



hepc.bull

BC's Hepatitis C News Bulletin

"Promoting HCV Wellness"

MARCH 2000

Issue No. 21

LAWYERS GET PAID, VICTIMS WAIT

By Joan King

"Nearly two years after federal and provincial governments promised compensation for tainted-blood victims with hepatitis C, not a single red cent has been given to the thousands of Canadians who qualify," says reporter Mark Kennedy.

Some of the Class Action lawyers, however, have received "interim" payments to cover their mounting expenses. The money, totalling approximately \$4 million, has been taken from the \$1.2-billion granted to the victims.

There is still a legal battle going on as to how much the Class Action lawyers should actually receive.

Among the lawyers who have been paid interim funds are Windsor lawyer Harvey Strosberg, who received \$3.2 million, and Vancouver lawyer J.J. Camp, who received \$950,000.

Toronto lawyer Bonnie Tough turned down the \$913,000, approved by a court, preferring to wait until her clients get their money. Quebec lawyers also chose to forego applying for interim funds.

In the meantime, victims are having to pay for home care and drug therapies out of their own pockets, or must sit and wait while their disease worsens, some no longer able to work and on disability pensions or welfare. Some, if they were to receive compensation based on the indications of their liver biopsies, would eventually get more than \$1 million, but those same people are denied disability benefits because it has been determined that they are not sick enough. And, as we well know, some victims have died waiting.

There is another problem. No one has yet been hired to administer the fund. That administrator would be in charge of reviewing the applications and handing out the cheques. Choosing an administrator may slow down the process even more.

Critics say that governments should have established a compensation program like they did in the early 1990s for HIV tainted blood victims.



LEARNING TO LIVE

By Dave Lalonde

My name is Dave Lalonde, my wife's name is Sharon. We joined the Hepatitis C Society of Canada a few years ago after being introduced to it, by Leslie Gibbenhuck. We also joined JJ Camp's "march to the altar" at that time. We requested a blood trace back be done as a result of blood my wife had received in 1988.

Sharon was the recipient of five units of blood with a wide range of unit numbers. She started to feel ill and tested positive for hepatitis C, in January 1997. I began to feel ill and tested positive in October 1997.

Until recently, we were resolved to accept our fate and "learn to live" with the tainted blood transfusion, with the knowledge that we would, at least, be compensated.

Camp's office cut us loose and returned our files one month before Christmas with a strong assurance that the cheque is virtually in the mail. The administrator had been accepted and compensation to all, forthcoming.

I have since found out that the lawyers have requested \$58,500,000.00 for their services, and that the Canadian Blood Services (CBS) has requested \$16,000,000.00 to complete trace backs, from the funds allocated to the victims of this tragedy. Yesterday, I became a tad impatient and called the CBS myself. After being told that the blood trace back would take a while longer, I suggested showing up on the front stairs with the news media. Within one hour, I received a call telling us that all five donors had been located and all five had tested negative.

This profound news leaves us to question their methods and tactics. How could this feat have been accomplished in just one hour, when for the past three years we had heard nothing at all? How is it that the same people who have lied, cheated, destroyed records and handed out bad blood can now determine this quickly what three years of waiting could not?

Sharon and I have been partners in life for 18 years with no drug abuse. I do have tattoos, however, the newest being 25 years old. My ex-relationship of 20 years ago and bearing a son now 19 years of age, show no indications of any hepatitis C.

We are now left to wonder about a very bleak future, and indeed will have to "learn to live" all over again with no hope of compensation.

PS: NO+TRACEBACK = NO MONEY

ASK THE ADVOCATE

Canada Pension Plan Disability Benefits—Part 1

by Sheila Puga,
Community Law Clinic, Vancouver

The Canada Pension Plan legislation is long and complicated. However, an advocate only needs to be familiar with a few sections of the legislation to work with clients who are applying for disability benefits. The two most important sections are 44(1)(b) and 42(2). Section 44(1)(b) outlines who a disability pension is payable to—someone who:

- i) is less than 65 years old;
- ii) is not receiving a retirement pension;
- iii) is disabled; and
- iv) has made sufficient contributions to the Plan within the contributory period, or
- v) would have qualified for a disability pension had that person applied sooner.

Section 42(2) defines "disability" under the legislation. In order to be considered for disability benefits under the Canada Pension Plan, the person applying must have a "severe" and "prolonged" disability.

A disability is considered severe only if that disability makes the applicant incapable of performing any substantially gainful occupation on a regular basis.

A disability is considered to be prolonged if it is likely to continue for a long time and be of indefinite duration, or is likely to result in death.

Most disability benefit applications are denied because the minister finds that the disability is not severe. However, applications may also be denied because the disability is not prolonged, or because the applicant has not made sufficient contributions to the plan. We will go into more detail in each of these areas in subsequent articles.

Appeal structure

There are three possible levels in the appeal process

1. A reconsideration request
2. The CPP Review Tribunal
3. The Pension Appeals Board

A reconsideration request

If an application for disability benefits is denied, the applicant can request a reconsideration within 90 days of receiving the denial letter. The reconsideration request is sent to the regional director (in Victoria). The request should be sent

(Continued on page 6)

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Please fill out & include a cheque made out to **HepCBC** - Send to:

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2741 Richmond Road
Victoria BC
V8R 4T3

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2741 Richmond Road
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REPRINTS

Past articles are available at a low cost in hard copy and on CD Rom. For a list of articles and prices write to HepCBC.

COMING UP IN BC:

Castlegar/Grand Forks/Trail Contact: Robin, 365-6137

Comox Valley Liver Disease Support Group Meetings: Third Tuesday of each month, 6-8 PM, St. George's United Church on Fitzgerald. NEXT MEETING: March 21st. Drop in daily for coffee. Contact: Ingrid or Nicky, 335-9167, nickyruessell@sprint.ca

Cowichan Valley Hepatitis C Support Contact: Debbie, 715-1307, mygirl@olink.net, or Leah, 748-3432, r_attig@bc.sympatico.ca

Downtown Eastside Hep C Support Group Meetings: Each Monday, 6 to 8 PM, Carnegie Center, 401 Main St., Vancouver. Contact Carolyn: momma@vcn.bc.ca

Enderby HepCURE Meetings: Last Sunday of each month, 2-4 PM, for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: March 26th. Contact: Marjorie, 558-7488. www.junction.net/hepcure/index.html

Kelowna HeCSC Meetings: Last Saturday of each month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: March 25th. Contact: Michael, 860-8178 or Elaine, 768-3573, eriseley@bcintemet.com

Kootenay Boundary Meetings: Second and fourth Tuesday of each month, 7 PM, 1159 Pine Ave. upstairs from Lordco auto parts. NEXT MEETINGS: March 14th and 28th. Contact: Brian, 368-1141, k-9@direct.ca or Pat, 364-1555

Mid Island Hepatitis C Society Meetings: Second Thursday of each month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St., Nanaimo. NEXT MEETING: March 9th. Contact: Susan, 245-7654, hepc@nanaimo.ark.com, or Rose, 714-1937.

Mission Hepatitis C and Liver Disease Support Group NEXT MEETING: Contact: Patrick, 820-5576.

New Westminster Support Group Meetings: Second Monday of each month, 7:00-8:30 PM, First Nation's Urban Community Society, Suite 301-668 Camarvon Street, New Westminster. NEXT MEETING: March 13th. Contact Dianne Morrisettie, 525-3790.

Parksville/Qualicum 1-291 East Island Hwy, Parksville. Open daily from 9AM to 4 PM, M-F. Contact: (250) 248-5551. dbamford@island.net

Penticton HeCSC Meetings: Second Wednesday of each month, 7-9 PM, Penticton Health Unit, Board rooms. NEXT MEETING: March 8th. Contact: Leslie, 490-9054, bchepc@telus.net

Powell River HepC Information and Support: Contact Cheryl Morgan for time and place info. 483-3804.

Prince George Hep C Support Group Meetings: Second Tuesday of each month, 7-9 PM, Health Unit Auditorium. Next Meeting: March 14th. Contact Sandra, 962-9630 or Ilse, ikuepper@pgrhosp.hnet.bc.ca

Prince Rupert Contact: April, 627-7083.

Princeton Meetings: Second Saturday of each Month, 2 PM, Health Unit, 47 Harold St. NEXT MEETING: March 11th. Contact: Brad, 295-6510, citizenk@nethop.net

Quesnel Contact: Elaine, 992-3640.

Slocan Valley Support Group Meetings: Third Tuesday of each month, 7-9 PM, W.E. Graham Community School Youth Centre, Slocan. NEXT MEETING: March 21st. Contact: Ken 355-2732, keen@netidea.com, or Community School Coordinator 355-2484

Sunshine Coast NEXT MEETING: Contact: Kathy, 886-3211. kathy_rietze@uniserve.com

Vancouver CLF Meetings: Second Thursday of each month, 7:30 PM, Nurses' Residence, VGH (12th & Heather). Signs will direct you. NEXT MEETING: March 9th. Contact: CLF, 681-4588, or Herb, 241-7766, HMOeller@compuserve.com

Vancouver Support Group Meetings Last Wednesday of each month, 10:30-12:30, BC CDC Building at 655 West 12th (12th and Ash, next to the Cambie Street City Square Mall- park here) There will be someone outside the building to direct. NEXT MEETING: March 29th. Contact Darlene N., 685-3813, djnicol@atglobal.net, or Darlene M., 608-3544, hepcvsg@canada.com

Vernon HepCURE Meetings: First Tuesday 12-2 PM and third Tuesday of each month, 6-8 PM, the People Place, 3402-27th Ave. NEXT MEETINGS: March 7th and March 21st. Contact: Marjorie, 558-7488. www.junction.net/hepcure/index.html

HEPLIFE, Vernon HeCSC Meetings: Second and fourth Wednesday of each month, 10 AM-1 PM, The People Place, 3402-27th Ave. NEXT MEETINGS: March 8th and March 22nd. Contact: Sharon, 542-3092. sg-grant@home.com

Victoria HeCSC Meeting: Last Wednesday of each month, 1-3 PM and 7-9 PM, NEXT MEETING: March 29th. Contact: 388-4311. hepcvic@idmail.com for possible new location.

OTHER PROVINCES

Central Alberta CLF Hepatitis C Support Group Meetings: Every 2nd Thursday of each month, 6-8 PM, Provincial Building, Room 109, 4920 51 St., Red Deer. Enter at southeast entrance. NEXT MEETING: March 9th. Contact Shane, 309-5483.

Durham Hepatitis C Support Group Meetings: Durham Region Health Dept., 1615 Dundas St. E., Whitby Mall, Whitby, Ontario. (Call for directions.) NEXT MEETING: March 2nd, 7-9 PM. Speakers: Dr. Peter Campbell, Gastroenterologist, Martha Attley, R.N., Rebetrn Support Nurse, and Jennifer Crowe, Schering Plough Canada. Contact: Jim 743-0319, tndrhart@idirect.com or Smilin' Sandi smking@home.com, <http://members.home.net/smking/>

Edmonton, Alberta Hepatitis C Informal Support Group Meetings: Every third Thursday of each month 6-8 PM, 10230-111 Avenue, Edmonton, Conference Room "A" (basement) NEXT MEETING: March 16th. Contact: Tracey Peddle, NitNGale@telusplanet.net or Jackie Neufeld: 939-3379 Parking: Meter Parking (underground and surface) roughly \$3 per evening. Free street parking.

Hepatitis C Society of Ottawa-Carleton Centertown Comm. Health Center, 420 Cooper St. (Ottawa) between Bank and Kent St. We offer one on one peer counseling Mon. afternoons. NEXT MEETING: March 21st. Contact: 233-9703 or sue.rainville@sympatico.ca

Kitchener Area Chapter Meetings: Every 3rd Wednesday, K-W Elks Lodge, 38 Bridgeport Rd E, Waterloo, 7:30 PM. NEXT MEETING: March 15th. Contact Carolyn, 893-9136 or annetteb@golden.net

NOTE FROM DURHAM

We had 20 people at our last meeting and with more exposure and more phone calls, we expect even more. I have heppers coming from Peterborough and Kingston as well as our own area.

I was able to contact book some great speakers for the meeting. It should be very informative.

Thanks,
Sandi



SQUEEKY'S CORNER

Well, I hope this issue serves as a wake-up call. Please pass it on to your neighbours, your physicians and others you know who might be under the mistaken impression that things have changed for the better with respect to HCV.

As they say here in Canada... "plus ça change.."

Let's talk about the traceback, about Dave and Sharon and you and me. Does anyone find it odd that so few located donors actually test positive? I certainly do, and I'm not alone.

Over 2 years ago, I wrote the Red Cross informing them that I had given blood quite often and that not only would my providing them MY records help them to see if, *God forbid*, I had unwittingly infected another, but, as I argued, my records could also help establish the date of my infection.

I have a card at home which indicates that as of October 1977 I had donated 8 pints in Canada. Later I moved to Britain where I had donated another 5, and then when I came back to Canada in 1982, I donated blood at various university drives in Montreal. I can't remember exactly how much, but it was at least another 5 pints, if not more.

So: if I was infected by the gammaglobulin injections I had in England in 1980 (massive intramuscular and then IV drip), NONE of the individuals who received my blood before 1977 should have been infected. If, however, I was infected earlier, then all 18+ pints were tainted. On the other hand, if only those after 1982 in Canada were infected by my blood then we would know that I contracted it in England.

Also: what if those who received my blood between 1977 and 1988 were not infected, but only those who received blood I donated at McGill blood drives? What would this mean? Did I get HCV when I was teaching in Prince George from a barber or a dentist? Certainly a traceback of my donations would be quite revealing.

Recently one of our members on the HepCAN posted with regard to the same issue. She says: "I donated blood years ago after I was infected and I have never received a letter from CBS." And what about a letter we printed in the bulletin 2 years ago in which the writer tells us that she was:

- Infected in 1978
- Began donating in 1980
- Was called many times to come in for donation
- Was called in 1988 and offered cab fare to come in and donate
- Was notified in 1993 that she was HCV positive.

What about those who received her blood from 1980 to 1990? And more astonishingly, what of those who received her blood after 1990 when the **blood supply was supposed to be safe?**

I urge you to join me in a campaign to demand accountability from the CBS in this regard. If you have a similar story, please send it to me c/o the *hepc.bull* (see page 2) and I will present them in the flesh to the appropriate persons.

C.D. Mazoff

VIRAL HEPATITIS: MORE THAN THE ABC'S

UVIC Continuing Ed Course

Instructor: Wayne G. Ghesquiere, M.D., F.R.C.P.(C), is an infectious diseases and internal medicine specialist practicing in Victoria.

Course Code: HPCE186 2000S1 S01

Date: Wednesday, March 8: 7 to 9:30 pm, 1 session

Fee: \$32.10 (includes \$2.10 GST)

Registration: (250) 472-4747

Fax/Registration: (250) 721-8774

E-Mail Registration: register@uvcs.uvic.ca

Web Site: www.uvcs.ca

Health and Wellness Department: (250) 721-8558

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More of Peppermint Patti's FAQ are now available. The new version includes an HIV co-infection section as well as updated Canadian Links. Place your orders now. Over 100 pages of information for only \$2 each plus S&H—but if you can afford more we'll take it. Contact HepCBC at (250) 361-4808, or at the address on page 2, "How to Reach Us."



HepCBC acknowledges the personal donations, donations in kind received to date, and the following for discounts, donations of services, or equipment: The BC Ministry of Health, Steve Orcherton, Fernwood Home Services, Kiwanis, CFAx 1070, AM 900, CompuSmart, BC Transit. We also wish to acknowledge the generosity of the residents of VIRCC, Uncle Dave The law firm Woods Adair, D. Putsey, John and Shirley Hiley, Cassandra McColm, Christina M. Reid, and some wonderful anonymous donors. Additional thanks to Margison Bros. Printers. Special Thanks this month to Jerry & Esther Dewit, and to Frank & Arlene Darlington

To the Editor:

Re: Fundraising

Fundraising for many non-profit groups is a matter of staying viable. There are some groups who, through good fortune or management, have a constant and unvarying income from commercial or other sources. The average non-profit society, however, must constantly scramble to attract funding. There is an alternative way which many organizations employ for fundraising. This is the method used by public television, Timmy's Telethon, B.C. Heart and Stroke Foundation, Canadian Cancer Society and other worthwhile groups.

We, as a family, donate to many of these causes. We have had relatives and friends pass away from cancer, heart disease and hepatitis C. I could list all of the needy causes from the Salvation Army to the local food bank, but the point I am trying to make is that direct participation by donation is a recognized part of our democratic society. We believe that the time has come for us as individuals to help all the Hep C victims in British Columbia.

We have a brand new society formed. It is a registered society called *HepCBC Hepatitis Education and Prevention Society*. A tax refund status has been applied for. This new group is applying for funding through government sources, but like all government assistance programs this takes time. Money is needed now to provide the services envisioned.

We have donated a modest amount to this new group because I have hepatitis C and this society will provide educational information for all B.C. We invite you, the hepatitis C victims and your families, to play a direct part in the education and prevention of this debilitating virus by donating to **HepCBC** at: 2741 Richmond Road, Victoria, B.C., V8R 4T3.

Frank Darlington

Dear Editors:

I began treatment for my Hep C last April. My doctor told me that I had the strongest strain and that nothing, so far, had been successful. I first heard of the dual therapy from you, and when I asked my doctor about it, he felt that it might at best lower my virus rate, since I was critical. After two months my virus levels dropped and after three months they weren't even detectable. After six months he could not detect the virus in my blood at all.

I just thought that you might have the resources to pass this on. I thank God for Rebetrone and my prayer is that this is the cure for Hep C.

I would love to hear from others with Hep C.

Your friend,

Gary

GMuffitt@aol.com



WHAT'S NEW

HCV AND MUSCLE INFLAMMATION

A Hep C patient with weakness in the right arm and leg and high creatine kinase levels had a muscle tissue biopsy done. The tissue was studied using immunocytochemical and polymerase chain reaction (PCR) techniques.

The biopsy showed hepatitis C virus in the muscle of the patient, along with immunological reactions and inflammation, which suggests that **the virus may induce muscle damage.**

Acta Neuropathol (Berl) 2000 Jan 31;99(3):271-276:Hepatitis C virus infection and myositis: a polymerase chain reaction study. Villanova M, et al, Laboratory of Neuromuscular Pathology, Istituto Ortopedico "Rizzoli", Viale Pupilli 1, I-40136 Bologna, Italy—PMID: 10663969

ARE YOU A MUTANT? (It's Okay to Blame Your Parents)

Scientists have found that some people of European descent have mutated genes that make them immune to most kinds of HIV infection, and now investigators in New York have found that these same genes may also protect these people from HCV.

Normally HIV uses ccR5 receptors to enter cells, but these mutated receptors are "defective" and don't let the virus in. People may inherit the mutated gene from just one parent, and may become infected, but aren't likely to develop AIDS, but if they inherit the gene from both parents, the person can only rarely be infected with HIV. The NY investigators have found that those with the mutated gene have a lower viral load of HCV than normal patients, and it is twice as probably for them to spontaneously clear the disease.

In a study of 79 co-infected patients, they found that 20% inherited the mutated gene from one parent. One woman patient had been an IV drug user for around 20 years and never got HIV or HCV, even though she shared needles with infected people.

Doctors at the National Cancer Institute are studying haemophiliacs who are co-infected, and have found that the gene does not seem to protect them from infection with HCV. It remains to be seen if their survival rate is better. Perhaps these studies will lead to gene therapy.

*Mutation May Offer Hepatitis C Defense, Laurie Garrett, Staff Correspondent, Newsday - Tuesday, February 1, 2000
<http://www.aegis.org/news/newsday/2000/ND000201.html>*

ARTIFICIAL LIVER

VitaGen's Extracorporeal Liver Assist Device ("ELAD") an artificial liver "is the first medical device of its kind to incorporate "immortalized" human liver cells. Other devices utilize pig cells, which can only be used for eight hours at a time. **The ELAD enables treatment to be performed 24 hours a day for up to 10 days.** Clinical trials are currently being undertaken. For more information about the company or the ELAD clinical trials, please call Cynthia Hoy of VitaGen at 858/552-1522.

LA JOLLA, Calif.--(BW HealthWire)--Feb. 9, 2000

RECYCLING MEDICAL DEVICES

To us, Hep C sufferers, it is just too horrible to contemplate: In the US it is being discovered **that medical devices intended to be disposable are being sterilized—hopefully—and reused in more patients.** Yes, of course, recycling is good, but just how safe is re-sterilizing? This practice has not been regulated, but now the FDA is looking into the matter. Is this going on in Canada, as well? There have been reports in the US of reused materials breaking or causing infections. Is it worth it, just to save money? We've already been through that, with the blood supply. And we know from reports how hard it is to kill the hepatitis C virus.

The FDA says it doesn't have evidence that reusing devices is riskier, saying that brand new devices can break, and many devices are made to be reused, and they, too, cause infections, if not properly re-sterilized. Still, the FDA has decided to propose that hospitals and re-sterilizing companies be obligated to prove they can safely clean these devices, and to determine how many times they can be safely reused.



*FDA Targets Recycled Medical Devices By Lauran Neergaard
AP Medical Writer
Thursday, Feb. 10, 2000; 4:38 p.m. EST*

TREATMENT

TRIPLE THERAPY

A study was done on Hep C patients who did not respond to interferon. The purpose of the study was to test the safety of a combination of 6 months of interferon, ribavirin and amantadine. The 20 patients were divided into two groups, one group receiving a combination of IFN plus ribavirin and the other group receiving the triple therapy.

By the end of therapy, 2 out of the 10 patients on double therapy had normal ALTs versus 7 out of 10 who were on triple therapy. One patient taking double therapy had a negative viral load, compared to seven taking triple therapy. Six months later, the patient on double therapy had normal ALT levels, as did 4 patients on triple therapy. None of the double therapy patients sustained a negative viral load, but 3 patients on the triple therapy had a sustained virological response.

Triple therapy may be more effective than double therapy in non-responders to IFN alone.

Pilot study of triple antiviral therapy for chronic hepatitis C in interferon alpha non-responders. Ital J Gastroenterol Hepatol 1999 Mar;31(2):130-Brillanti S, et al, Dept. of Internal Medicine and Gastroenterology, Policlinico S. Orsola, U. of Bologna, Italy—PMID: 10363198, UI: 99291377

Book Review

The Hepatitis C Handbook

By Will Lawson

If you have been told that you have Hep C, but not what you can do about it, I would like to suggest a book that is a very good place to start.

It is *The Hepatitis C Handbook* by Matthew Dolan et al. (Berkeley: North Atlantic Books, 1999, ISBN 1-55643-313-1, 473 pp., CDN\$38.95).

I am no expert on either the disease or the literature, but I have spent money on two or three other books, and this one is far superior. Dolan understands you; he has the virus too, and so do a lot of the people he knows.

The purpose of the book is to inform and, by informing, to empower.

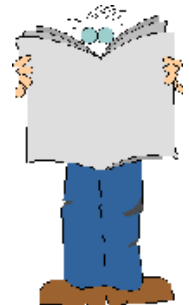
You will find it, in everyday English, a description of the disease and all of its suspected symptoms and manifestations. This includes many verbatim testimonials by other sufferers. You are not alone with all those nasty ailments that your doctor denies have anything to do with the virus—but can't treat either.

You will find a broad description of the various tests, and current approaches to treatment and coping, from diet to Qigong, from interferon to urine drinking—?? Dolan obviously sees great promise in traditional Chinese medicine, but he approaches the pros and cons of all of these with objectivity and intelligence. This is because, as he freely admits, and as you probably suspect yourself, no one knows for certain what is to be done with this disease.

You will also find sufficient technical treatment of these subjects, and references to hard scientific and other literature, to interest and earn the respect of your GP. (Lend him/her your copy with instructions not to come back until he/she has read it.)

Finally, you will find, if not guarantees, at least sincere and informed encouragement that there is worthwhile action which you can take in your treatment and lifestyle.

If you're determined to fight back, I think *The Hepatitis C Handbook* is a good place to start



RECOMMENDATIONS AND WARNINGS

HAVE YOU CHECKED YOUR TRIGLYCERIDES?

A case of hypertriglyceridemia, or high triglycerides, associated with IV interferon use for melanoma was reported in the cited article. This is important because **high triglycerides provoked by interferon (IFN) can cause a potentially life-threatening case of pancreatitis.** It is important to diagnose this problem early so that it may be treated. The problem of high triglycerides during IFN treatment has been reported several times during the past 10 years, and usually goes away after stopping treatment. The above mentioned case did not go away, even after almost one year. In spite of a high incidence rate (15 to 90%), the problem is not listed as an adverse reaction. Levels exceeding 1,000 mg/dL are thought to be capable of causing acute inflammation of the pancreas. **As use of IFN increases, doctors should be aware of this possible complication.**

Drug-Induced Hypertriglyceridemia With and Without Pancreatitis. [South Med J 92(9):912-914, 1999. © 1999 Southern Medical Association]

HEP C FROM SURGEON

Doctors at the Pilgrim Hospital in Boston, Lincolnshire, England, found that a surgeon passed hepatitis C on to one of his female patients during an operation in 1997. Around 1500 women and children will be tested for the virus as a result.

*Tuesday, October 26, 1999
<http://news2.thls.bbc.co.uk/hi/english/health/newsid%5F486000/486814.stm>*

SAM-E: THE WONDER SUPPLEMENT?

Feb. 7 - Some say SAM-e, the latest fad in dietary supplements, can treat an amazing variety of health problems—a claim that has led to its use by more than 140,000 people, mostly women, nationwide. But others argue that the evidence for its effectiveness is lacking.

"This drug is supposed to cure depression, sexual dysfunction, liver disease, diabetes, nerve trouble and arthritis," said Dr. Robert Packman, at the University of Washington in St. Louis.

SAM-e is actually a laboratory-produced version of a chemical found naturally in the body—part of the process for burning energy. It's expensive, costing \$75 to \$200 a month depending on the dose

Packman has extensively reviewed the studies to date and says they don't prove much. "What I think is actually happening in the case of SAM-e is a placebo response." Apart from whether SAM-e works, there are also questions on whether people who buy it may not be getting what they think—in fact, some of these capsules may contain no SAM-e at all.

The laboratory for Good Housekeeping analyzed samples of eight brands. Five contained more SAM-e than the label said, two had less and one had none.

"We were not able to detect SAM-e. Now, the label claim on the product is 100 milligrams per tablet," said Dr. Gerald Buonopane of the Good Housekeeping Institute. These types of questions about scientific proof and proper labelling are common complaints these days in the \$14 billion a year dietary supplement industry.

Source: MSNBC News

HEPPER HELPERS

Okay, well, I did it! I started a group for supporters on egroups. I have never managed an egroups list before, so anyone who joins please be patient with me! The list is called Hepper Helpers.

Here is the necessary info for any supporters who want to join, or any of you who would like their supporters to join!

1. Users add themselves by entering their e-mail addresses into the membership form found with the group's messages on the eGroups.com site.

OR

2. Users send an e-mail to hepelpers-subscribe@egroups.com

OR

3. Of course, I can sub you with your email.

I am going to give this my best shot. I would love to have someone help me run it since I will be having this baby in another 15 weeks. But if not, that's cool, I will get Gareth or Stonie to help me. I hope this works out and provides a much needed service!!!

Hepper hugs and love to all,
Janece janece@somerled.net

THE CO-INFECTION SECTION

A SIMPLER FORM OF INTERFERON

A report from the 7th Conference on Retroviruses and Opportunistic Infections, January 30 to February 2, 2000, San Francisco.

A disadvantage of current formulations of interferon alpha is that they must be injected often, usually three times weekly. To help simplify interferon treatment, researchers have developed a new formulation of interferon alpha that is joined to a compound called PEG, which stands for polyethylene-glycol. This combination of interferon and PEG is called pegylated interferon or PEG interferon. PEG interferon remains in the blood at high levels for longer periods of time than regular interferon. As a result, it needs to be injected only once a week.

PEG interferon may offer not only a simpler dosing regimen than regular interferon but also a therapeutic advantage. When regular interferon is administered three times weekly, hepatitis C virus (HCV) levels fall after each injection but quickly rise as levels of interferon drop. Since PEG interferon levels remain high for longer periods of time, HCV production is more effectively suppressed than with regular interferon. (Various sources)

Although PEG interferon is being developed for the treatment of hepatitis C, it may also be useful against HIV. The following article presents preliminary results from a trial of PEG interferon in people with HIV infection.

PEG interferon -- A new weapon against HIV?

Researchers in France recruited 31 subjects co-infected with hepatitis C and HIV for a study designed to assess the safety and anti-HIV activity of PEG interferon. Half the subjects had a CD4+ count below 378 cells and the mid-way point for the group's viral load was 24,000 copies. Fifteen subjects were taking triple combination therapy, eight others were taking two nucleoside analogues and the remaining eight were taking four or five drugs. Subjects received PEG interferon injections at doses ranging from one to 3.5 micrograms per kilogram of body weight once weekly for eight weeks.

The researchers found that CD4+ cell counts did not change during treatment. Viral load, however, fell quickly within the first week and remained at about 10 per cent of its pre-study level. Two subjects did not complete the study, one because of tiredness and depression and the other for personal reasons.

The drug was well tolerated according to the researchers, although all subjects experienced such side effects as fatigue and muscle aches. Further research is needed to establish the best dose of this product to use as well as the duration of its effect against HIV. PEG interferon should be licensed for the treatment of HCV in North America within the next 12 months.

From Community AIDS Treatment Information Exchange (CATIE). For more information visit CATIE's Information Network at <http://www.catie.ca>

Hepatitis Day
Saturday March 4 2000
10:00 am to 8:00 pm
Carnegie Community Center
401 Main Street (corner of main and Hastings)
Vancouver BC
Information booths, Pharmaceutical Companies
workshops, panel discussions
community walkabout, speakers, videos
lunch, dinner, coffee and refreshments
Sponsored by:
DTES HIV/IDU Consumers' Board
Carnegie Community Center
B.C. P.W.A.
AIDS Vancouver
For further information please contact
Carol Romanow (604) 899-9401
momma@vcn.bc.ca
or
DTES HIV/IDU Consumers Board
(604) 688-6341 cnsbd@direct.ca
Everyone Welcome !
If you or your group are interested in providing an information table please contact me. There is no charge for non-profits !

TRANSFUSED? HAVE YOU GOT A COMPLETED TRACEBACK?

In the January 2000 *hepc.bull*, some may have noticed that on page 7, I recommended getting our Canadian Blood Services (CBS) traceback completed as soon as possible, and, on page 8, David Klein cautions to not do the traceback. I have no idea how many calls he got on the subject, but I do know how many I got!!

In order for transfused victims to be compensated, it is believed you will have to have a completed traceback, or the file number from a started one, and this must be given to the administrator for them to complete on your behalf. Either way, it appears the traceback will have to be done!

A traceback is not any of the paperwork British Columbians may have received from the provincial government. That is called a lookback. The traceback involves the CBS contacting those who donated the blood you received, requesting that the donor get tested, and informing you of the results of those tests.

From a letter addressed to me from Camp Church and Associates, dated November 24th, 1999 on the subject of tracebacks: "All issues pertaining to tracebacks are still being resolved. We are confident that problems associated with getting tracebacks done and getting the results of tracebacks will be resolved in short order."

Now, if you were following the events leading to today, you would be aware that the CBS has requested 16 million dollars from the victims' compensation fund to conduct and complete the required tracebacks. When the CBS went to court over this, the Judge reserved his decision (meaning he will decide at a later date) but did not say NO to them—this in the light of a guarantee of smooth transition between Red Cross and CBS by CEO Lynda Cranston. "In short order" may then mean the CBS will get awarded the money they have requested, and they will make all of the potential claimants happy by providing them with prompt, completed tracebacks. From the same letter by Camp Church and Associates, on the subject of class members' files and documents, it is stated that: "To make a claim your client will need to have certain records such as hospital records, traceback results, antibody test results, PCR test results, etc."

Money set aside to compensate the victims of a healthcare disaster unprecedented in Canadian history may very well be allocated to locate the very people who infected those victims in the first place. In other words, the victims will bear the costs of the required tracebacks. Many victims have been waiting more than three years to hear the results of their tracebacks. Repeated calls to the CBS are answered by "we are too busy," "we have no time" and "we may get around to sending out your results in a few months." How long are the victims expected to wait in order to find out if they qualify for compensation? Why won't the Federal government force the CBS to complete tracebacks in a timely fashion and report the results in writing to victims right away? After all, the CBS is simply the Canadian Red Cross with a name change.

There is mounting frustration among the victims. They feel they are being stalled and fear they may never see the money referred to in the same letter of November 24th, 1999. Persons are calling the CBS and making demands for the results and vowing to bring the media with them to wait at the CBS, until the traceback is complete.

Dave and Sharon were told, after three years of waiting, that the results would be awhile longer. At the mention of the media, the results were relayed to them within 1 hour!!! Amazing but true. They were told no donors tested positive. How convenient!

I believe this whole class action turned compensation is a travesty. The victims of bad blood are victimized again and again. Many have waited years for diagnosis, being told the illness was in their heads! They have been told to wait an unreasonable amount of time (four years) for the results of Krever, only to watch as his number one recommendation is ignored. In March and April 1998 the sick and dying were forced from their beds to demand compensation for all. They fought a good fight, but lost. The government would not budge on compensating anyone outside of the 1986 to 1990 time frame. The lawyers were meeting behind closed doors, banging out a deal, excluding from these discussions the victims who had hired them in the first place. The lawyers were hired to represent the best interests of the victims, protect their rights, get their information and to fight for justice.

The victims have been forced to wait for two years while the RCMP traverses the world putting together enough information to possibly recommend charges against the persons responsible for poisoning the victims and robbing them of their health. The victims have had to wait for years for the results of tracebacks, only to be told the donors' right to privacy supercedes their right to see the results of the donor tests. The victims are still waiting on judges to finalize everything, so that the cheques promised can get to the hands of those for whom they are intended—the victims. The victims, poisoned by tainted blood have no rights, no say and are losing hope! Lawyers have succeeded at keeping them in the dark for so long, they are beginning to believe they are mushrooms. Their fate has been determined by those who condoned the poisoning and the lawyers who will get rich off the backs of the sick and dying.

(Continued on page 7)

(CPP DISABILITY—Continued from page 1)

by registered mail to ensure that it is received within the limitation period. Any additional information to be submitted to CPP for their consideration should be sent with the request or as soon as possible after. The minister makes a new decision based on all of the information he or she has received. There is no hearing at this level.

The CPP Review Tribunal

A refusal of the reconsideration request can be appealed to a CPP Review Tribunal. Such an appeal must be requested within 90 days of receiving the reconsideration decision. The review tribunal is made up of three members. The chair of the tribunal is a lawyer. One of the panel members must be from the medical profession, and is often a doctor or nurse, although this person could be someone from a number of other professions within the medical field.

The review tribunal considers all of the medical evidence, as well as the verbal evidence provided by the appellant and any other witnesses, at the hearing. The minister is represented by a regional representative. The decision of the review tribunal is mailed to the appellant and the minister after the hearing ends.

The Pension Appeals Board

The decision of the review tribunal can be appealed to the Pension Appeals Board. This is the last possible level of appeal. To appeal to the board, the appellant must first obtain leave to appeal from either the chairman or the vice-chairman of the board. Both the minister and the applicant have the right to ask for leave to appeal to the Pension Appeals Board. Therefore, a win at the review tribunal level does not necessarily mean that the applicant will receive disability benefits. Benefits are not paid until the minister has decided whether or not to seek leave to appeal further.

The board is the most formal level of appeal in the CPP process. The appeal is conducted in the Federal Court of Canada, before federal court judges. Although the board is considered to be an administrative tribunal, its format is much more judicial than most tribunals in administrative law.

Most disability benefit appeals at the board level are heard before a panel of three federal court judges, although some appeals may be heard before a single member. A majority decision is required in order to succeed in the appeal.

An appeal before the board is considered a trial *de novo*. That is, it is a new hearing, and the case is reheard in its entirety. The onus is on the applicant to show that he or she meets the eligibility requirements for the benefits he or she seeks. This is the case whether the applicant is the appellant or the respondent in such an appeal.

The minister is represented by a lawyer at the board. The minister calls a doctor, employed by CPP (who has never examined the applicant), to present the evidence used by the minister to find that the applicant does not qualify for disability benefits. The applicant is then given an opportunity to cross-examine this medical witness.

Both CPP Review Tribunals and the Pension Appeals Board have their own rules of procedure, which should be consulted before initiating an appeal at either level. Failure to do so may prevent an appeal from proceeding, especially at the board level.

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CUPID'S CORNER

This column is a response to requests for a personal classified section in our news bulletin. Here is how it works:

To place an ad: Write it up! Max. 50 words. Deadline is the 15th of each month and the ad will run for two months. We'd like a \$10 donation, if you can afford it. Send cheques payable to **HepCBC**, and mail to **HepCBC, Attn. Squeeky, 2741 Richmond Road Victoria BC V8R 4T3**. Give us your name, tel. no., and address.

To respond to an ad: Place your written response in a separate, sealed envelope with nothing on it but the number from the top left corner of the ad to which you are responding. Put that envelope inside a second one, along with your cheque for a donation of \$2, if you can afford it. Mail to the address above.

Disclaimer: The hepc.bull and/or HepCBC cannot be held responsible for any interaction between parties brought about by this column.

Ad No. 10

Respectful, respectable man (49) but looks younger who is very active and loves life. I'm 6' tall, 210 lbs. and considered nice looking, emotionally and financially secure and non-symptomatic. I won't let Hep C rule my life and am looking for a positive female to share a long-term happy life together. Vancouver area.

Ad No. 14??

Attractive, healthy, working male seeks female companion and/or roommate 28-38 yrs. Newly renovated 2 bedroom house. Great kitchen, garden, yard, etc. Fernwood area in Victoria



(TRANSFUSED?—Continued from page 6)

The lawyers in Ontario and Quebec will go to court to request their portion of fifty two and a half million dollars plus six million in taxes, on the day set for lovers—Valentine's Day, February 14th, 2000. They who sat in back rooms cobbling together a sweetheart deal will see their full payout before any victim even gets to level two! Some of the class action lawyers have succeeded in getting appointed to joint counsel, thus guaranteeing themselves yet more money from the fund set aside for the victims of tainted blood.

Lawyers downplay their fees and do not like to talk about the excessive amounts they will be asking for. Lawyers have cleverly split the fees up, so that the BC lawyers request 15 million dollars, the Ontario lawyers, 15 million, and the Quebec lawyers, 15 million, and the lawyers representing hemophiliacs, 7.5 million. That totals exactly 52.5 million dollars, as allowed for in Eckler Partners actuarial report of July 1999. If these legal fees are reasonable, why are lawyers reluctant for the public, especially the victims, to know what is going on? The victims have not been forewarned about any court dates. News of B.C. fee approvals has been kept secret. Why has Camp Church written to me, asking for retractions about the fees and recommendations (November 17th, 1998) and requested I change the wording surrounding fees on a commentary I wrote (March 12th, 1998)? I stand by everything I have ever said.

Do the lawyers not realize we are tired of waiting, too? Hepatitis C has cost some people everything they have worked for their entire lives, eaten up savings and retirement nest eggs, forced people into bankruptcy. Can the lawyers recall the names of those who have passed away without fanfare or headstones, as penniless families have mourned alone?

So much time has ticked by since first we heard a "settlement agreement" had been reached just before Christmas 1998. This fund was intended for the victims, but they have not seen a penny. In my opinion, only greedy class action lawyers will benefit from this tainted blood disaster!! I am so tired of being asked, by friends and family, what we have done with all our money, so tired of the media portraying this as a dead issue, so tired of the Hepatitis C Society of Canada telling members, "Now that we have resolved the issue of compensation, it is time to get on to other things"!!! Agreed, there are a lot of hepatitis C issues that we need to work on but Back up the bus!

This issue appears to be far from resolved. Rumour has it the administrator has been rejected by the Quebec Judge and new dates have been set in the courts to review the administrator. The victims have not received a penny. Yet another delay! Victims groups requested those in desperate situations to be advanced some funds, only to be told the settlement would be "soon". That was two years ago! Hepatitis C, and least of all compensation for the thousands of Canadians infected with it, is not a dead issue! We must have media and political help to resolve this situation. The victims, as sick and tired as they are, must collectively start screaming murder!

What if you have waited years, believing all along that you were infected through a transfusion, suddenly you are told no donor tested positive. You, like Dave and Sharon, are now out in the cold and no lawyer will want you. You can no longer look forward to compensation covering you when you are too sick to work, cannot look forward to it reimbursing your out of pocket expenses and definitely not the cost of your transplant.

But now I see it differently. Few will qualify for compensation because records will be incomplete. The fund will, indeed, be robust!! Despite some documentation, the CBS will report that their records

HepCAN DATABASE

Did you know that the HepCAN site has a searchable database with thousands of articles on hepatitis C? The "INFO" posts are updated daily, and cover subjects such as nutrition, treatments, side-effects, complications, alternative therapies, related illnesses, and more.

To search the database go to <http://www.egroups.com/group/hepcan/> and type in the words you are looking for in the "search" box. If you need help, click on the help button at the top of the page and it will give you instructions. Remember if you want to find a phrase, i.e., Alpha Lipoic Acid, type it in this way: "Alpha Lipoic Acid," otherwise you will just get every post that also contains the word "Alpha," which in our case can be a lot—Intron alpha 2b.

If for some reason you cannot find what you are looking for, just drop us a line at hepcbc@pacificcoast.net or post your question to the [HepCAN](#) list itself and someone will get back to you with the answer you need.

indicate you never got blood from the Red Cross or that no donor tested positive. What will you do then? You will be out and on your own. It will be too late for planning for your future, the powers that be will have determined it for you. Accept your fate learn to live with it

The victims are broken, beaten down by the very system set in place to help them. They have lost their fight and their energy. They are sick and dying. For too long they have been kept in the dark and have become accustomed to not knowing what is happening, believing the lawyers they hired would do the best they could for them and would contact the clients whenever they had something important to say. They have no idea what has taken place in December 1999 or in January 2000. They mistakenly believe claims would have started to be paid in mid-January, when the appeal periods expired. They have no idea how much work is ahead of them and how many documents must be verified before they will ever see a cent. They are at least 6

(Continued on page 8)

(TRANSFUSED?—Continued from page 7)

years sicker than they would have been if hepatitis C had received the same swift compensation as those infected with HIV. All transfused with HIV/AIDS were compensated—no time frame, no traceback!!

The federal government has generously set aside 50 million dollars over the next five years for care, awareness, education, support and research. That works out to 10 million per year for the 400,000 infected with hepatitis C in Canada. That computes to just \$25.00 per year per HCV infected individual!!! The federal government should take a lesson from themselves: they have even more generously allocated 47 million per year to cover the same issues with HIV/AIDS, yet HIV/AIDS infects less than 50,000 Canadians. That works out to over \$900.00 per infected person. Why does HIV/AIDS deserve more than HCV? It is obvious—HCV is not the politically correct disease.

Mr. Paul Martin has no idea how to spend the surplus he claims the government will accumulate. Ask the victims of this disaster about the quality of their health care. Ask them if they think \$25.00 per individual is enough, then triple the current health care transfer payments to each province and match the HIV/AIDS funding for the HCV program, just for a start.

Finally I have to ask who is representing the victims of this disaster? Camp Church and Associates, the lawyers I hired to represent my son's best interests, will not even return my telephone calls and will only respond to simple yes/no questions via fax. The response I am referring to took one week and two requests to finally get. So who do they care about, and who are they protecting?

Somewhere along the way, the victims of this disaster have been forgotten by everyone—lawyers, media, politicians and the national stakeholder organisations supposedly there to protect them. Maybe the victims were never considered in the first place.

Please, don't abandon us until the cheques are cashed and every victim is satisfied that they have not been forgotten! If information presented here is incorrect, I ask that the class action lawyers come forward with proof to the contrary. If information is not shared, it becomes obvious that rumours start and it is important to keep all victims informed with only the facts. I have attempted to do this all along.

Leslie Gibbenhuck 180 Kruger Place,
Penticton, B.C., V2A 8H4
(250) 490-9054, (250) 490-0620
bchepc@telus.net



CHECK YOUR DATES

The latest numbers for Nova Scotia are in: There are 458 know cases of PTI Hep C—170 pre-'1986, 195 in '1986-90 and 93 post-1990. According to this the PTI rate only dropped by 53%, not nearly enough to reflect testing all the blood. Is it possible that, like they did with the old untested HIV stock, the Red Cross- and the government-run health care system used up the old, untested stock before switching?

If you were infused after the test date, and with frozen products, this could run for over a year or more. Talk to a lawyer and have a trace back done on the **dates the product you were given was taken, not when you received it.** If it was a pooled product, the danger for this is even greater, so push to have the numbers from the original pool checked. They must exist somewhere.

Check the numbers in your own province and see if they are the same as ours.

Bruce DeVenne
Hepatitis C Society of Nova Scotia
bdevenne@sprint.ca



Dear Squeaky,

Thanks for your forwarding Leslie's e-mail to me so promptly. It is much appreciated and very informative. No wonder I, too, have been given such a runaround. It is endemic in this crazy bureaucratic nightmare we now call Canada. Where did our freedoms go? Into some capitalistic bottle corked up for the very rich and influential, to be opened when the poor and suffering have been eliminated? I know this is harsh talk, but I'm dying, and there is no way out for us. At least give us some dignity in our slow inevitable struggle to stay alive. The system has the money. Let's put it in the hands of the suffering. I'm quite sure we could manage it better.

Enough of that outburst. Peace to all, and the best of what health we have left.

Smiles,
Rob Crosson

CLASS ACTION SUITS:

BRITISH COLUMBIA

Camp Church and Associates
Sharon Matthews / Kim Graham
4th Floor, Randall Building
Vancouver, BC V6B 1Z5
1-(888)-236-7797

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 or 1990-1991
Klein Lyons
David A Klein
805 West Broadway, Suite 500
Vancouver, BC V5Z 1K1
(604) 874-7171 or 1-(800) 468-4466
(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 AND OTHER PROVINCES

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:

INQUIRIES-CONTACT:

The Canadian Red Cross Society
4750 Oak Street
Vancouver, BC, V6H 2N9
1-(888) 332-5663 (local 207)

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.

CLASS ACTION/COMPENSATION

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

Leslie Gibbenhuck Tel. (250) 490-9054

E-mail: bchepc@telus.net

Anyone who has started a lookback and wants it completed let me know. I need your name, address, birth date, transfusion dates, and traceback number and they have guaranteed us they will move on it right away!!!

National Compensation Hotline
Tel. 1-(888) 726- 2656

