800-667-3355 (No stamps needed.)

:
Victoria McClelland
Monday, April 20, 1998

Legal Fees

I am concerned about those of you who are currently eligible to make a claim for compensation! I do agree that it is wise to obtain legal advice, but that when it comes to retaining a lawyer to represent you in making a claim for compensation, then personally, I refuse to pay any lawyer between 30-40% of any money I may receive. If, in fact, the matter proceeds to litigation, only then I can see paying a lawyer this outrageous fee.

Unfortunately, this process has become an agreement between lawyers and politicians, and, as a result, it has prejudiced so many people. I think that the issue surrounding legal fees in the recent passing of the Class Action Act has been overlooked by both Parliament and the Legislative drafters in a rush to have this Bill enacted as a response to those women claiming compensation for breast implants.

As far as I understand the current situation is as follows: Once retained, your lawyer may charge up to 30% of your award for legal fees only. Then they add disbursements filing fees, and other related expenses, the total of both of these not to exceed 40% of the total award. This type of legal fee does work in cases where the lawyer represents only one person as is the norm in most retainer agreements. In contrast though, a law firm representing hundreds of victims and communicating once on behalf of many victims, should not be able to charge these high rates on an individual basis. In some cases, this means that the lawyer will receive more than the victim after taxes has been paid. I find this offensive and a violation of what justice and fairness is meant to be.

In my recent letter to Allan Rock, Reed Elly MP and others, I have suggested that this matter needs prompt revisiting. If any of you have hired lawyers, do not be afraid to ask questions and make sure you read those retainer agreements carefully. If, in fact, you have a similar point of view, please write Allan Rock and our Attorney Generals provincial and federal.

Phoebe McCulloch

April 21, 1998

(Editor's note: Please address any replies to this article to Ms. McCulloch, c/o the Victoria Office of HeCSC)



CLASS ACTION SUITS: BRITISH COLUMBIA

Camp Church and Associates
Sharon Matthews / Kim Graham
4th Floor, Randall Building
Vancouver, B.C. V6B 1Z5
1-800-689-2322

Grant Kovacs Norell
Bruce Lemer
Grosvenor Building
930-1040 West Georgia Street
Vancouver, BC, V6E 4H1
Phone: (604) 609-6699 Fax: (604) 609-6688

Before August 1, 1986
Klein Lyons
David A Klein
805 West Broadway, Suite 500
Vancouver, B.C. V5Z 1K1
(604)874-7171
(604)874-7180 (FAX)

also:

Dempster, Dermody, Riley and Buntain
William Dermody
4 Hughson Street South, 2nd Floor
Hamilton, Ontario L8N 3Z1
(905) 572- 6688

The toll free number to get you in touch with the Hepatitis C Counsel is 1-(800)-229-LEAD (5323).

ONTARIO

Pre 1986/post 1990
Mr. David Harvey
Goodman & Carr
200 King Street West
Suite 2300
Toronto, Ontario, M5H 3W5
Phone: 416.595.2300
Fax: 416.595.0527

TRACEBACK PROCEDURES:

This information is for anyone who has received blood transfusions in Canada, if they wish to find out if their donors were Hep C positive.

TRACEBACK INQUIRIES

Contact:
Dr. Lisa Jeppesen, Dr. P Doyle, or Glenda
The Canadian Red Cross Society
4750 Oak Street
Vancouver, BC, V6H 2N9
1-888-332-5663 (local 207)

Class Action/ Compensation

If you would like more information about the class action/compensation, you can contact:

Tricia Plunkett. Tel. (250) 479-5369

e-mail: plunket@islandnet.com

Meetings will be set up so that we can share our experiences dealing with lawyers, the results of our own investigations, and so that we can decide what is in our own best interest as far as legal steps to take.