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Canada's Hepatitis C News Bulletin

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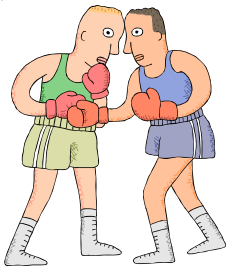
NEWS



PEG-INTRON-A VS PEGASYS

Responding to requests by patient communities, Schering has announced a study involving 2880 HCV patients, to compare the two approved therapies, Schering's peginterferon alfa-2b (PEG-INTRON-A) and Hoffman-La Roche's peginterferon alfa-2a (PEGASYS), combining both with ribavirin.

The Schering product will use individualized weight-based dosing of interferon, plus Rebetol (ribavirin), while the Pegasys arm of the trial will use the same dose in all patients, combined with Copegus, Roche's ribavirin, at 1000 mg or 1200 mg, depending on weight. The trial will use genotype 1 patients, the most difficult to treat.

The two treatments have never been compared directly, and the results of the trial should help doctors and patients to decide on treatment based on the patient's individual needs.

Source: Schering-Plough to Initiate First Head-to-Head Study Of Leading Hepatitis C Therapies; www.newswire.ca/releases/September2003/24/c4230.html

REUSE OF NEEDLES CAUSE OUTBREAKS

Four hepatitis outbreaks in the US, infecting more than 300 people in 2000-2002, have been attributed to the reuse of syringes and needles, and other risky procedures such as contamination of multi-dose vials, according to a new CDC study.

Apparently some medical personnel are not aware of the dangers of reusing needles…a shocking thought.

One nurse in Oklahoma normally reused implements in up to 24 patients, causing 100 infections. In Nebraska in 2001-2002, 184 patients may have been infected with Hep C when a nurse reused the same syringe on several chemotherapy patients.

In cases like these, infected patients return to the same office, and unwittingly infect more patients.

It is necessary to find ways to ensure that doctors' offices carry out infection control policies, and to implement disciplinary action. The key is awareness. Health authorities should work with medical personnel. Safer implements should be developed. There should be zero tolerance for non-compliance.

Source: Steve Mitchell, United Press International via COMTEX Sep 26, 2003; Needle reuse in clinics imperils patients.

"WHITEY" DIES FROM HEP C

Stanley Fafara, aka "Whitey" on "Leave it to Beaver", died on September 20th, at the age of 53, in an Oregon hospital, of hernia surgery complications. He was weak because of his Hep C infection, contracted from IV drug use.

Unfortunately, the lifestyle on "Leave it to Beaver" was far from true life for the actor, who started drinking and doing drugs as a teen, and was arrested for burglary in the 1980s. After leaving a detox centre in 1995, he remained clean and sober and lived first in a halfway house, and then in a subsidized apartment, until he was hospitalized. He had been hoping to return to acting.

Source: Steve Gorman, Reuters, 9/26/2003, 'Whitey' from 'Leave It to Beaver' Dies

INSIDE THIS ISSUE:

HYPERTHERMIA PLUS PEG INTRON/RIBAVIRIN CLINICAL TRIAL: OCT 10, 2003

by Darlene Morrow
The Hague, Holland

Hi Everyone,

There have been a number of developments in the last few weeks.

A number of patients are suffering serious side effects, primarily large-fibre neuropathy. This is not an unknown effect of using this particular method of fluid replacement in the hyperthermia procedure.

They had tried different body positioning and other techniques to reduce the occurrence of the neuropathy. Apparently this was not sufficient for a small number of patients.

Fortunately, I did not have these problems, but then, because of my small-fibre neuropathy, I had requested they reposition my body, and they did this four times.

Part of the problem is that the physician in charge of the clinical study withheld important information on the hyperthermia treatment from the ethics committee.

In the event of all of this, the study has been halted and the physician has resigned. I am really sorry to see this happen as I believe he was a very nice man who appeared to go the extra mile for his patients.

I still think that the hyperthermia has the potential to get rid of the disease, in combination with standard drug treatment. Perhaps they will develop a better method of fluid replacement.

I have done some further research into the aplastic anemia. In rare cases it can be caused by the medication, in which case it will reverse. Also, the genetic testing did not show the marker for aplastic anemia, so I am very optimistic.

My hemoglobin and white count dropped to a critical level three, and so they withdrew

(Continued on page 6)

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Peppermint Patti's FAQ Version 5.6 is now available in English and Spanish. The English version includes updated Canadian Links and both include the latest TREATMENT INFORMATION. Place your orders now. Over 100 pages of information for only $5 each, plus S&H—but if you can afford more, we'll take it. Contact HepCBC: (250) 595-3892, info@hepcbc.ca

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THANKS!!

HepCBC would like to thank the following institutions and individuals for their generosity: The late John Crooks, Bryce Brogan, Bruce Lemer, Lexmark, Health Canada, Pacific Coast Net, Margison Bros Printers, Royal Bank, Brad Kane, Arlene Darlington and friends, Chris Foster, Ian Campsall, Darlene Morrow, Will Lawson, Judith Fry, Ron Comber, and Stacey Boal. Heartfelt thanks to Blackwell Science for a subscription renewal to gastrohep.com

Special thanks to Roche Canada for an unrestricted grant to help publish this newsletter!

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. Joan, #5-915 Glen Vale Rd, Victoria BC V9A 6N1, (250) 595-3892.**

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.

CONFERENCES

November 14-15, 2003
CLF: HEPATITIS- MEETING THE CHALLENGE
Centurion Conference & Event Centre
170 Colonnade Road South
Ottawa, Ontario
(613) 733-1433 or (613) 489-5208

February 27-March 1, 2004
Canadian Digestive Disease Week
Banff Springs Hotel, Banff, Alberta

February 26 - March 5, 2005
Canadian Digestive Disease Week
Banff, Alberta

September 12, 2005
WCOG Conference - 14th Annual Meeting - World Congress of Gastroenterology:
Montreal. Quebec

March 4 - 12, 2006
Canadian Digestive Disease Week
Quebec City, Quebec

DIAL-A-DIETITIAN

732-9191 (Vancouver Area)
1-800-667-3438 (Toll-free elsewhere in BC)

Got Hep C? Single? Visit:

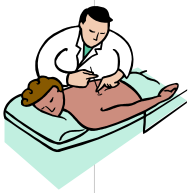
http://nationalhepatitis-c.org/singles/list.htm
http://clubs.yahoo.com/clubs/ontariohepcsingles
http://groups.yahoo.com/group/hepsingles-1/
http://forums.delphiforums.com/HepCingles/start
http://clubs.yahoo.com/clubs/hepcingles
http://groups.yahoo.com/group/PS-Hep/
www.hepcmeet.com

SURVIVAL OF RECIPIENTS OF STANDARD VS ePTFE-COVERED TIPS

Researchers have concluded that patients receiving ePTFE-covered shunts have better survival rates than recipients of conventional TIP shunts.

The 3-month survival was 93% in the ePTFE group, compared to 83%. The 1- and 2-year survival was 88% and 76% for the ePTFE-group, compared with 73% and 62% for conventional TIPS patients.

The implantation of a transjugular intrahepatic shunt (TIPS) in cirrhosis patients reduces portal pressure. However, this does not necessarily reduce mortality, possibly because the bare shunts often narrow and must be revisited. Implanting a ePTFE-covered shunt reduces this occurrence.



Stent type, patient age, and Child-Pugh Class are considered to be independent predictors of patient survival.

Source: Hepatology 2003, 38(4), 1043-50 (02 October 2003).
http://www.gastrohep.com/news/news.asp?id=2306;

LIVER TRANSPLANTATION WITH LIVERS FROM DONORS WITH HEP B ANTIBODIES

Doctors at the University Hospital Marques de Valdecilla, Faculty of Medicine, Santander, Spain, have developed a method of transplanting liver tissue from donors with hepatitis B (HBV) antibodies without transmitting HBV infection.

Such tissue is widely used because of the constant shortage of organ donors.

From November 1999 to March 2002, 77 liver transplantations were performed in 73 patients, 7 of whom received livers from HBV antibody-positive donors. All recipients received 10,000 U/d of intravenous HBIg for 7 days and 100 mg/d of lamivudine until the surgeons could obtain the HBV-DNA from the donor tissue samples.

If the results of the HBV-DNA from the donor samples were positive, the patient would continue with the preventive measures; if they were negative, the combined preventive measures would be ended. After transplantation, HBV serologic markers and HBV-DNA in serum and lymphocytes were tested by PCR in the recipients on the seventh, fifteenth, thirtieth, and ninetieth days, as well as every 3 months.

All 7 donor organs were negative for HBV-DNA in serum and liver tissue. Therefore, the combined prophylaxis was stopped in all recipients (range, 7 to 10 days). None of the 7 patients developed an HBV infection over the 3-year study period (range, 9 to 36 months).

The approach is considered reasonably safe and very effective in preventing HBV infection after liver transplantation.

Source: Liver Transplantation, 9(9), 916-920 (Sept 2003).

WEEK TWO BEST TIME TO PREDICT RESPONSE IN RELAPSERS

During treatment with interferon plus ribavirin in relapsed hepatitis C patients, viral kinetics have shown that the second week of treatment appears to be the time point most predictive of a sustained viral response.

Eighteen patients, relapsed from a first course of interferon monotherapy and then treated with interferon and ribavirin, were studied in France. Samples were obtained before therapy and each week for 6 weeks during therapy; HCV RNA levels were determined using quantitative bDNA.

A sustained virological response was obtained in 12 patients.

At the end of week two, a viral-load drop of more than 2.20 log was observed in all the 12 patients with a sustained response and in none of the six other patients (positive predictive value 83%; negative predictive value 92).

Source: PMID, 14501613 [PubMed - in process].

PREDICTING EARLY MORTALITY AFTER TRANSPLANTATION

Investigators from Spain have found that pre-transplantation renal insufficiency is the most significant risk factor for early mortality in liver transplant patients.

245 patient histories dating back to 1991 were involved in the study. The main reason for transplant was post-necrotic cirrhosis, and the majority of patients were Child-Pugh C status.

Post-operative mortality at 3 months was 15%. Risk factors predicting death were identified as pre-liver transplant renal insufficiency (OR 5.8), complex surgery requiring cross-clamping (OR 4.9), malnutrition (OR 2.9), and Child-Pugh C status (OR 1.3).

Donor factors were not found to be significant.

The team concluded that liver transplantation should be performed before there is evidence of irreversible renal insufficiency.

Source: Clin Transplant 2003, 17(5), 401-11 (22 September 2003)
.http://www.gastrohep.com/news/news.asp?id=2288;

SURGICAL REMOVAL OF LIVER CANCER IN PATIENTS ELIGIBLE FOR TRANSPLANTATION

There has been a 75% increase in hepatocellular carcinoma (HCC) in the United States over the last decade.

Researchers in New York think that partial hepatectomy (removal of the affected lobe) results in survival rates comparable to those for liver transplantation, the current accepted treatment for patients with early HCC.

The team evaluated 611 patients with HCC, between 1989 and 2001. Of the 180 patients who underwent partial hepatectomy, the 5-year disease-free survival was 48%.

20% were considered eligible for transplantation; median tumour size was 3.5 cm; median number of lesions was 1; 78% patients overall had pathologically confirmed cirrhosis; 86% had normal liver function. There was 1 death during surgery.

Source: Ann Surg 2003, 238(3), 315-23 (19 September 2003).
http://www.gastrohep.com/news/news.asp?id=2286;

HISTOACRYL OR BETA-BLOCKERS

A Belgian study of 41 patients with primary bleeding from esophageal or gastric varices finds that repeated endoscopic injections of histoacryl are no more effective, and are associated with more complications, than beta-blockers in eradicating the varices.

10 out of 21 patients receiving histoacryl injections suffered adverse effects, compared with only 2 of the 20 patients receiving beta-blockers.

There was no significant difference in the incidence of early or long-term rebleeding, or of mortality, between the 2 treatment groups. 5 of the 21 patients who underwent histoacryl injection and 3 of the 20 patients taking propanolol re-bled within the first 6 weeks.

Source: Endoscopy 2003, 729-735
http://www.gastrohep.com/news/news.asp?id=2232; (22 August 2003).

Phyllis Chuly, Acting Executive Director,
BC PharmaCare
PO Box 9655 Stn Prov Govt
Victoria, British Columbia V8W 9P2

September 14, 2003

Dear Ms. Chuly,

We were very pleased that Pharmacare and the Minister of Health announced its decision on June 12, 2003, to provide Pegetron to persons infected with hepatitis C in British Columbia. As you know, BC was the last province in Canada to make this drug available to patients, in spite of its substantially enhanced efficacy over the previously available Rebetron.

We were, however, alarmed by the criteria which have been set for accessing this drug. It is our understanding that the inclusion and exclusion criteria for accessing Pegetron are as follows:

Inclusion Criteria

·hepatitis C treatment naïve
·ALT >1.5 ULN on two consecutive occasions at least 3 months apart
·GT 1, 4, 5, 6: >2 log reduction in HCV RNA by week 14 (if yes, additional 34 weeks coverage)
·GT 2, 3: maximum period of coverage is 24 weeks

Exclusion Criteria

·aged less than 18 years
·decompensated liver disease
·active alcohol abuse
·higher risk of non-compliance
·pregnancy or lack of appropriate contraception
·illicit IV drug and/or intranasal cocaine use

Our primary concern is that these criteria are not based on currently available scientific evidence from the medical literature.

For your convenience, we are providing an outline of the evidence that we hope will provide the basis upon which the criteria will be changed. As they are, the criteria place undue and unnecessary limitations on accessing what for many may be a life-saving drug.

Treatment Naïve

This criteria is presumably based on the thinking that people who have tried and failed previous hepatitis C treatment stand little chance of succeeding with Pegetron. However, the evidence clearly indicates that the issue is not nearly so simple.

Not all people who have taken hepatitis C treatment and have not achieved a sustained virologic response (SVR - what is considered the gold standard of success of Hepatitis C treatment) are alike. There are non-responders (people whose virus didn't respond to treatment), relapsers (people whose virus did respond but once treatment ended the virus came back), and breakthroughs (people whose virus responded but came back while still on treatment). These groups have very different response rates upon re-treatment, contingent on a variety of factors, including what they were initially treated with [1].

Non-Responders:

Within non-responders, there are the people whose virus didn't respond at all to therapy, and there are those whose virus decreased at least two logs but remained detectable. The latter group may have significant improvements in their ALT and hepatic histology; they may also have improved response to more efficacious treatment [2, 3].

Most data on the re-treatment of non-responders is based on standard interferon (IFN) treatment (with or without ribavirin). Whether people took interferon monotherapy or Rebetron (i.e. combination interferon and ribavirin) has a significant impact as to whether their virus will respond to pegylated interferon [1].

Among non-responding people who were re-treated with regular interferon (IFN) and ribavirin (RBV):

·From meta-analyses, it was found that among non-responders to IFN mono-therapy when retreated with IFN+RBV, 26-32% became HCV RNA negative, and an average of 15% achieved a SVR [1].

When re-treated with pegylated interferon plus ribavirin:

· A study of 17 non-responders to IFN-monotherapy and 84 non-responders to IFN+RBV, all having genotype (GT) 1, found 25-40% of people achieved a SVR with PEG+RBV (only 10-11% among people who had previously not responded to IFN+RBV) [4]
·In a study of 212 non-responders to either IFN-mono or IFN/RBV combination, re-treated with PEG+RBV, all with advanced fibrosis or cirrhosis, and 88% GT1: among IFN-monotherapy non-responders, 53% responded to re-treatment, and 34% achieved a SVR; among non-responders to IFN/RBV, 30% became HCV RNA negative, and 11% achieved a SVR. SVR occurred in 15% of patients with GT1, and 60% of GT2/3. Only 11% of African-Americans became HCV RNA negative during retreatment, none achieved SVR [5].

Presentations at Digestive Disease Week 2003:

·Among 219 individuals, some IFN-monotherapy non-responders, some IFN/RBV non-responders; some IFN/RBV relapsers; SVR for relapsers was 42%, for combination therapy non-responders, 8%; for mono-therapy non-responders, 21% [6]
·Non-responders re-treated with Peg+RBV [6],
-SVR in all GT: 15%
-SVR in GT1: 5-9%
-SVR in GT 2/3: 13-25%
·In an on-going study of 439 non responders to IFN with or without RBV, the end of treatment response (ETR) so far is 46% and SVR was 33%; SVR higher in GT-non 1 and those who previously failed IFN monotherapy; SVR in GT1 pre-treated with IFN/RBV was 15% [7]
·Among 193 non-responders to IFN+RBV, treated with PEG+RBV, there were improvements in inflammation (as measured by HAI), but not fibrosis (most improvements seen in those who became HCV RNA negative); SVR was 9% [8]
·Brazilian study presented at the Annual meeting of the European Association for the Study of the Liver (2003) found that among 131 individuals who had been treated for at least 6 mths with Rebetron found upon treatment with PEG/RBV at 24 weeks, 89% of relapsers and 67% of non-responders became HCV RNA negative, and after 48 weeks of treatment, 80% of relapsers and 58% of non-responders were HCV RNA negative [9].

Relapsers:

·Re-treated with IFN mono vs. IFN/RBV for 24 weeks [10]
-49% of relapsers treated with IFN mono became HCV RNA negative, and 5% had SVR
-82% of relapsers treated with IFN/RBV became HCV RNA negative, and 47% achieved SVR
·Re-treated with PEG/RBV [4]:
-87% achieved EOT response, and 60% SVR

ALT Levels:

One of the key criteria for accessing

(Continued on page 5)

(TREATMENT LETTER—Continued from page 4)

Pegetron is persistently elevated ALT levels. ALT levels are well known to be poor correlates of disease progression [11]. Based on a study of 867 patients, among those with persistently normal ALT values, 65% had a METAVIR score of at least F1, indicating at least some liver fibrosis (PPV=99%, NPV=35%) [12]. Furthermore, factors that may affect ALT levels are HLA class, sex, and body mass index [12], all suggesting that ALT levels are a poor marker of disease. Alarmingly, reports in the community indicate that some individuals are so desperate to elevate their ALT's in order to access Pegetron that they are consuming large quantities of alcohol before having blood drawn.

It is also important to note that people with chronic hepatitis C infection are more likely to achieve a sustained virologic response if there is no fibrosis or cirrhosis [11]. This would suggest that early treatment is better, and that individuals should not wait until their liver is inflamed or diseased before taking treatment.

Stopping Rules:

It is very important for policy-makers to consider that although a sustained virologic response is the gold standard of effective hepatitis C treatment, from the patient's perspective the key issue is to a) maintain liver function, and b) to improve liver function even if there is still virus present. There are many new treatments and therapeutic vaccines for hepatitis C in development, and for patients currently infected with hepatitis C, if the goal of a sustained virologic response is not possible, then keeping one's liver functioning until there are more effective treatments available becomes the goal. There is research that indicates that in spite of a lack of virologic response, histologic response is achievable using "maintenance therapy". The concept of maintenance therapy is based on the observation that up to 40% of non-responders have a histologic response during treatment [2, 3].

In a meta-analysis examining histologic improvements following PEG/RBV treatment, Poynard et al. found [13]:

Treatment response	SR	Relapsers	NR
Number	1094	464	1452
Fibrosis Improved	25%	16%	17%
Fibrosis Stabilized	68%	67%	62%
Fibrosis Worsened	7%	17%	21%

Another important consideration regarding the stopping rules for Pegetron is that people co-infected with HIV may have altered HCV viral dynamics in response to HCV treatment and may therefore require a longer period to reach >2 log reduction in HCV RNA [14].

Pegetron in children:

One of the exclusion criteria is if patients are aged less than 18 years. Although data are limited on the use of pegylated interferon in children, a small study of 14 children, of whom 13 were GT1, who were all treated with PEG monotherapy, found that at 72 weeks 42% achieved a SVR. [15]

Other Exclusion Criteria:

Active alcohol abuse, higher risk of non-compliance, pregnancy or lack of appropriate contraception, illicit IV drug and/or intranasal cocaine use are all listed as exclusion criteria. However, none of these issues are defined. What constitutes alcohol abuse? What is 'appropriate contraception'? Is the illicit IV drug and/or intranasal cocaine use based on ever having used, or currently using? And while the reason behind the latter criteria is presumably to prevent re-infection, what if an individual only uses sterile paraphernalia?

Management of Ribavirin Toxicities:

An important and thus far completely neglected issue by Pharmacare in relation to treatment of hepatitis C infection, are the hematologic toxicities associated with ribavirin treatment, specifically anemia. These result in discontinuation of treatment in 10 to 14% of patients [11], and the reduction of ribavirin dose (resulting in poorer response rates) among many, many more. There are few treatments available for the treatment of ribavirin induced anemia. However, Eprex (epoetin-alfa) is a licensed glycoprotein product manufactured using recombinant DNA technology. It contains the identical amino acid sequence of isolated natural erythropoietin, and is indicated for use in patients with kidney failure, surgery patients, cancer patients (because both cancer itself and chemotherapeutic agents can induce anemia), as well as zidovudine induced anemia in patients with HIV infection. Although not well studied in the setting of ribavirin induced anemia, a preliminary study found that 88% (vs. 60% on placebo, $p<0.001$) of patients who received the recombinant epoetin-alfa were able to maintain full dose ribavirin therapy , and that quality of life measures were much higher in the Eprex treated group compared to placebo [16].

In summary, we feel that given existing data, the criteria for accessing Pegetron in British Columbia are lacking in a number of important ways that have direct impact on patient's lives. While we understand the need to contain costs, this need must be balanced against the medical needs of people struggling against chronic hepatitis C infection. Hepatitis C treatment is not a life-long treatment. The lifetime costs, however, of chronic hepatitis C disease are substantial if one considers the costs of hospitalization, health care utilization, and transplantation. The BC Center for Disease Control has estimated that the medical costs without treatment for a person with hepatitis C, from diagnosis to death, are approximately $1 million [17]. This is compared to the approximately $11,000 for a 32-week course of Pegetron.

We strongly urge you to consider the data we have presented to you, and to conduct your own research on these issues. We are confident that you will agree that the science does not support the criteria, and we eagerly await your response.

Sincerely, on behalf of the BC HIV/Hepatitis C Co-Infection Action Coalition,

Paula Braitstein, BC Persons with AIDS Society, Malsah, BC Persons with AIDS Society, Ken Thomson, BC Hepatitis C Collaborative Circle, Terry Howard, BC Persons with AIDS Society, Evin Jones, YouthCo AIDS Society, Rick Barnes, AIDS Vancouver, Miki Hansen, AIDS Vancouver Island, Ann Livingstone, Vancouver Area Network of Drug Users

cc.

Hon. Minister Colin Hansen, Premier Gordon Campbell,. Penny Ballem, Lorne Mayencourt, Dr. Urs Steinbrecher, Dr. Eric Yoshida, Dr. Frank Anderson, Dr. Valentina Montessori, Dr. Mel Krajden, Mr. Brian Harrigan,

[Editor: References available upon request]

LETTERS TO THE EDITOR

(Editor's note: I asked John for permission to print this letter at the time he sent it, and gave him the information I could at the time. He never gave nor denied me his permission. Now that he is deceased, I consider this an appropriate time to publish his important comments. They have been edited for style and to protect personal material.)

5/3/2002

Dear Joan,

Thank you for your quick reply to me. Your *hepc.bull* is excellent and rates a 10 out of 10. I've been reading it since 1998. However, I'm 90% sure that there hasn't been one article relating to hemophiliacs who have hepatitis C.

I'm very bitter towards the doctors and the B.C. Hemophilia Treatment Centre for refusing my requests for a transjugular biopsy. All my tests indicate that I should have this procedure. A Vancouver Hemophilia Treatment Centre employee told me that they don't do this procedure on hemophiliacs. Yet I've also been told by two doctors that, without the biopsy, they could not consider me for drug treatment. Joan, this is a classic "catch 22".

What really upsets me is that other hemophilia treatment centres in Canada promote this safe procedure. In 2001, the province of Ontario hemophilia centres had performed 40-plus transjugular biopsies on hemophiliacs. Only one hemophiliac needed to stay in the hospital longer than the others – two days instead of one.

The two doctors I mentioned above were all set to perform this procedure on me until they spoke with the Vancouver Hemophilia Treatment Centre. The key word here is "spoke". Neither doctor has any thing in writing. If they did, I would sue the Vancouver Centre. One doctor told me they have an "unwritten policy". My family doctor said because of this, it would be a waste of my time and money. After I told him that I would like to write my story and publish it in the *hepc.bull,* he said the Centre would probably sue me. I have no proof and they would just call me a liar. I agree with him 100%.

Joan, I really hope that you get a chance to read this, because of the lack of articles in your publication. My guess is that you aren't aware of the hemophilia–hepatitis C situation in B.C. And it's not only I. I have spoken with three other B.C. hemophiliacs who are in the same boat. One made arrangements to travel to another province two years ago and had this procedure performed.

To quote a noted doctor in Ontario, a director of a Hemophilia Centre: "Every Canadian hemophiliac that is refused this procedure *should* have the right to sue the doctor and/or the Hemophiliac Centre that says no because of risk."

John Crooks

VANISHING LUNG SYNDROME AND CANNABIS

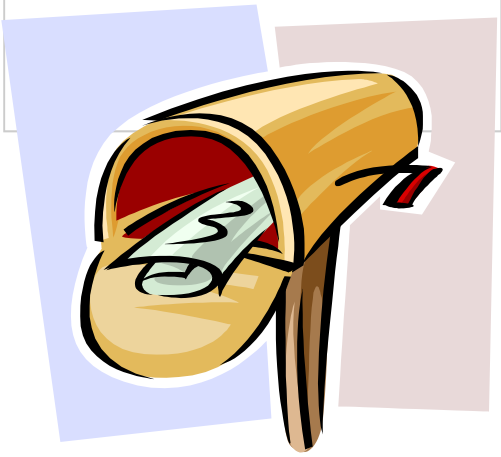
The June/July 2003 issue of *hepc.bull* reported a possible link between the terrifying-sounding "vanishing lung syndrome" and smoking cannabis. This is of concern to hepatitis C sufferers, since cannabis is sometimes used to ameliorate their symptoms.

It turns out that the allegations are based on the anecdotal evidence of one person, Dr. Mark Johnson at the Royal Glasgow Infirmary, issued in a press release in February 2003.

As such, there does not appear to be any scientific validity to his claim. This does not mean there is no truth in it, just that it is unsupported. Scientific validity means that a hypothesis has been examined in a controlled scientific study which is then published in a respectable peer-reviewed journal.

Certainly, inhaling any type of smoke on a regular basis is probably unhealthy for the lungs. Cannabis users can mitigate this by smoking only the highest grade cannabis, since that minimizes the quantity that needs to be smoked. Otherwise, they can avoid lung damage by ingesting orally or using a vaporizer.

Arthur Ralfs



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PREPLANNING YOUR FINAL ARRANGEMENTS?

Please consider arranging for donations to your local hepatitis C organization.

LETTERS TO THE EDITOR:

The *hepc.bull* welcomes and encourages letters to the editor. When writing to us, please let us know if you do not want your letter and/or name to appear in the bulletin.

(DARLENE—Continued from page 1)

the peg for one week. I am tired as all get out and nauseated.

The infection in my mouth has flared up after two courses of antibiotics, so I am now on a third. My diet consists of meal replacement shakes and the odd bit of meat (for hemoglobin) I can choke back.

My hair has sufficiently thinned to warrant the vanity of a wig. I never have a bad hair day anymore. We must be grateful for small mercies.

However, I am beginning to feel better as the doctor has given me something for the nausea, and the time for seeing Bill is coming closer – October 9th.

The hospital is continuing to treat the patients according to protocol. This means that I will not have to fulfill the original agreement of making myself available for the full eighty weeks, and so I will not have to travel back and forth as much. At the moment, I plan to return in January when I will receive my final three-month prescription. I will also have to return three months after treatment ends in March for a second bone marrow biopsy.

So, this will be my last update for three months unless I can manage to type a bit myself. (My sister Joan has been very helpful.)

Take care,

Darlene

RCMP UPDATE

RCMP Blood Task Force
Project Oleander
345 Harry Walker Parkway S.
Newmarket, ON L3Y 8P6

To whom it may concern,
2003-09-10

RCMP Blood Task Force – Toronto North

The RCMP Blood Task Force would like to update you on the court appearances for those who were charged with criminal offences relating to the Canadian blood system.

Legal counsel for Dr. Roger Perrault, Dr. John Furesz, Dr. Wark Boucher, Armour Pharmaceutical Company, and Dr. Michael Rodell appeared in court on September 4, 2003 for a Case Management Conference. Typically, a Case Management Conference is a meeting with a judge and counsel to deal with the time management and logistical issues relating to the court case. The evidence is not discussed nor are witnesses heard at a Case Management Conference.

The next scheduled court date for these individuals is as follows:

November 10, 2003 at 9:00 a.m.
Courtroom 111
Old City Hall
50 Queen Street West
Toronto, Ontario

As a reminder, legal counsel for Canadian Red Cross and Dr. Roger Perrault will be appearing on September 24 at 9:00 a.m. at the Hamilton Court House in Courtroom 100. The Hamilton Court House is located at 45 Main Street East in Hamilton, Ontario.

The toll free line and the web site are still available for those who wish to contact the Blood Task Force.

1-888-530-1111
www.rcmp-grc.gc.ca/html/bloodtaskforce_3.htm (English)
www.rcmp-grc.gc.ca/html/bloodtaskforce_f.htm (French)

Sincerely,
H. Jamieson, Cat.
BTF Liaison Officer

R.R. Knecht, C/Supt.
OIC RCMP Blood Task Force

HepC BC

VOLUNTEER APPLICATION FORM

NAME: _____

ADDRESS: _____
_____

CITY: _____

PC: _____ **PROV:** _____

TEL: ( ) _____

FAX: ( ) _____

EMAIL: _____

ABILITIES OR AREA OF INTEREST:

Library Printing Copying
Phoning Fundraising
Counseling Research
Refreshments Special Events
Publications Computer Help
Errands Grant Applications
Board Member Other

Experience:
_____
_____
_____
_____

Time available:
_____
_____

SEX M F

Date of Birth: ____/____/_____

Mo Day Year

Contact: HepCBC
#5-915 Glen Vale Rd
Victoria BC V9A 6N1

Tel. 595-3892 or Email: info@hepcbc.ca

COMPENSATION

LEGAL ACTION

Hepatitis C Class Action Suit Line:
1-800-229-LEAD (5323)

1986-1990
Bruce Lemer/Grant Kovacs Norell
Vancouver, BC
Phone: 1-604-609-6699 Fax: 1-604-609-6688

Pre-86/Post-90
Hepatitis C Settlement Fund—KPMG Inc.
Claims Administrator
2000 McGill College Avenue, Suite 1900
Montreal (Quebec) H3A 3H8
1-888-840-5764 (1-888-840-kpmg)
HepatitisC@kpmg.ca
www.kpmg.ca/microsite/hepatitisc/english/forms.html

Klein Lyons
Vancouver, BC 1-604-874-7171,
1-800-468-4466, Fax 1-604-874-7180
www.kleinlyons.com/pages/class_actions/Hepatitis_C.htm

Mr. David Harvey/ Goodman & Carr
Toronto, Ontario
Phone: 1-416-595-2300, Fax: 1-416-595-0527

Ernst & Young Law Office (Ontario)
1-800-563-2387

Lauzon Belanger S.E.N.C. (Quebec)
www.lauzonbelanger.qc.ca.

Goodman and Carr LLP
pre86hepc@goodmancarr.com
www.goodmancarr.com

Other:

William Dermody/Dempster, Dermody, Riley and Buntain
Hamilton, Ontario L8N 3Z1
1-905-572-6688

LOOKBACK/TRACEBACK

The Canadian Blood Services, Vancouver, BC
1-888-332-5663 (local 207)
Lookback Programs, Canada: 1-800-668-2866
Lookback Programs, BC: 1-888-770-4800
Canadian Blood Services Lookback/Traceback & Info Line: 1-888-462-4056
Hema-Quebec Lookback/Traceback & Info Line: 1-888-666-4362
Manitoba Traceback: 1-866-357-0196

RCMP Blood Probe Task Force TIPS Hotline
1-888-530-1111 or 1-905-953-7388
Mon-Fri 7 AM-10 PM EST
345 Harry Walker Parkway, South Newmarket, Ontario L3Y 8P6 Fax: 1-905-953-7747

CLASS ACTION/COMPENSATION

National Compensation Hotline: 1-888-726-2656
Health Canada Compensation Line: 1-888-780-1111
Red Cross Compensation pre-86/ post-90 Registration: 1-888-840-5764
Ontario Compensation: 1-877-222-4977
Toronto Compensation: 1-416-327-0539, 1-877-434-0944
Quebec Red Cross Compensation: 1-888-840-5764
1986-1990 Hepatitis C Class Actions Settlement 6/15/99 www.hepc8690.ca/

ADMINISTRATOR

To receive a compensation claims form package, please call the Administrator at 1-888-726-2656 or 1-877- 434-0944.
www.hepc8690.com info@hepc8690.com

MISCELLANEOUS

Excellent Website!!: HCV Tainted Blood, Canada: http://members.rogers.com/smking/tainted.htm

COMING UP IN BC/YUKON:

Armstrong HepCure Office and library, by appointment. Contact: Marjorie, 546-2953, amberose@sunwave.net, www.junction.net/hepcure

Campbell River Hep C Support Group Support and information, call 830-0787 or 1-877-650-8787 or email niac_hepc@hotmail.com

Castlegar Contact: Robin, 365-6137

Comox Valley: Contact North Island Hep C Community Support Project 1-877-650-8787,

Cowichan Valley Hepatitis C Support Contact: Leah, 748-3432.

Cranbrook HeCSC-EK: 1st & 3rd Tues. monthly, 1-3 PM, #39 13th Ave South, Lower Level. Next meetings Nov. 6th & 18th. Contact: 426-5277 or 1-866-619-6111 hepc@cmha-ek.org, www.hepceastkootenay.com

Creston/Golden/Invermere Educational presentation and appointments: Contact Katerina 426-5277

Grand Forks Hep C Support Centre—Closed due to lack of funding. Contact Ken, 1-800-421-2437

Kamloops Phone support. Contact Susan, 554-7055, or the Liver Clinic, 851-7300.

Kelowna Hepkop: Last Sat. monthly, 1-3 PM, Rose Ave. Meeting Room, Kelowna General Hospital. Next Meeting: Nov. 29th. Contact Elaine Risely (250) 768-3573, eriseley@shaw.ca or Lisa Mortell 766-5132 lmortell@silk.net or toll-free 1-866-766-5132.

Kimberley Support Group 2nd Tue. monthly, 7-9 PM. Next meeting Nov. 18th Contact Katerina 426-5277

Kootenay Boundary 2nd Tues. monthly, 7 PM, Room 108, Selkirk College, Trail. Next meeting: Nov. 18th. For individual support, info & materials, contact: Brian Reinhard, (250) 364-1112, reiny57@yahoo.ca

Mid Island Hepatitis C Society Friendship and support group, 2nd Thurs. monthly, 7 PM, Central Vancouver Island Health Centre 1665 Grant St. Nanaimo. Next meeting: Nov. 13th. Contact Sue for info 245-7635. mihepc@shaw.ca

Mission Hepatitis C and Liver Disease Support Group 3rd Wed. monthly, 7 PM, Springs Restaurant, 7160 Oliver St. Next meeting Nov. 19th. Contact Gina, 826-6582 or Patrick, 820-5576. missionsupport@eudoramail.com

Nakusp Support Group Meetings: 3rd Tues. monthly, 7 PM, Nakusp Hospital Boardroom. Next meeting: Nov. 18th. Contact: Vivian, 265-0073 or Ken, 1-800-421-2437

Nelson Hepatitis C Support Group 1st Thurs. monthly. ANKORS Offices, 101 Baker St., Next meeting: Nov. 6th. Contact: **Alex Sherstobitoff**, 1-800-421-2437, 505-5506, info@ankors.bc.ca

New Westminster Support Group 2nd Mon. monthly, 7-8:30 PM, First Nations' Urban Community Society, 623 Agnes Street, New Westminster. Next meeting: Nov. 10th. Contact: Dianne Morrissettie, 604-517-6120, dmorrissettie@excite.com

Parksville Support Group Contact Ria, 248-6072

Parksville/Qualicum 102a-156 Morison Avenue, PO Box 157, Parksville, BC V9P 2G4. Open daily 9 to 4, M-F. Contact: 248-5551, sasg@island.net

Penticton Hep C Family Support Group Contact: Leslie, 490-9054, bchepc@telus.net

Powell River Hep C Support Group Next meeting: Contact the Health Unit, 485-8850.

Prince George Hep C Support Group 2nd Tues. monthly, 7-9 PM, Prince George Regional Hospital, room 105-107 Next meeting Nov. 18th, Contact: Gina, 963-9756, gina1444@yahoo.ca or Ilse, 565-7387 ikueper@northernhealth.ca

Princeton 2nd Sat. monthly, 2 PM, Health Unit, 47 Harold St. Next meeting Nov. 8th. Contact: Brad, 295-6510. kane@nethop.net

Queen Charlotte Islands/Haida Gwaii: Phone support. Contact Wendy: 557-2487, e-mail: wmm@island.net, www.island.net/~wmm/

Quesnel HeCSC Last Mon. evening every other month. Contact Elaine Barry, 992-3640, ebarry@goldcity.net

Richmond: Lulu Island AIDS/Hepatitis Network: Meetings/drop-in dinner each Mon. 7-9 PM. Contact Phil or Joe, 276-9273.

Slocan Valley Support Group Contact: Ken, 355-2732, keen@netidea.com

Smithers: Positive Living North West 2nd Wed. monthly, 12 noon, **3862 Broadway (back door)** Next meeting: Nov. 12th. Contact: Deb. 877-0042, 1-866-877-0042, or Doreen, 847-2132, plnw_hepc@bulkley.net for times.

Sunshine Coast—Sechelt: Contact: Kathy, 886-3211, kathy_rietze@uniserve.com—**Gibsons**: Contact Bill, pager 740-9042

Vancouver: Healing Our Spirit—Offering Hep C and HIV education and support to Aboriginal People in BC. 100 - 2425 Quebec St. Contact: 1-800 336-9726 info@healingourspirit.org www.healingourspirit.org

VANDU Vancouver Area Network of Drug Users Each Mon., 2 PM, **412 East Cordova** Bus fare & snack. Contact: Cristy or Ann, 604-719-5313, or 604-216-2776 (ask for VANDU). Space limited—come early. vandu@vcn.bc.ca, www.vandu.org

Vernon HeCSC HEPLIFE 2nd & 4th Wed. monthly, 10 AM-1 PM, The People Place, 3402-27th Ave. Next meetings Nov. 12th & 26th. Contact: Sharon, 542-3092, sggrant@telus.net

Victoria HeCSC Last Wed. monthly. Contact: 388-4311, hepcvic@coastnet.com

Victoria Support and Information Information about support groups and other services: Contact the Needle Exchange, 384-2366, hermione.jefferis@avi.org

Victoria HepCBC & INFO line —Contact: (250) 595-3892, info@hepcbc.ca, www.hepcbc.ca

YouthCO AIDS Society HepCATS Education and information to youth infected or affected with hepatitis C. #205- 1104 Hornby St., Vancouver. Contact Caitlin Padgett 604-688-1441 or 1-877-YOUTHCO

Yukon Positive Lives 3rd Wed. monthly, Whitehorse. Next meeting Nov. 19th. Contact Heather 660-4808, fromme@marshlake.polarcom.com, www.positivelives.yk.ca

OTHER PROVINCES

ATLANTIC PROVINCES:

HeCSC NB Meetings:

- **Fredericton, NB** Contact: Bob, 453-1340
- **Saint John & Area**: Information and Support. Contact: Allan Kerr at kerrs@nbnet.nb.ca

Moncton. N.B. Contact Debi, email support only: hepcmonc@rogers.com

The Hepatitis Outreach Society The organization is undergoing reconstruction, for telephone support call: 1-800-521-0572 (902) 733-2214 Fax (902) 733-2043

ONTARIO:

Barrie HepSEE Chapter 3rd Tues. monthly, 7-9 PM, AIDS Committee of Simcoe County, 80 Bradford St, Suite 336 Contact: Jeanie, 735-8153 hepseebarrie@rogers.com

Durham Hepatitis C Support Group 2nd Thurs. monthly, 7 PM, St. Mark's United Church, 201 Centre St. South, Whitby. Next meeting: Nov. 13th. Speaker: Tobin Brown, RN, Whitby Hospital, "Ongoing Care of Hepatitis C". Contact: Smilin' Sandi smking@rogers.com "Sandi's Crusade Against Hepatitis C" http://members.rogers.com/smking/ or Ken Ng, (905) 723-8521 or 1 (800) 841-2729 (Ext. 2170)

Kitchener Area Chapter 3rd Wed. monthly, 7:30 PM, Cape Breton Club, 124 Sydney St. S., Kitchener. Contact: Carolyn, (519) 880-8596 lollipop@golden.net

Niagara Falls Hep C Support Group Last Thurs. monthly, 7 PM, Niagara Regional Municipal Environmental Bldg., 2201 St. David's Road, Thorold. Contact: Rhonda, (905) 295-4260, Joe (905) 682-6194 jcolangelo3@cogeco.ca or hepcnf@becon.org

Trenton ON support. Contact: Eileen Carlton 394-2924 carfam@quintenet.com

York Chapter HeCSC 3rd Wed. monthly, 7:30 PM, York Region Health Services, 4261 Hwy 7 East, B6-9, Unionville. Contact: (905) 940-1333, 1-800-461-2135. info@hepcyorkregion.org www.hepcyorkregion.org

Hepatitis C Network of Windsor & Essex County 3rd Thurs. monthly, 7 PM, 1100 University Ave. W. and 1st Mon. monthly, 491 Victoria Ave, 11 AM. Contact Andrea 250-5399 or Michelle, 256-1878, hepcnet@cogeco.ca http://home.cogeco.ca/~hepcnet/

PRAIRIE PROVINCES:

HeCSC Edmonton: Contact Jackie Neufeld: 939-3379.

HepC Edmonton Support Group: Contact Fox, 473-7600, or cell 690-4076, fox@kihewcarvings.com

HepSEE WPG: Contact David: hepsee@shaw.ca or 1(204)897-9105 for updates on meeting schedules.

Winnipeg Hepatitis C Resource Centre 1st Tues. monthly 7-9 PM. # 204-825 Sherbrook St. (south entrance—parking at rear) Contact: 975-3279, hcrc@smd.mb.ca

QUEBEC:

Hepatitis C Foundation of Quebec, Contact Eileen, 769-9040 or fhcq@qc.aibn.com. **Meetings:**

- **Hull:** Each Tue. 7-8 PM, 57 Rue Charlevoix.
- **Sherbrooke** 2nd Mon. monthly, 7-9 PM, Les Grandes Coeurs D'Artichauts Au Centre Jean-Patrice Chiasson (2e etage) 1270 Galt Street West. Contact: 820-7432
- **Verdun:** 1st Tues. (French) & 3rd Tues (Eng) monthly, 7-9 PM. Verdun General Hospital, Room 3121.

HeCSC Quebec City Region, 1st Wed monthly, 7 PM, 876 rue D'Alençon, St. Nicolas, QC. Contact: Renée Daurio, 836-2467, reneedaurio@hotmail.com

TIP OF THE MONTH:

Get your flu and pneumonia vaccines now! You can get those, and your Hep A & B vaccines free in BC if you have Hep C.