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Canada's Hepatitis C News Bulletin

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CONSENSUS HIGHLIGHTS

This is a summary Jules Levin's highlights of the draft of the NIH Consensus Statement which is expected to be released soon. The Consensus Statement is based on the decisions of a panel of neutral experts after a 2-day conference June 10-12, 2002, including presentations by investigators and discussion periods. It is made clear that the statement is an independent report of the panel, not a policy statement of the NIH or the government.

The last Consensus Statement was in 1997, and was accepted widely as the standard of care. Since then, knowledge about the virus has led to new treatments and developments, and a need for updating the Statement.

A diagnosis of chronic infection with HCV can be made when HCV is detected over a period of at least 6 months. Most of those infected develop chronic infection, which can lead to fibrosis progressing to cirrhosis, end stage liver disease (ESLD), and liver cancer (HCC). The number of people who develop cirrhosis 20 years after infection is approximately 17-55% (previously thought to be 7-16%) Progression does not seem to be affected by viral load, genotype, or quasispecies diversity, but age at infection, gender, and co-infection with HIV seem to matter, as does alcohol use, especially more than

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DDW 2002 PRESENTATIONS

The most important news discussed at this conference was the use of the pegylated interferons. The pegylated interferon alfa-2b is now approved, and alfa-2a should be approved late this year in the US. Many of the presentations dealt with this therapy in different patient groups.

In the area of epidemiology, there was a study about the possibility of spreading Hep C by sharing **toothbrushes**, and although most of us already know that, this study actually found HCV in the saliva of 30% of the patients before brushing and in 31% after brushing. HCV was found in **40% of the samples** of water used to rinse the brush, as well.

Regarding **tests,** it was noted that the alpha feto-protein (AFP), used to test for liver cancer, can be high in Hep C patients even if they don't have cancer. Investigators found that the **AFP levels were lower after treatment**, even in non-responders. The correlation between the AFP and biopsy results was not studied.

Some points were brought out about **fibrosis progression**. Major factors affecting progression are the use of alcohol, being male, contracting HCV at an older age, and co-infection with HBV or HIV. Progression is often faster in transplanted patients, and a study by Rayhill, et al,

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A BIT OF ACTIVISM

The following letter is an adaptation of a letter written by Brian Klein, HAAC-SF, which he asked people to send to the US FDA. Please copy, sign and send this letter!

The Honourable Anne McLellan
Minister of Health
House of Commons
Parliament Buildings
Ottawa, Ontario K1A 0A6
Telephone: (613) 992-4524
Fax: (613) 943-0044
Email: McLellan.A@parl.gc.ca

Dear Minister:

As a person affected by hepatitis C (HCV), I ask you to review and approve Roche's Pegasys (pegylated interferon alfa-2a) monotherapy and Pegasys/ribavirin combination therapy as soon as possible. We desperately need improved treatment and individual treatment choice. Recent studies show these treatments to be the safest and most effective yet seen for any HCV therapy, even for harder to treat groups such as genotype 1 or high viral load patients, which includes the majority of Canadians who have HCV.

Pegasys data also show reductions in the incidence of depression and flu-like symptoms so common to interferon treatments. In addition to its effectiveness, its improved side effect profile will give people like me better quality of life and a better chance for successful completion of treatment.

I hope you will review and approve Pegasys and the Pegasys/ribavirin combination at the earliest possible date. Thank you for your consideration in this matter.

Sincerely,

[YOUR NAME and COMPLETE CONTACT INFO]

BIRDLADY

The HEPV-List is in mourning. One of its first members (since 1995), feisty **Jeanne McLaughlin**, aka Birdlady, passed away in her sleep on June 18, 2002 after suffering from end-stage liver disease for many years. She was 51 years old. Jeanne held the world's first HepFest (she coined the word) in Plymouth, MA in June of 1996, and was the owner of one of the very first Hep C websites, Hepatitis Haven.

INSIDE THIS ISSUE:

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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.

NEW

Peppermint Patti's FAQ Version 5.6 Available NOW!!

Peppermint Patti's FAQ Version 5.6 is now available. The new version includes an HIV co-infection section as well as updated Canadian Links and 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.

HepCBC Resource CD: The CD contains back issues of the *hepc.bull* from 1997-2002; the FAQ V5; the Advocate's Guide; the slide presentations developed by Alan Franciscus; and all of HepCBC's pamphlets. The Resource CD costs $10, including shipping and handling. Please send cheque or money order to the address on the subscription form on this page.

THANKS!!

HepCBC would like to thank the following institutions and individuals for their generosity: Lexmark, David Klein, Bruce Lemer, Elsevier Science, Health Canada, Pacific Coast Net, Margison Bros Printers, Carousel Computers, Arlene & Frank Darlington and friends, Karolyn Sweeting, Alysn Mika, John Hasell, Gordon Mastine, Chris Foster, Ian Campsall, Darlene Morrow, Rick Wiertz, Will Lawson, Judith Fry and Claire Cassidy.
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, 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. 21: Hep C Positive Man 40+
Independent, active, caring, compassionate, romantic, would like to meet Hep C positive woman 30-40+ with positive attitude and similar traits.

Ad No. 22: 44 year old man, employed, enjoys fishing, camping, hunting. Own home. Likes country/western music. Separated 2 yrs. Would like to meet someone with similar intents, age 35-45.

Ad 23: Hep C+ Lady 50+
Young looking, 5'6", 125 lbs, long hair, very attractive, seeks positive, upbeat man for mutual support, love, laughs, possible travel. Must love animals, the arts, spirituality. Please reply with sign. I am a Capricorn. Friends first. All replies answered.

Got Hep C?... Single?

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http//nationalhepatitis-c.org/singles/list.htm

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Order Your "Hepper Bear" Now!

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WARNINGS

SMOKING

According to researchers in Taiwan, those infected with HCV should abstain from alcohol and cigarettes because they damage the liver. Alcohol boosts ALT levels, and in this study, participants filled out detailed forms about smoking and drinking habits.

In subjects with HCV, 31% had high ALT levels. Alcohol consumption more than doubled the ALT levels in those with HCV, and smoking almost doubled them. For those who smoked a pack or more of cigarettes daily and drank alcohol often, the chance of having elevated ALTs was 7 times greater than for abstainers.

The study strongly advises those with HCV not to smoke or consume alcohol.

Another study found that among patients who have received transplants, those who smoke are at a higher risk for developing vascular problems, especially in the arteries. Researchers studying 388 transplant patients between 1995 and 2001 found that 18% of smokers had vascular complications, vs. 8% of non-smokers. Those who quit smoking 2 years before transplantation reduced their chance of vascular complications by 59%, and arterial complications by 78%. These authors believe that all transplant candidates should be required to stop smoking.

Sources: Wang, et al, Archives of Internal Medicine 2002;161:811-815, Smoking Can Aggravate Hepatitis C Liver Damage and Liver Transpl 2002; 8: 582-7 01 July 2002 http://www.gastrohep.com/news/news.asp?id=1399

WATER

Many of us have had the fact drilled into us that we must remain hydrated, especially if we are on treatment, but how many of us are aware that too much water can be deadly? A new review of three deaths of US military recruits highlights the dangers of drinking too much water. Three soldiers between ages 19 and 20 recently died from too much water, and were highlighted in this report. Two died of low blood sodium levels, and the third, of a coma and brain swelling. The body can't get rid of too much water, which goes to the bowel and pulls salt from the body and causes a shift of body fluids and swelling of the brain which can cause damage. The Army recommends a maximum water intake of 1 to 1 ½ quarts per hour or 12 quarts per day.

Source: Reuters Health, July 2, 2002, Drinking Too Much Water Can Kill You, by Alison McCook, from Military Medicine 2002;167:432-434.

ARAVA

A consumer advocacy group has called for the drug Arava, prescribed for rheumatoid arthritis, to be banned since it has apparently caused 130 liver injuries, including 56 hospitalizations and 12 deaths. The group says that methotrexate works just as well, and is safer. A warning has gone out to doctors to check patients' livers. Arava is especially dangerous because it stays in the body for months.

Source: The Associated Press March 28, 2002, Arthritis Drug May Cause Liver Damage, by LAURAN NEERGAARD AP-NY-03-28-02 1606EST

ALCOHOL

Since even moderate use of alcohol seems to increase the progression of fibrosis in Hep C patients, these researchers say that total abstinence should be recommended. The study included 78 Hep C patients who drank less that 40 g daily. All the patients had 2 biopsies, with an average of 6.3 years in between biopsies. None had been on treatment. Those with more fibrosis on the 2nd biopsy were those who consumed more alcohol, more frequently.

Source: http://www.blackwell-synergy.com/ Low to Moderate Alcohol Intake Increases Fibrosis Progression In Hepatitis C by By Anne MacLennan 06/04/2002, based on Journal of Viral Hepatitis Volume 9 Issue 3 Page 235 - May 2002. "Moderate alcohol intake increases fibrosis progression in untreated patients with hepatitis C virus infection"

COUNTERFEIT EPOGEN

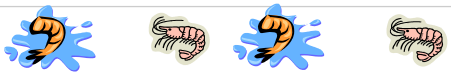
For those of you who use Amgen's Epogen (epoetin alfa), please note that there is a counterfeit batch in circulation which is 20 times weaker than it should be. The fake Epogen comes in 40,000 U/mL vials in ten-pack boxes, lot number P002970, expiration date: 7/03

Source: MedWatch: The FDA Safety Information and Adverse Event Reporting Program, http://www.fda.gov/medwatch/SAFETY/2002/safety02.htm#epogen, Epogen counterfeit product alert

SHRIMP

Because ready-to-eat shrimp can contain a bacteria which, although they aren't dangerous for most people, is resistant to antibiotics and those with weak immune systems should not eat them. The authors of this study tested grocery store prepared and/or packaged shrimp, and found them to contain several types of bacteria. Several types of the bacteria were not found in water which leads them to think that the contamination happened during the packaging. If you **cook the prepared shrimp**, you will destroy any bacteria.

Source: Reuters Health May 22, 2002, Ready-To-Eat Shrimp a Threat to Immune-Compromised, by Anne Harding



TIP OF THE MONTH:

Don't wipe your toothbrush against the toothpaste tube if you are sharing the toothpaste.

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60 g/day in men and 40 g/day in women, but lower amounts also increase the risk of damage.

Most HCV deaths in the US are from ESLD, not HCC. In 1999, 4000 deaths were said to be caused by HCV infection, which is probably an underestimate. The only treatment for those with ESLD is transplantation, and HCV is the most common reason for this procedure in the US. HCC due to HCV is increasing everywhere, in part due to better management of complication and longer survival rates.

The biopsy remains the best source of information on fibrosis and histology. Liver enzymes have little value in predicting fibrosis. Extracellular matrix tests can predict severe stages but are not consistent in predicting intermediate stages. Only biopsy gives information about iron, fatty liver, and concurrent alcoholic liver disease, and how they affect the progression towards cirrhosis.

The best response rates result from PEG-IFN combined with ribavirin. Genotypes are taken into consideration for treatment purposes. SVRs were similar in both PEG-IFNs when combined with ribavirin. Favorable outcome is predicted by genotype non-1, low viral load, and less fibrosis. Twenty-four weeks of treatment and less ribavirin is enough for genotypes 2 and 3. Early viral response (EVR), which is, at a minimum, a 2 log decrease in viral load in weeks 12-24 of treatment can usually predict a SVR. Those who still have a viral load at this point rarely respond, even if they continue treatment for 48 weeks. SVR has not been proven to correspond to improved survival, so long-term follow up is needed. It is related to reduced fibrosis as it can heal the injury to the liver

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CLINICAL TRIALS

IDN-6556

Idun Pharmaceuticals announced that the results of its Phase I clinical trial of IDN-6556 showed that the drug is safe. The trial included 76 adults, some healthy, and some with mild liver disease. In the patients with abnormal liver enzymes, improvement in the levels were clinically relevant. Some of these patients had HCV infection. Phase 2 trials are planned. IDN-6556 is a caspase inhibitor, the first studied in humans. It is supposed to preserve cells under stress. It is not an anti-viral agent, but it may protect the liver from the effects of the virus by controlling the cell death process.

Source: PRNewswire http://www.prnewswire.com, May 20, 2002: IDN-6556, A caspase inhibitor completes Phase 1 clinical trial for HCV

VitaGen's ELAD

VitaGen is beginning a multicenter Phase II clinical trial in the US, and they are enrolling patients with fulminant hepatic failure (FHF). This Phase II trial will include patients at earlier stages of liver disease than the Phase I/II trial. The goal of the treatment with ELAD is an improvement in survival without transplant.

The Phase I/II trials showed 80% of the ELAD-treated patients reached transplant or recovery, compared to only 56% in the control group. In a subset of the patients that included only those on the transplant list, 92% of ELAD patients vs. 43% of the controls reached transplant or recovery.

The ELAD system combines cell therapy with a sort of dialysis treatment. It takes over several essential liver functions, such as metabolizing toxins and producing proteins. VitaGen's C3A immortalized hepatic cells permits continuous treatment for more than seven days.

Source: PRNewswire March 14, 2002, VitaGen Announces Enrollment for Phase II Trial Of ELAD(R) Bioartificial Liver Support Therapy

DIABETES AND FIBROSIS

Elevated glucose levels and diabetes are related in Hep C patients. Researchers from France presented a report and the DDW conference (see page 1) showing an association between high glucose levels and fibrosis. They retrospectively looked at 710 patients with Hep C and no HIV or HBV. 55% of them had fibrosis grade 0 or 1, and 45% had grades 2-4. Risk factors of fibrosis were age >30 yrs, daily alcohol consumption >40g,

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NEWS

PEGETRON COMBO APPROVED IN CANADA

Health Canada has approved Schering's Pegetron (pegylated IFN alfa-2b + ribavirin) for treatment of adults with chronic Hep C. This treatment has a sustained response rate of 61%, compared to 47% for Rebetron therapy, and involves only one injection per week, rather than three. The treatment was approved in Europe March 2001, and in the US last August. Although it is commercially available in Canada as of July, it is hoped that health plans, both government and private, will soon cover the treatment.

Sources: Financial Post, June 7, 2002, Schering gets OK for hepatitis treatment, by Michael Lewis and CNW June 6, 2002- Pegetron(TM) Receives Health Canada Approval for the Treatment of Chronic Hepatitis C http://www.nationalpost.com/search/story.html?f=/stories/20020607/479091.html&qs=hepatitis---

SCHERING FINED $500 MILLION

Schering has agreed to pay $500 million to the US government because it failed repeatedly to fix manufacturing problems in dozens of drugs at four of its factories in a series of cases dating back to 1998, including lack of controls to identify faulty medicines, outdated equipment, and faulty record-keeping. The US government has launched a criminal probe on one or more of Schering's products in Puerto Rico, where their ribavirin is produced.

Schering must submit a plan to the US FDA to comply with federal rules, and to station trained personnel at each factory as overseers. They must have annual inspections done by outside consultants and federal regulators.

There is some speculation as to the amounts of active ingredients in the drugs, such as what happened with the company's asthma inhalers and Nasonex nasal spray. The company has recalled two of its asthma drugs, and stopped production of some older products. Some animal health products have been suspended. The production of Hep C treatments may be temporarily disrupted.

Sources: NYTimes.com, Drug Maker to Pay $500 Million Find for Factory Lapses, by Melody Petersen; Reuters, May 15, 2002, Schering-Plough: FDA Conducting Probe, by Edward Tobin; Reuters, May 17, 2002 Schering-Plough signs consent decree, cuts outlook http://biz.yahoo.com/rc/020517/health_scheringplough_7.html

YOHEI KONO RECEIVES LIVE DONATION FROM SON

Former Foreign Minister Yohei Kono, 65, owes his Diet member son his life. Both men are reknowned for their stubborn characters. The son, Taro Kono, 39, prevailed, and persuaded his father to accept part of his liver. The operation took 15 hours. The father was reported as saying that, after receiving his son's liver, he might be even more stubborn than before. He was on the verge of death when he received the transplant.

Source: The Asahi Shimbun, April 19, 2002, Liver sparked war of words in Kono family http://www.asahi.com/english/national/K2002041900428.html

EVEL KNIEVEL IS BACK

Evel Knievel, the famous dare-devil, wants to do a final jump of 200 feet, the longest yet, to promote the opening of the Evel Knievel Xperience Café in Primm, Nevada, near Las Vegas. The café will be a sports bar-museum, with several virtual reality rides based on his past jumps. He is also planning with Universal Pictures to produce a project called "Pure Evel." The new jump would be the first since 1980 in Seattle's King Dome. Because of heavy drinking and hepatitis C, he had to get a liver transplant a year and a half ago. He recently went through a divorce, ending an 11-year relationship. The jump is expected to raise about $12 million. He says he's not doing it for the money. He just wants to do the jump, and says he doesn't mind taking a vacation for the rest of his life.

Source: Reuters Jun 4, 2002, Evel Knievel Is Back and Wants to Jump Again, by Doug Young http://story.news.yahoo.com/news?tmpl=story&u=/nm/20020604/lf_nm/knievel_dc_1

TREATMENT

BLOOD TEST vs. BIOPSY

According to researchers from Australia, the use of a FibroTest can reveal the degree of fibrosis in some Hep C patients in order to help decide whether or not they qualify for standard therapy. They were able to predict the presence or absence of fibrosis stages 2 to 4 in about 50% of cases. Researchers in France were able to predict up to 90% of cases. The test may have to be adjusted for each population. This test was mentioned in Lancet 2001; 357:1069-75 and tests haptoglobin, gamma glutamyl transferase, bilirubin, alpha 2 macroglobulin and apolipoprotein A1. Doctors can now submit the results of blood tests to the researchers for a small fee.

Source: http://www.docguide.com/news/ May 23, 2002 DDW: Blood Test Successfully Used to Replace Liver Biopsy in Some Hepatitis C Patients, by Larry Schuster

LOW BLOOD COUNTS?

Many patients taking IFN treatments for Hep C have problems with a low white blood cell count. The most important white blood cells are the neutrophils, also called PMN's or leukocytes. Normal range is considered to be 2500-4500 PMN/ml, but having more than 700 PMN/ml is thought to be safe. Counts below 500 are worrisome, and below 200 indicates a high risk of infection. Changes in therapy are considered when the count drops to around 750. Since better antiviral results come from higher doses of IFN, doctors now prefer to treat the low blood count before decreasing the IFN when possible, which they do with Neupogen, or G-CSF, given by injection 1-3 times a week. However, this costs about $200 US per injection, and sometimes the therapy can be stopped if counts stay stable.

Ribavirin can cause anemia, a reduction in red blood cells. When this is caused by the inability of the bone marrow to produce new red blood cells, using erythropoeitin (Epogen or Procrit) may help raise the red blood cell count. Epogen is used only with those suffering anemia due to renal failure, but Procrit is used for anemia caused by other medications, and costs $300-400 US per dose, which are usually given 3 times a week.

Source:
http://www.gulfcoastliversupport.com/news.htm
Volume 5, Number 2 February 2002 Treating Low Blood Counts Caused by Hepatitis C Therapy

PROPOFOL FOR ENDOSCOPY

A research team from Cleveland, OH evaluated propofol versus meperidine and midazolam for advanced upper endoscopy in 75 patients. Those who received propofol had shorter recovery times and a better recovery of baseline activity level and dietary intake 24 hours after the endoscopy, although it cost $403 US more per patient, and would need to be administered and monitored with capnography by a trained, registered nurse rather than a gastroenterologist for it to be cost-effective.

Source: Gastroenterology 2002; 123 (1): 8-16, July 11, 2002 Propofol versus meperidine and midazolam for advanced upper endoscopy
http://www.gastrohep.com/news/news.asp?id=1422

ERYTHROMYCIN BEFORE ENDOSCOPY

Swiss researchers suggest that to make endoscopy shorter and easier, patients should be administered Erythromycin before the procedure, which promotes gastric emptying. In this study, 105 patients admitted after bleeds were randomly given 250 mg. of erythromycin or a placebo 20 minutes before the endoscopy. Also taken into consideration was the need for a second look, complications, need for blood, and length of hospital stay. There was no difference in these last two items.

Source: Gastroenterology 2002; 123 (1): 17-23, July 10, 2002 Erythromycin infusion makes endoscopy easier in patients with upper GI bleeding
http://www.gastrohep.com/news/news.asp?id=1419

HepCAN

I would like to invite you to join the eGroup HepCAN. It is a Canadian based group where we deal with the problems surrounding Hepatitis C.

There is no charge, and, like any Yahoo! group, you can chose to have all mail sent to you, receive a weekly summary, or receive no mail at all and simply check the mail on the website when you wish and respond to what is of interest to you.

The group is 4 years old and is very interesting, educational, sometimes argumentative, but never dull.

To join, click on the URL below and follow instructions:

http://groups.yahoo.com/group/hepcan/

Bruce DeVenne, Moderator

NATURAL TREATMENT

VITAMIN K2 TO FIGHT BONE LOSS

According to Japanese researchers, patients with cirrhosis who often exhibit bone loss can be helped by taking vitamin K2 supplements daily. The study was done in 50 women with cirrhosis due to either hepatitis B or C. Half were given 45 mg/day of the vitamin, and bone mineral density (BMD) was measured at the lumbar spine before the treatment and 1 and 2 years after the treatment. After 1 year, the women receiving vitamin K had a BMD of +0.1% compared with –2.2% in the other women. At 2 years the results were –0.5% and –4.6%.

Source: Reuters Health May 27, 2002, Vitamin K prevents bone loss in women with cirrhosis Am J Gastroenterol 2002;97:786-787,978-981.
http://www.4woman.org/nwhic/News/2002/02May28-3.htm

THIAMINE DEFICIENCY

A new study shows that, contrary to popular belief, thiamine deficiency is just as common in people with cirrhosis caused by hepatitis as in those with cirrhosis caused by alcohol. This study included 40 patients with cirrhosis caused by alcohol, 48 patients with Hep C-related cirrhosis, and 59 patients with Hep C but no cirrhosis. Erythrocyte transketolase activity and thiamine levels were tested. All of the cirrhotics were similarly thiamine-deficient. None of the Hep C patients without cirrhosis were deficient. The author thinks that thiamine supplements should help all cirrhotics.

Source: Hepatitis Weekly, May 20, 2002, Page 3, Thiamine deficiency likely in cirrhotics regardless of underlying cause, by Sonia Nichols. See Digestive Diseases and Sciences, 2002;47(3):543-548

IRON OVERLOAD

Iron overload is a problem in some Hep C patients. All of us know about anemia, or a lack of iron, but too much can also be a problem. It can cause oxidation of the body's tissues, and can turn vitamin C into a pro-oxidant instead of an anti-oxidant. Too much iron can cause joint pains, especially in the hip, hair loss, fa-

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(CONSENSUS—Continued from page 3)

with very little chance of progression to HCC or of the disease returning.

Re-Treatment: Decisions to re-treat should be based on: (1) previous type of response, (2) the difference in potency of the new therapy, (3) the severity of the disease, (4) genotype and other predictive factors (5) tolerance of and adherence to previous therapy.

Relapsers achieve end of treatment response (ETR), but it is not sustained. Nonresponders never achieve an ETR or SVR. Included among nonresponders are partial responders who have a significant viral load reduction. Even without SVR, the liver may improve. 15-20% of combo non-responders achieved SVR using the PEG-combo. Non-1 genotypes respond better to re-treatment. When the same treatment is used again, virtually all patients relapse when treatment stops. Extending the time of treatment may improve the response rate.

Non-responders to the PEG-combo, especially those with advanced disease, present a serious problem. Maintenance therapy is being investigated in the HALT-C trials using only PEG-INF. In the meantime, long-term therapy is experimental. Patients with advanced disease should be considered for re-treatment. For patients with less damage, the factors above should be considered.

WHO SHOULD BE TREATED

All patients with HCV are posible candidates for therapy, and therapy is recommended for those who are at risk for progression. These include those who have HCV RNA, a biopsy with fibrosis, and moderate inflammation and necrosis. Most have elevated ALTs. Many patients have been excluded because of alcohol or drug abuse (IDU), age, certain medical or mental condi-

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*(**DDW 2002**—Continued from page 1)*

found that this is the case especially in patients who suffered **cryoglobulinemia before transplantation**. Donor and recipient age may also be factors in progression after transplantation, while rejection episodes don't seem to affect progression to fibrosis.

The treatment of **blacks** has resulted in **poor response rates**, and it was thought that this was due to genotype and lack of compliance, but these factors have been disproved by Muir, et al, where blacks and nonwhite Hispanic patients were treated, and 98% of each group were genotype 1. The response rates at 24 weeks were 25% and 62%, respectively.

Treatment of patients with **normal ALTs** was studied. Treatment of this group of patients has been controversial. In a study by Metwally, et al, 25 of 198 naïve HCV+ patients were found to have normal ALTs. They tended to have lower body mass indexes than the other patients. They also generally had less inflammation as shown by biopsy, but there was no difference in scarring between the 2 groups. The conclusion was that a biopsy might help to assess liver damage in these patients, since some may even have cirrhosis. The New York Normal ALT Study Group reported that their study subjects were treated and 28% received 3MU of IFN 3x/week + ribavirin (standard therapy) and had a SVR (sustained viral response, or undetectable HCV 6 months after finishing treatment), and 37% receiving 5 MU of IFN 3x/week (high-dose) + ribavirin had a SVR. Genotype 1 patients on standard therapy had a 10% SVR, compared to 37% with high-dose therapy. Genotype 2 and 3 patients had a SVR of >80%. The SVR was comparable to that of patients with elevated ALT levels. **Studies with PEG-IFN were recommended for patients with normal ALTs.**

A study by Helbing, et al, of treatment of patients with **compensated cirrhosis** was presented. Patients were all given 180 mcg/wk of Peg-IFN alfa-2a plus either 1000-1200 mg/day or 600-800/day of ribavirin. The response rates at 24 weeks were 87%. **The rate is 93% in the high-dose combo patients**. Ten patients withdrew because of adverse events.

Another group of patients in which treatment is controversial is that of **relapsers and nonresponders** to previous treatment. Several papers with preliminary results were presented that discussed treatment of these patients, who were re-treated with PEG-IFN combo. The New York Peg Intron Study Group compared 2 dose regimens. Group 1 received PEG-IFN alfa-2b 1.0 mcg/kg + ribavirin 1000-1200 mg/day; Group 2, PEG-INF alfa-2b 1.5 mcg/kg + ribavirin 800 mg/day. The total SVR of all those completing follow-up was 21%. The overall SVR of blacks infected with genotype 1 was 8%. The SVR in previous nonresponders (NR) to the combo in groups 1 and 2 was 10% and 11%, respectively. The SVR in previous NR to IFN monotherapy for groups 1 and 2 was 40% and 25%, respectively. The SVR in previous relapsers to the combo for those in groups 1 and 2 was 43% and 60%, respectively. Those with more fibrosis had better response rates with the higher dose of PEG-IFN. **The response in relapsers is promising, but in NRs, poor**.

Lawitz, et al, presented a report of the use of an **induction dose** of PEG-INF + ribavirin in these patients. The patients were divided into 2 groups. The induction group were PEG-IFN alfa-2b 1.5 mcg/kg/wk + ribavirin 1000-1200 mg/day for 12 weeks, and PEG-IFN 1.0 mcg/kg/wk plus ribavirin 800 mg/day for another 36 weeks; Group 2 took PEG-IFN alfa-2b 1.0 mcg/kg/wk + ribavirin for 48 weeks. Only end-of-treatment results were available: NRs to combo, induction--25%; NRs to combo, fixed dose-- 16%; NRs to monotherapy, induction--34%; NRs to monotherapy, fixed dose--30%; relapsers to combo, induction--55%; relapsers to combo, fixed dose--58%; blacks, induction--14%; blacks, fixed dose-- 13%.

Yet another study of **amantadine** was presented. 152 patients were treated with 100 mg twice daily for 6 months, or a placebo. During the last 6 months, all patients received amantadine. The **SVR was 15.4%,** and the researchers consider that amantadine is a **safe alternative** for nonresponders to IFN, or for those who can't tolerate IFN.

There is no standard treatment yet for **HIV/HCV coinfection**. Preliminary data of treatment of a small group of these patients with the PEG-combo (IFN alfa-2b) or PEG-IFN alone in patients with no previous HCV therapy showed a response in 14 of 25 patients in the combo group, and 3 of 24 in the monotherapy group. 35 patients withdrew because of flu-type symptoms.

Source: Digestive Disease Week 2002, Liver Disease: Clinical Highlights and Viral Hepatitis CME, May 19 - 22, 2002, San Francisco, California, Recent Advances in the Understanding of Hepatitis C, David Bernstein, MD

(CONSENSUS—Continued from page 6)
tions, or incarceration. Efforts to treat these patients should be made. Periodical monitoring is recommended for patients with normal ALT, no fibrosis, and little inflammation.

One of the goals of treating the patient with advanced liver disease is to delay disease progression. Patients with advanced cirrhosis should be studied in clinical trials or considered for transplantation. In those with ESLD, the main option is transplantation. There are studies of therapy of patients awaiting transplants, but the side-effects of the therapy can be life-threatening.

HIV Coinfection: All those with HIV should be tested for HCV. Co-infected patients may have faster progression of the Hep C. There are no specifically approved therapies for those who are co-infected, but these patients should be evaluated for treatment. Studies have been done in those with stable HIV infection and compensated liver disease. SVR is possible in those who are co-infected, and there are better response rates to the PEG-combo than to the standard combo. Treatment of the Hep C hasn't seemed to affect control of the HIV.

Injection Drug Users: 20 IDU's were recently treated successfully, even when the patients have continued injecting illicit drugs or methadone. Treatment of this group is important, since it is the largest group of HCV+ people in the US, and transmission could be reduced. Linking treatments of IDU's to drug-treatment programs is a key to success. Collaboration between HCV experts and substance-abuse providers should be encouraged.

(Continued on page 8)

(TRIALS—Continued from page 4)
serum glucose >6.1 mmol/l, anti-HBc and being male. BMI, triglycerides, ferritin and fatty liver were associated with glucose, but did not predict fibrosis independently. Taking into account how long infection had lasted, patients with serum glucose greater than >6.1 mmol/l had progressed to fibrosis faster than those with normal levels. Counts over 6.1 were associated with fibrosis grades 3 and 4, but not with early grade 2, and this association could help explain why some patients progress and others don't.

Source: NATAP, DDW, San Francisco, May 19-22, Imapct of high serum glucose on liver fibrosis in chronic hepatitis C, reported by Jules Levin

ONCE AGAIN AMANTADINE

Although Amantadine cannot compare to the effectiveness of IFN or the IFN combos, it is effective to some degree against HCV, and has fewer side effects. When combined with IFN or the combos, it tends to improve the response rates slightly. Triple therapy with pegylated IFN alfa-2b, ribavirin and amantadine may be even better and just as safe as standard treatment. An ongoing trial of 130 patients completing 3 months of treatment showed negative HCV RNA in 54% of those taking the triple therapy, 42% of those receiving pegylated IFN alfa-2b alone, and 42% of those receiving the Peg IFN + ribavirin.

In patients who have relapsed after an initial response to IFN alone or combo therapy, the triple therapy results in a high SVR (71-73%).

Sources: MedscapeWire May 20, 2002, DDW Abstracts 107224, 101352, 107199, Amantadine Role in Hepatitis C Treatment Debated, by Laurie Barclay, MD, and Zilly, M, et al, Eur J Med Res 2002 Apr 30;7(4):149-54, Triple Antiviral Re-Therapy for Chronic Hepatitis C with Interferon-alpha, Ribavirin and Amantadine in Nonresponders to Interferon-alpha and Ribavirin, PMID 12010649

(NATURAL TREATMENT—Continued from page 5)
tigue, and heart irregularities. Pre-menopausal Women are at less of a risk.

Tips: Limit meat, beets, leafy green vetetables like spinach, molasses, and dried fruits. Don't cook with iron or stainless steel cookware. Olive oil, caraway, cumin, mint, and vitamin C help to absorb iron. Stay away from eggs, soy and milk if you suffer from iron overload. Bet tested for levels of hemoglobin and ferritin, and saturation levels of transferring, or test total iron with an IBC test. Phytic acid found in bran removes excess minerals. It is available as a supplement. Don't take it if you're anemic. Don't take iron supplements or food with iron added. Avoid alcohol especially if you are an older man. Exercise gets rid of excess iron through perspiration.

Source: Do You Have Iron Overload? http://www.alternativemedicine.com/whatshot/whatshot55.shtml

BIMRAM YOGA

Bikram Yoga is now used at the Bastyr Center for Natural Health in Seattle. It is practiced in rooms heated to 85-105 degrees Fahrenheit, with a humidity of 60-70%, which, combined with a sequence of 26 poses, raises the heart rate and flushes out toxins through heavy sweating. It increases the blood circulation through the liver, hopefully reducing white blood cells and inflammation, and boosting the immune system, keeping the liver healthy until better treatments come along.

Source: New Hope for Hepatitis C: The detoxifying effects of Bikram Yoga may help in treating this deadly liver disease, by Sally Squires, May 1,2002: http://www.yogajournal.com/health/585_1.cfm

VICTORIA HepCBC
GENERAL MEETING
August 6th 7-9 PM, 541 Herald St.
Nominations to the Board requested
Contact: 595-3892

Please attend this important meeting. If you like the things that HepCBC has provided you, like the *hepc.bull*, *Peppermint Patti's FAQ, Advocate's Guide to Hepatitis C,* HepCAN list, pamphlets, counselling, computers, then we need YOUR help to ensure that these services continue. We are very short of volunteers, and need new ideas, energy, and fundraising efforts.

VANDU

VANDU Information Fair May 6, 2002 Commemorates Hepatitis Awareness Month

VANDU (Vancouver Area Network of Drug Users) is holding Hepatitis information fair at Pigeon Park at Carrall and Hastings St. in Vancouver's Downtown Eastside at 1pm to 3 PM.

VANDU has 1200 members and virtually all of them have Hep C. "Hepatitis C is a preventable disease and yet we watch in horror as our friends and neighbours continue to become infected because they lack access to proper housing and effective harm reduction initiatives" said Dean Wilson, President of VANDU. "Other countries have curbed the spread of this debilitating virus by implementing Safe Injection Facilities and by making Heroin prescription available."

Over 5,000 people living in the immediate vicinity of Pigeon Park are infected with Hepatitis C and research from the Vancouver Injection Drug Users Study has shown that a non infected person who uses illicit drugs in the downtown eastside will become infected with hepatitis C within a year.

"The new drug users who continue to become infected are young with a median age of 20 years" added Wilson, "Surely we can implement basic public health initiatives to protect our youth who make the mistake of getting involved with drugs. A hugely disproportionate number of these new infections are amongst Aboriginal youth and young women."

Thomas Kerr, an award winning researcher on Safe Injection Facilities, states "The evidence is in, safe injection facilities are proven effective at reducing the behaviour that spreads Hepatitis C and operate in many countries around the world effectively. Any further foot dragging by government here will result in unnecessary misery and costs for all British Columbians. Ironically polls show that a majority of people in BC support their implementation."

The British Columbia Legislative Assembly declared May 2002 as Hepatitis Awareness Month.

Contact:

Ann Livingston cell 604-719-5313
Project Coordinator
Vancouver Area Network of Drug Users

VANDU 604-683-8595
Thomas Kerr cell 604-619-2312

HEALTH CANADA LAUNCHES HEP C "GET THE FACTS" CAMPAIGN

Health Canada has launched a national public awareness campaign designed to inform Canadians about hepatitis C. This infectious disease of the liver is caused by the hepatitis C virus (HCV). It is usually spread through direct contact with infected blood. An estimated 240,000 Canadians are infected with the hepatitis C virus and, because there are usually no symptoms, 70 per cent of them are unaware. The objective of the hepatitis C "Get the Facts" campaign is to raise awareness of the risk factors of this disease.

The campaign's public education materials include a brochure with general information about the virus, a poster and bookmark as well as an information sheet for health professionals.

A website has also been developed to provide information on prevention, risk behaviours and treatment; it can be accessed at http://healthcanada.ca/hepc. For more information on the campaign, visit: http://www.hc-sc.gc.ca/english/media/releases/2002/2002_39.htm.

To access these materials, or to help distribute them, contact your local support group. In Victoria, call HepCBC at 595-3892.

YOU MAY BE ELIGIBLE TO PARTICIPATE IN A **CLINICAL RESEARCH STUDY** IF YOU:

Have chronic hepatitis C infection

Are between the ages of 19 and 75 years of age

Have already been treated with but not benefited by interferon-a-based therapies or such therapy is contra-indicated

Are willing to undergo pre and post treatment liver biopsies

IF YOU ARE INTERESTED, PLEASE CONTACT:
The Research Co-ordinator
Viridae Clinical Sciences, Inc.

(604) 689-9404

(CONSENSUS—Continued from page 7)

Alcohol and HCV: Using alcohol adversely affects treatment resonse. Treatment of HCV would best be done together with treatment of alcoholism. Drinking more than 80 g/day compromises HCV treatment.

RECOMMENDATIONS

- Educate about transmission so as to identify victims and prevent the spread.
- Develop reliable culture systems for growing HCV and study the mechanisms of fibrosis.
- Standardize HCV tests for earlier diagnosis and treatment.
- Refine current application of treatment by expanding the list of manifestations of Hep C, noninvasive tests and the role of the biopsy.
- Form a network for conducting research on the natural history, prevention and treatment of Hep C.
- Extend treatment to populations not included in current trials such as children and adolescents, those with acute hepatitis, hemophiliacs, IDUs, alcoholics, those with depression, the HCV/HIV coinfected, those with ESLD, and those transplanted, to reduce the death rate and prevent transmission.
- Look for a way to stop mother-to-child transmission.
- Try new therapies in nonresponders, including antifibrotic drugs, drugs that affect the immune system and alternative treatments.
- Promote collaboration between health and addiction management professionals to deal with societal, medical and personal issues in IDUs with Hep C.
- Look for support from government agencies and from the private sector for support of research on epidemiology and treatment.

Source: Selected highlights from the draft NIH HCV Consensus Statement June 10-12, NIH Campus, Bethesda, MD, reported by Jules Levin

HIGHER WAGE EARNERS HIT HARDEST IN HEP C COMPENSATION DEAL

It appears that people who were working at well-paying jobs are being hit hardest in the Hep C Deal. First, when calculating your pre-claim imcome, you cannot claim UI benefits, even though they were a taxable part of your income. When Crawford's starts to deduct from the gross to arrive at the net they deduct all taxes, UI, and CPP contributions. Then they deduct CPP and any other disability pensions you may be receiving. They then take 70% of the total of what's left, and one-third, if you're lucky, is what you get on your check. To back this up, in case you manage to slip through a loop hole like the "tax free perk" and may be entitled to substantially more money, they have a Catch 22 that limits the total of your claim, regardless of what the money is for. However, I know of people who never worked, or worked part time at minimum wage jobs, who applied for loss of services in the home, and are receiving over $13,000 this year. In one specific case this amounts to just over 3 times what the claimant earned in his best year. Aren't you sorry you listened to your parents, studied, and got a good job?

Bruce DeVenne

A COMPENSATION TIP

Are you just a month or two too late to qualify for the '86-'90 "window"?

Get the documentation on the blood you received and find the exact date it was collected. Frozen cells, etc., have a shelf life well over one month.

Even after testing became available in 1990, the Red Cross continued to use unscreened plasma to make hemophilia products.

Bruce DeVenne

DIAL-A-DIETITIAN

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

Hep C 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
2741 Richmond Rd, Victoria, BC V8R 4T3
Tel. 595-3892 or Email:
info@hepcbc.ca

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 to appear in the bulletin.

Are you in the 86-90 Window? Are you having any problems?

Contact: Terry Waller
(250) 642-6766
(Terry is not a lawyer but a concerned victim)

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