hepc.bull
BC's HEPATITIS C NEWS BULLETIN
JULY 1998
Issue No. 2

Hepatitis C Society of Canada
Message from the Chairman of the Board of Directors

June 17, 1998

The last few weeks have been particularly busy with compensation issues. This message is being sent to HeCSC Board Members and Chapter Heads as a way in which to keep HeCSC volunteers and members up-to-date with the issues. It is expected that an update will be sent on a bi-weekly basis to all of you for the next couple of months.

Jeremy Beaty, HeCSC Chair, continues to lead the organisation on compensation matters. Jeremy Beaty and David Smith, HeCSC Vice-President (Victoria Chapter Head) attended a meeting in late May in Edmonton of the Federal/Provincial/Territorial (F/P/T) Working Group on Hepatitis C. No decisions were made at this meeting; however, it was important for HeCSC to be there. Thanks to the Edmonton Chapter for organising a small rally during these meetings. It was widely covered by the press.

HeCSC has begun to investigate the possibility of establishing a HepC Carrier Compensation Advisory Group to provide the HeCSC Board with input. More information will be available in the near future.

HeCSC has been invited to participate in an Expert Panel hosted by Health Canada. Epidemiologists will present their assessment of the number of individuals infected with Hep C from blood transfusions. Jeremy Beaty, HeCSC Board Chair, and Tim McClemont, HeCSC Executive Director, will be representing HeCSC at these meetings later this week.

The Kitchener-Waterloo Chapter held an informal, private meeting with The Honourable Alan Rock last week. Chapter Head Carolyn Cavaney lead the HeCSC delegation for this meeting, where personal stories of the challenges people faced as a result of Hep C were recounted to the Minister.

Jeremy Beaty and other members of the HeCSC Compensation Task Force have met with officials of the Ontario provincial government to discuss and further clarify the position of the Ontario government on

(Continued on page 5)

Research and HCV- How YOU Can Make a Difference

by Darlene Morrow, BSc

At the *hepc.bull* we are making a concerted effort to become directly involved in our own therapies and research into HCV. We are pushing for more HCV research and ultimately a cure.

With that in mind we have sent out letters to the drug companies that are directly involved in research into HCV. A copy of a similar letter appears on page 5 of this newsletter. We have sent letters to over 25 companies and will follow through, ***unrelentingly***, until we get a response and help. We want YOU to send the letters, too. You can copy the letter here, write it in your own hand, or write a different one altogether. We must take charge of what is happening with the research and/or treatment. The more of us that get involved, the more likely we are to succeed. Let's all work together for a CURE.

I am listing the companies, their addresses and a brief description of what they are researching.

1. SciClone
Donald R. Sellers
901 Mariner's Island Blvd., San Mateo, CA, 94404

Zadaxin, Zadaxin/IFN. ZADAXIN (thymosin alpha 1) was originally isolated from the thymus gland and is now produced through chemical synthesis. ZADAXIN has been shown to stimulate the human immune system by promotes the maturation of T cells, which are involved in the control of various immune responses.

2. Schering-Plough,
DNAX Research Institute
901 California Ave., Palo Alto, CA, 94304-1104

Pegylated IFN, Rebetron (Intron A and ribavirin combination), Intron A, IFN/iron reduction, Rebetron in treatment naive patients, Induction Combo- high dose IFN for 30 days followed by traditional dose for 11 months. Intron A-Interferon, Alpha-2b [Recombinant] - a water soluble alpha-interferon protein produced in recombinant E. coli containing the interferon alfa-2b gene from human leukocytes. Pegylated (PEG) Interferon is a long acting interferon that only requires a once a week injection. Ribavirin— a guanosine analogue antiviral drug

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COMING UP:

Victoria HeCSC Meetings: Last Wednesday of each month 1-3 PM, and again at 7-9 PM, St. John the Divine Church Lounge, 1611 Quadra St. (Entrance through the rear, marked Annex) NEXT MEETING**:** July 29th.

Penticton HeCSC Meetings: Third Thursday of every month, 7-9 PM, Penticton Health Unit — Board rooms. NEXT MEETING: July 16th.

Kelowna HeCSC Meetings: Last Saturday of every month, 1-3 PM, Rose Avenue Education Room in Kelowna General Hospital. NEXT MEETING: July 25th.

Nanaimo HeCSC Meetings: Second Thursday of every month, 7 PM, Health Unit-Central Vancouver Island, 1665 Grant St. NEXT MEETING: July 9th.

Vancouver CLF Support Group Meetings: Second Thursday of every month, 7:30 PM, Nurses' Residence of VGH (12th and Heather). Signs will direct you. NEXT MEETING: July 9th. Contact the CLF 681-4588 or Herb 241-7766.

Sunshine Coast Support Group Meetings: First Thursday of each month, 7:30 PM, Coast Garibaldi Health Unit in Gibsons. NEXT MEETING: July 2nd. Contact Carol: 886-4298 <ryker@cheerful.com>

Vernon HepCURE Meetings: 1st Tuesday 12-2 PM and 3rd Tuesday 6-8 PM of each month, the People Place, 3402 - 27th Ave. NEXT MEETING: July 21st. Contact: Marjorie 558-7488 <www.junction.net/hepcure>

Enderby HepCURE Meetings: Last Sunday of each month 2-4 PM for High Tea, The Raven Gallery, 701 George St. NEXT MEETING: June 28th. Contact: Marjorie (250)558-7488 <www.junction.net/hepcure>

Shall We Dance?

Come support the Victoria Chapter of HeCSC. Mark the date on your calendars now: October 10, 1998 (subject to change,) place to be announced. Bring friends, and dance to the music of the band "Rukus."

Volunteers are needed for decorations and food. Please call (250) 388-4311 to sign up.

SUBSCRIPTION FORM

Please fill out include a check made out to **HeCSC - Victoria Chapter**. Send to:
Hepatitis C Society of Canada
Victoria Chapter
1611 Quadra St.
Victoria, BC V8W 2L5

Name: _____

Address: _____

City: _____ **Prov**. ___ **PC**_____

Home(___)_____**Work**(___)_____

One Year Subscription: Donation **$10.00**
Member of:
Victoria HeCSC_____[]
Vancouver HeCSC_____[]
Okanagan HeCSC_____[]
Other_____[]

"I cannot afford to subscribe at this time, but I would like to receive the newsletter.
I am applying for a grant."____[]

"I would like to make a donation so that others may receive the newsletter without charge"_____[]

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

THANK YOU!

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

A heartfelt thanks is extended this month to the people at **CompuSmart** in Victoria, for exceptional discounts on computer software and hardware. Thanks to Brian Norton and others who helped lower prices and get us the tools we needed to keep all of us informed and up to date.

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

NEW VICE CHAIRS

David Smith was chosen Vice-Chair of the National Board of HeCSC

Dr. C.D. Mazoff was elected Vice-Chair of the Victoria Chapter of HeCSC.

Marjorie Harris Re-elected President of HepCURE

Marjorie Harris was recently elected president of HepCURE for a second term. The Hepatitis C United Resource Exchange (Hep CURE) is a registered non-profit organization. The executive has five members drawn from the hepatitis c and academic communities. Their application for federal charitable status is still in process. HepCURE has a research list on the internet, indexes of articles on HCV, and provides educational and support group activities. The internet research group is a closed list of scientists from various specialities that review the latest journal articles and discuss the connections between them in the hope of finding a cure for HCV.

HepCURE's mission statement is to cultivate an international network promoting Hepatitis C education, support and research.

Donations go to cover internet and telephone costs at present. In the future they would like to rent a small office space in Vernon so that volunteers can help with the ongoing work and to give a public focal point to work from so that funds can be generated to aid HCV researchers directly as is done similarly by other large campaigns for cancer and diabetes. *Darlene Morrow*

HOW TO REACH US:

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(Parksville)

TED KILLOUG **TEL:(250)752-1718** ***gjones@qb.island.net***
(Qualicum Beach)

HELEN HUBBARD **TEL:(250) 245-8759**
Ladysmith/Nanaimo)

FOUR HCV CLINICAL TRIALS IN BC

1. Interferon and Ribavirin Combination Therapy

Non-responders or relapsers to interferon alone are being studied in a combination therapy trial using 3 million units of interferon injected three times a week (which the patient pays for) and 1000-1200 mg of ribavirin orally twice a day (which is paid for by the drug company.)

THIS STUDY WILL BE CLOSING SOON.* This is now done on compassionate grounds, i.e., it isn't a study.

2. Amantadine Therapy in Combination with Interferon in non-responders or relapsers.

This trial is looking at amantadine in the treatment of HCV. THIS IS AN OPEN STUDY.

3. PEG Interferon Trial

Pegylated (PEG) Interferon is a long acting interferon that only requires a once a week injection. Patients are randomly assigned to one of two therapies:

a) PEG interferon injection once a week OR

b) induction of Interferon at a high dose for one month followed by the standard dose of 3 million units three times a week for the duration of the trial.

This trial is for a period of one year and the cost of the drug is paid for by the drug company and is OPEN to naive patients only (not previously treated with interferon).

4. **Low Dose Maintenance Schedule with Interferon**

This trial will begin sometime in the new year and will look at low dosage maintenance therapy of interferon.

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

ADVERTISING: ***The deadline for placing advertisements in the* hepc.bull *is the 15th of each month. Rates are as follows:***
Newsletter Ads:
$10 for 1/6th page, per issue
$100 for 1/6th page, 12 issues (in advance)
$20 for 1/3rd page, per issue (vertical or horizontal)
$200 for 1/6th page, 12 issues (in advance)
whole page:
$60 per issue
$600 for 12 issues
1/2 page:
$30 per issue
$300 for 12 issues

MELATONIN WARNING

"Is melatonin associated with the development of autoimmune hepatitis?"

Melatonin is a neurohormone produced by the human pineal gland that plays a role in the regulation of many physiologic processes and has been proposed as a therapy for everything from insomnia to metastatic carcinoma. Melatonin is available in the United States without prescription, and adverse effects appear to be uncommon. However, because melatonin appears
to have immunomodulatory properties, the potential exists for the development of autoimmune-related side effects. We describe a patient in whom characteristic clinical and laboratory features of **autoimmune hepatitis developed after beginning melatonin therapy** for the treatment of insomnia. Liver biopsy demonstrated histologic features of autoimmune hepatitis. Rapid symptomatic and biochemical improvement resulted from the initiation of immunosuppressive therapy; however, hepatitis recurred after the withdrawal of steroid therapy. The temporal relation observed between melatonin use and the development of autoimmune hepatitis raises the possibility that the drug might be involved in the pathogenesis of this patient's autoimmune disease.

Hong YG, Riegler JL Department of Gastroenterology, Wilford Hall Medical Center, Lackland Air Force Base, Texas, USA.
J Clin Gastroenterol 1997 Jul;25(1):376-378
PMID: 9412927, UI: 98074407

Amgen Building HCV Support Group Data Base

by Darlene Morrow

Amgen is gathering information for a patient HCV support group database. If you wish to have your support group listed, please include the following information:

Group Name
Contact
Address
City
State
Zip
Telephone Number
Fax Number
Email Address
What day and how often
What time
Notes-such as men only, woman only, group size, etc.

For more info call Melissa at: (805)447-3339
Fax: (805)480-1268
Email Melissa at <melissa@amgen.com>

Snail mail:
1840 DeHavilland Drive. Bldg. 36-1-B
Newbury Park, CA 91320

Duract: Painkiller Linked to Deaths is Withdrawn

UPI Science News
Monday June 22 2:54 PM EDT

WASHINGTON, June 22 (UPI) - The manufacturer of the painkiller **Duract** says it it withdrawing the drug because of reports of rare severe liver failure and deaths.

Wyeth-Ayerst Laboratories, of St. Davids, Pa., says Monday it is advising doctors to discontinue prescribing and dispensing the drug, generically known as bromfenac, immediately.

The drug was approved in July l997 for management of acute pain for 10 days or less. The company says the reports of deaths and injuries were associated with long-term use, beyond 10 days.

In a statement, the company notes the drug was never approved as a treatment for longer term use for chronic conditions such as osteoarthritis or rheumatoid arthritis. Also, it says, no cases of serious liver injury were reported in clinical trials.

But because researchers recorded a higher incidence of liver enzyme elevations in patients treated long term in clinical trials, the product was
approved for use for 10 days or less. The information about the elevated liver enzymes was included in the product labeling.

After Duract was marketed, the Food and Drug Administration and the company received reports of several cases of rare **severe hepatitis and liver failure**, some of which required transplantation, in patients taking the drug for more than 10 days. In February l998, in response to the reports of severe liver failure, and transplants, the FDA and the company strengthened the warnings in Duract's labeling with a special black box warning and Wyeth-Ayerst issued a Dear Doctor letter.

The revised label re-emphasized that patients should not take the drug for more than 10 days and alerted physicians and other health care professionals to the cases of severe hepatitis and liver failure, and cases in which patients required a transplant, in patients who had taken Duract. Despite these efforts, the agency and the company continued to receive reports of severe injuries and death with long-term use of Duract.

In the statement, the company says, given the availability of other therapies, the FDA and Wyeth-Ayerst concluded that it would not be practical to implement the restrictions necessary to assure the safe use *limited to less than 10 days* of Duract. The company and FDA agreed that it would be prudent to withdraw the drug from the market.

Questions about withdrawal of Duract can be addressed to Wyeth-Ayerst's hotline at 1-(800) 281-9260.

REPRINTS

Past articles are available at a low cost. For a list of articles and prices, write to the hepc.bull, via Darlene Morrow at 1203 Plateau Drive, N. Vancouver, BC, V7P 2J3 < hepcbc@sprint.ca>

The Quiet and Deadly Game

by Connie Lake

As I laid in my hospital bed
And watched the blood drip into my veins
I was not aware of the risks
And the quiet and deadly virus was born.

In the new vessel it called home
It silently began to invade
Never quite showing its vengefulness
While it played its quiet and deadly game.

When I was caring for my babies
It watched and waited
For just one little chance
To continue its quiet and deadly game

When I made love to my husband
It watched in hopefulness
Waiting for for the opportunity
To play its quiet and deadly game

As the years followed
I would feel achy and tired,
Not aware my body had an invader
Playing its quiet and deadly game.

Then one day I turned yellow
And felt pain beneath my ribs
I could no longer get out of bed
And the virus began to show its face.

While having routine bloodwork done
My liver enzymes began to climb
I was tested for hepatitis C
And the virus was no longer quiet

For seven years it conquered and destroyed
It made my liver its home,
Unwilling to release its strong grip
And continued its quiet and deadly game.

When I was found positive
I had two choices in life.
I could continue to be its victim
Or I could be a survivor in the quiet and deadly game.

I chose to stand up and fight.
I would learn to be strong.
I would not allow it to have my family
And I would not let it attack society through me.

I give my body the best fuel to fight.
And through the desperation and pain
I continue to walk through the fog
Because it is my turn to play the quiet and deadly game.

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 checks payable to **HeCSC Victoria Chapter,** and mail to **HeCSC, Attn. Squeeky, 1611 Quadra St., Victoria, BC V8W 2L5.** 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 check for a donation of $2, if you can afford it. Mail to the same address as above.

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

Ad No. 7
Sense of humour? Are you intelligent, articulate, fit and funny? So am I. What I miss is a romantic buddy to go out and play with. Slim, brunette, 48, financially secure, looking for SWM 48 to 55, Vancouver-based, for whatever.

HCV- The Taboo Subject

Some people may have skeletons in their closets, and when I was diagnosed with hepatitis C in September 1995, mine all came back to haunt me. It was in the fall of 1977 that I first tried injection drugs—cocaine was the first drug of choice. I would classify myself as an experimenter, rather than a physically-dependent drug addict. I never learned how to inject myself, sharing needles with either my heroin-addicted boyfriend or my girlfriend. When you're young, you do some stupid things sometimes. I always thought I was being careful, though.

Not careful enough. Eighteen years after I first had a needle in my arm, I learned during a routine physical exam that I was infected with hepatitis C, an insidious deadly blood-borne virus that attacks the liver. I am among the highest-risk group, which is composed of people who have shared needles to use drugs. The virus is not only spread by using intravenous drugs but also, some experts believe, by sharing the straws used to snort cocaine—a drug many North Americans in their forties and fifties have tried. Microdroplets of blood, dislodged when a coke straw bumps the delicate capillaries inside the nose, can be passed on the end of the straw.

Hepatitis C is already an inner-city and drug-user epidemic. Infection among IV drug users is estimated at up to 90% and in the prison population in Canada, hepatitis C infection accounts for a third of the inmates. The virus has infected not only people who are at the lower end of the social and economic scale, but also plenty of those in the middle class. With the prevalence of recreational drug use in the sixties and seventies, and the two- to three-decade progress of the virus, many people are just discovering now that they are infected with this stealth disease, known as "the dragon."

I'm among those tax-paying, law-abiding solid citizens today paying the price for the sins of my youth. While IV drug use, past and present, is the leading cause of HCV infection, other modes of transmission are blood transfusions, tattooing, body piercing, acupuncture, accidental needle stick injures to health-care workers with a contaminated needle, manicures, pedicures, sharing razors or toothbrushes, snorting drugs, sexual contact, childbirth and breast-feeding. No matter how low the risk is, the possibility is there. I also have read that HCV has been found in stored blood from the forties. Some people go even further implying the possibility of chemical warfare, a conspiracy. Who knows for sure?

I decided after a lot of pondering to tell my liver specialist at my first visit that I had used IV drugs in the past. I assumed revealing this fact would benefit my care and their research. I didn't have to reveal my sordid history, since the virus was possibly caused by the injection of gamma globulin that I had received, after I contracted hepatitis B, two years prior to any drug use. That makes it acceptable in the eyes of the society. I am disturbed by this self-righteous attitude a lot of people have towards ex-drug users and others who don't fit into society's perfect vision. My mistakes occurred over twenty years ago! Do I have to pay for those mistakes with my life? I am no less deserving of medical care than anyone else.

I would like people to understand the stigma involved with being an ex-drug user. I have honestly admitted to my past history of two years of illegal drug experimentation to my doctors. It seems irrelevant to the doctors that I had received a blood product prior to any drug use. The label is there and I'm stuck with it. It doesn't matter that I used drugs twenty years ago either. It is frustrating to always be on my guard, that I am not being overlooked for inclusion in a treatment program because there are other people "more deserving."

I have come forward to dispel the perception of former drug-users. With the support of my immediate family, I have been able to forgive myself for my past transgressions. I am not that person anymore. People can change to better themselves. I am trying to see the positive out of the negative. What I have learned from my past is compassion and tolerance for others.

I have been watching the news and reading the paper daily regarding the Krever report and the tainted blood issue. I sympathize with the people who did receive infected transfused blood and hope there is a light at the end of the tunnel, and you are all compensated accordingly.

My point is to show you the other side of the coin. I just want everyone to walk in my shoes and understand my feelings. Injustice is when the mere mention to someone that I probably acquired HCV through IVD use is met with a certain demeanour of repugnance. It is like I get pushed back twenty years over and over. I am suddenly stuck in a mold that no matter what I'm like today, it doesn't seem to make a difference with a person's attitude towards me. Especially a doctor's opinion. I can't change my past. I need compassion and support just like anyone else.

It is important to concentrate on enlightenment in education, to speak out for research money for a cure for HCV, and to not exclude people from treatment just because they may have acquired HCV through drug use. These issues are just as important as the fight for compensation for the "innocent victims." More research should be done for the numerous people that got hepatitis through other means. The blood scandal is bringing to the forefront the disease which was not talked about, and hopefully, through the press it is getting, there will be more funds for research.

Today I am a respectable, middle class, 41-year-old wife and mother of two sons, 8 and 16, presently living in Toronto, Ontario. I am university-educated, and over the years I have worked as a nutritional consultant. My volunteer community service has involved being a parent teacher's assistant in primary classes, a French language teacher's parent assistant for grades 7-9, a Beaver leader and group secretary for Scouts Canada, a Sunday school teacher and church secretary.

I really want more than anything for people to get a different view of those HCV sufferers who may have acquired the disease from past drug use. A majority of us experimented decades ago and are only now manifesting symptoms of the disease. We are the baby boomers with respectable positions in society today. We have various careers including teaching, social work, computing, office work and truck driving. We deserve just as much respect from doctors and availability to treatment as the next person.

No matter how we contracted this deadly virus, whether through blood transfusion, unclear reasons, or past IV drug use like myself, we are all in the same predicament. We are a large group of Canadian HCV sufferers who deserve mutual respect and all our voices to be heard.

Feel free to e-mail me. I will not judge you but support you in your struggle not only with this "dragon" but with the acceptance of you as a person. You are not alone in this battle.

"Smilin' Sandi" <smking@idirect.ca>

YOU Can Make a Difference*(Cont. from page 1)*
with actions

against a wide variety of DNA and RNA viruses including HCV.

3. Amgen
Gordon Binder
1840 DeHavilland Drive
Thousand Oaks, CA, 91320-1789
Infergen, Maxamine (see Maxim for details) Infergen; Interferon Alfacon-1; consensus interferon, recombinant. A non-naturally occurring, recombinant, "consensus" form of interferon-alpha protein derived from E. coli.

4. Amarillo Biosciences
Joseph Cummins
800 W 9th Avenue, Amarillo, TX 79101-3206
Sublingual IFN, Non Oral IFN. Studying the effects of low dose oral IFN with high dose injectable IFN.

5. Nabi
David J. Gury
5800 Park of Commerce Blvd. NW,
Boca Raton, FL, 33487
Nabi-Civacir (human polyclonal antibodies to HCV).

6. Chiron Corporation
Sean Lance
4650 Horton Avenue, Emeryville, CA, 94608
Beta IFN (recombinant).

7. Interferon Sciences, Inc.
Mei-June Liao
783 Jersey Avenue,
New Brunswick, NJ, 08901-3660
Alferon N (Interferon Alfa n-3). Alferon is a natural, human leukocyte-derived interferon alpha protein for use by injection.

8. Viragen, Inc.
Gerald Smith
865 SW 78th Avenue, Suite 100,
Plantation, FL, 33324
Natural Human IFN.

9. Glaxo Wellcome
Dr. Richard Sykes
Lansdowne House, Berkeley Square
London W1X 6BQ, UK,
Wellferon (Lymphoblastoid IFN). A highly purified blend of natural human alpha interferons, obtained from human lymphoblastoid cells following induction with Sendai virus.

10. Hoffmann-LaRoche
340 Kingsland Street
Nutley, NJ 07110
Roferon-A (IFN alpha-2a, recombinant), PEG IFN Recombinant E. coli-expressed interferon alpha-2a. Pegylated (PEG) Interferon is a long acting interferon that only requires a once a week injection. The interferon has been covalently bound to polyethylene glycol and is slowly released as these covalent bonds degrade. This offers the effect of a steady level of IFN in the blood.

11. Biogen Corp.
James R. Tobin
14 Cambridge Center, Cambridge, MA, 02142
Avonex— Interferon beta-1a, recombinant. Produced by mammalian cells (Chinese Hamster Ovary cells) into which the human interferon beta gene has been introduced.

12. ICN Pharmaceuticals
Milan Panic
3300 Hyland Avenue, Costa Mesa, CA, 92626
Ribavirin— see *Schering*

13. Maxim Pharmaceuticals
Larry G. Stambaugh
8899 University Center Lane, Suite 200, San Diego, CA, 92121
Maxamine is a form of histamine, in combination that is used with Amgen's Infergen. A recent publication demonstrated that patients with chronic hepatitis C (HCV) with low levels of histamine in blood did not respond to IFN-alpha. Maxamine is a histamine analog and has been shown to enhance or synergize with cytokines such as interferon-alpha.

14. Immunex Corporation
Edward V. Fritzky
51 University Street, Seattle, WA, 98101
Granulocyte-Macrophage Colony-Stimulating Factor (GMCSF) used with Interferon.

SAMPLE LETTER

[YOUR ADDRESS]
[DATE]

[RESEARCH COMPANY'S ADDRESS]

Dear Sir or Madam:

I am writing to you as a person infected with HCV. I would like to find out how my friends and I can get more involved in the clinical trials and sharing of information with regard to HCV therapy and research.

We are very interested in the work that you are doing on _____ and would like to see more clinical trials conducted here in Canada and would appreciate any direction that you can give us.

Sincerely,
[YOUR SIGNATURE]
[YOUR NAME - PRINTED OR TYPED]

Investigational Research Looking for Novel Treatments for HCV

by Darlene Morrow, BSc

There are well over 20 companies doing research into the following areas:

1. **Protease Inhibitor Therapy**— A protease inhibitor would be any substance which partially or completely blocks the ability of a proteolytic enzyme to carry out its activity. In HCV we have identified serine proteinases, HS3 helicase and HS5b polymerase. These enzymes are essential for viral replication.

2. **Antisense Based Therapy**—Antisense oligonucleotides are molecules that are highly charged that form DNA-RNA or RNA-RNA hybrids. The hybrid formation inactivates the viral replication by preventing the transcription of HCV proteins from the HCV genome.

3. **Ribozyme Gene Therapy**—RNA molecules that selectively degrade RNA, including viral RNA. When directed against HCV RNA it has the ability to destroy the virus's replicative material. These compounds are highly unpredictable and non-specific and therefore may be potentially toxic.

4. **Vaccine Based Therapy**— Using DNA-based immunization to study the immune responses against HCV.

HeCSC *(Continued from page 1)*
compensation for all persons infected with Hep C as a result of tainted blood.

Jeremy Beaty and Durhane Wong-Reiger (CHS) appeared on Mike Duffy's Sunday Edition June 7th to discuss the issue of compensation.

Joey Hache began his Cycle for Conscience on June 15th in Nova Scotia. He will be cycling across Canada to increase public awareness about Hep C. He is hoping to collect ***One Million*** signatures from Canadians coast-to-coast. More details will be available in the June edition of the HeCSC newsletter. The Webpage to track his progress is: **www.igs.net/~reflect/joey/schedule.htm**

Debi Ripley, HeCSC Board Member from New Brunswick, met with the NB Premier and Health Minister recently. It was a productive meeting and we are looking forward to a public announcement of support for compensation of all persons infected with Hep C as a result of tainted blood.

That's the news for now! If you wish to discuss any of the above, please feel free to contact the HeCSC national office.

Jeremy Beaty, HeCSC Chair

ARE YOU GETTING THE BEST TREATMENT?

by Joan King-Diemecke

"Cindy" was diagnosed with hepatitis C. "Don't worry," her doctor told her. "Your LFTs (Liver Function Tests) are stable and low. You don't want a biopsy, do you?" Of course she didn't. However, when her tests showed a gradual change for the worse, she reconsidered. Although her enzymes had never climbed above 80, much to her doctor's surprise, her biopsy showed grade II fibrosis. This is common. She started treatment, but did not respond, perhaps because she had the disease too long. Studies show IFN (interferon) works better when begun sooner.[1] A letter from Leah Hollins, the Assistant Deputy Minister, to HeCSC Victoria Chapter states, "...liver biopsy is expensive, is not appropriate in some patients, and is associated with some morbidity."

"Carl" asked his doctor to prescribe interferon for him. His doctor informed him that his enzymes weren't high enough for Pharmacare to approve treatment. Studies have shown that IFN may be beneficial in these cases.[2] Carl had to face paying the cost himself, about $600 a month, and the treatment normally runs for 12 to 18 months.

"Jane," a victim of tainted blood, was denied IFN by her local specialist. Her family doctor finally referred her to a specialist at UBC, after a long and tedious battle, and she was able to receive treatment.

"Jim" took IFN. A non-responder after 3 months, the doctor took him off treatment, although studies show that even in non-responders, IFN can help prevent liver cancer.[3]

"Andrea," another non-responder, officially qualified for the IFN + Ribavirin combo. She has been waiting now for 9 months for her local doctor to begin her therapy. In the meantime, her disease is progressing.

"Marian" was a partial responder to IFN, and a complete responder to the combo, but she relapsed upon finishing the 12 month treatment. She would like to try treatments which have shown promise elsewhere, such as the more effective high-dose IFN[4], IFN combined with thymosin, or consensus IFN, but they are not yet available here in clinical trials.

Not all hepatitis C sufferers are suited for treatment, and even those who are may not wish to be treated. Even those who ***do*** wish to be treated often have their desires thwarted by the government's worries about cost. This is where we, the infected, must step in, to ensure our best treatment. The AIDS groups in the US have pressured the FDA into fast-tracking the approval of the drugs that may save their lives. No one is going to do this for us. *We* must step in—each one of us—and take action, as we have with the compensation issue. We must write our MLAs and MPs, and other politicians who can influence the bureaucrats responsible for the decisions that will affect our treatment options. (You can get their addresses from your local support group.) We must write to the pharmaceutical companies, urging them to bring clinical trials here to Canada. (You can find a sample letter and addresses in this month's newsletter.)

Remember: Compensation is satisfying; a **cure** is forever!

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[1] M. Sata, M. Kage, O. Inoue, et. al., "Duration of chronic HCV infection and efficacy of interferon in chronic hepatitis C patients with a history of blood transfusion." Kansenshogaku Zasshi 71(5) (May 1997): 405-411.

[2] E. Orito, M. Mizokami, K. Suzuki, et. al., "Interferon-alpha therapy for individuals with normal serum alanine aminotransferase levels before treatment." J Gastroenterol Hepatol 12(1) (Jan 1997): 58-61.

[3] T. Ichida, "Risk-factors and the effect of interferon therapy in the development of hepatocellular carcinoma - a multivariate analysis in 343 patients." Journal of Gastroenterology and Hepatology 12(2) (Feb. 1997): 149-155.

[4] P. Ferenci, R. Stauber, R. Fiedler, et. al., "Dose increase augments response rate to interferon-alpha in chronic hepatitis C." Dig Dis Sci 41(12 Suppl.) (Dec. 1996): 103S-108S.

EMAIL JOEY HACHE ON TOUR:
Jhache@istar.ca

Keray Regan Sings for Hepatitis C

by Darlene Morrow

Country Music singer/songwriter Keray Regan gained local fame in 1948 for his hits "My Home by the Fraser" and "Poor, Poor Farmer."

In 1986 Keray received tainted blood (HCV) during open heart surgery. After struggling with numerous health problems, Keray decided to write a song to raise HCV awareness and funds for research. The CD has two songs on it—"I have Hepatitis C from Tainted Blood They Gave to Me" and "Thank the Good Lord." You can email Elaine, Keray's long-time friend at <eljoco@junction.net for more info or call Keray at (250) 503-1595.

In addition, Keray has donated 25% of the sales from his new country/western tape, "How's Everything at Your Place," toward hepatitis research, education and awareness through the HepCURE Society. You can order a copy of this tape from Tyra Regan McMahon at (250) 549-3359.

FROM THE OKANAGAN

Cycle for Conscience - Joey Hache Crosses Canada

Following the 'free vote' on April 28th in the House of Commons, to extend compensation to all hepatitis C victims of tainted blood, Joey told the Prime Minister—"I am your conscience." Joey told him he would not go away until the government extends compensation to all victims. This summer Joey will be biking across Canada to raise awareness about hepatitis C in general and the tainted blood issue in particular. His goal is to collect one million signatures in support of extending compensation equally to all tainted blood recipients.

"We were all infected the same; we should all be treated the same."

Joey Hache, a fifteen-year-old young man decided there was only one way he could really make a difference. So he decided to spend his summer enjoying the freedom that youth brings on a bicycle—***crossing Canada***.

Everyone is invited to join in, as Joey rides across Canada. This is a perfect time to show Canadians that children have hepatitis C, too. Families are invited to join the ride and to encourage children to show support for Joey. When he arrives in your town, please be there to welcome him, and arrange a party, complete with politicians.

Joey left Nova Scotia on Monday, June 15th, plans to arrive in Ottawa for July 1st and then head west. He will be travelling along the Trans Canada Highway, making stops to educate people about hepatitis C as well as to collect the one million signatures he has set as his goal.

Please help Joey attain his goal by copying the petition form. Pass it around, fill it out and then either hand it to him when he gets to your town or send it directly to his home. You can visit his Website for petitions, itinerary, hepatitis C facts and other info about Joey at:
http://www.igs.net/~reflect/joey/schedule.htm.
Or you can contact his Mom, Connie at (613) 445-0467, Jo-Anne Manser at (613) 828-3636 or Leslie Gibbenhuck (250) 490-9054 for further information.

If you should decide to plan something along the way, please make sure you let his Mom or Jo-Anne know so they can add your stop to the itinerary as soon as possible.

Another new web site has been launched. It is there for all blood injured Canadians. As well, we have started the Canadian Blood Injury Coalition, an organization to fight for the rights of all transfused Canadians. We will be fighting for accountability in Government, so another such tragedy never happens again. You can find the web site at http://www.igs.net/~reflect/

Have a great summer. Until next time ... Take good care of yourselves,

Leslie

CLASS ACTION SUITS:

BRITISH COLUMBIA

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

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

Before August 1, 1986
Klein Lyons
David A Klein
805 West Broadway, Suite 500
Vancouver, B.C. V5Z 1K1
(604)874-7171 or 1-(800) 468-4466
(604)874-7180 (FAX)

also:

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

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

ONTARIO AND OTHER PROVINCES

Pre 1986/post 1990
Mr. David Harvey
Goodman & Carr
200 King Street West
Suite 2300
Toronto, Ontario, M5H 3W5
Phone: (416) 595-2300
Fax: (416) 595-0527

TRACEBACK PROCEDURES:

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

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

CLASS ACTION/COMPENSATION

If you would like more information about class action/compensation, you can contact:
Tricia Plunkett Tel. (250) 479-5369
e-mail: plunket@islandnet.com

CAN HCV BE TREATED?

HEPATITIS C - A SILENT EPIDEMIC

Introduction:

The estimated number of new hepatitis C virus (HCV) infections annually in the United States is approximately 150,000 although the true incidence is probably greater. Screening of healthy blood donors indicates that the minimum prevalence of chronic HCV infection is 1 per 200 in this low-risk population. The true prevalence may be closer to 1.0 - 1.5%. An estimated 3 - 3.5 million Americans are carriers of the hepatitis C virus.

Transmission of Virus:

Transfusion of blood products used to be the primary source of transmission of the virus. Use of volunteer donors and screening of blood for the antibody to the virus has reduced the risk of acquiring hepatitis C from a transfusion to 1 per every 3000 units of transfused blood. Currently only 4% of patients with chronic HCV acquire the infection by blood transfusion, hence screening of transfused blood for HCV contamination is unlikely to reduce the prevalence of chronic HCV.

Thirty-eight percent of chronic HCV infections are due to intravenous drug use, 1% are dialysis patients, 10% are patients with a history of sexual contacts or a household contact with someone with hepatitis C. Although 30 - 45% of infected patients deny any discernible risk factors for the disease, many of these individuals have histories of high risk behaviors such as multiple sexual partners, illicit non-intravenous drug use or prior imprisonment.

Occupational Hazard:

Hepatitis C is a known occupational hazard. Two percent of cases of hepatitis C are due to occupational percutaneous exposures, mostly in the form of needle sticks in health-care workers. The risk of acquiring the virus from a single needle stick from an infected individual is estimated to be approximately 10%. There have been numerous studies of the prevalence of hepatitis C in different health-care populations. Some groups such as oral surgeons who are often exposed to aerosolized blood may have a prevalence of HCV as high as 10%, 4 - 6 times the national average. Dialysis and operating-room nurses are higher risk than non-surgical hospital personnel with prevalences ranging from 1.5 to 4%.

The majority of infections with HCV are clinically silent. The infected individual may have no symptoms for 30 - 40 years. The infection is often discovered accidentally during routine physical examinations or during applications for life insurance. The disease will occasionally present as new-onset liver failure or liver cancer.

The natural history of chronic HCV disease is still being defined. The virus has only been identified and sequenced within the last four years. It is generally accepted that 20 - 30% of patients with chronic HCV will progress to cirrhosis (scarring and malfunction of the liver), and liver cancer develops in about one fifth of patients with cirrhosis. The slowly progressive nature of this disease is apparent from a retrospective study of post-transfusion HCV showing that chronic hepatitis, cirrhosis and liver cancer developed after a mean of 10, 21 and 29 years respectively. Once cirrhosis develops the risk of liver cancer is from 3 - 6% per year. HCV accounts for 25% of patients undergoing liver transplantation.

The best current data suggest that the risk of developing clinical liver failure is 5 - 15% and the risk of dying from liver-related complications 3 - 9%. Conversely, 80 - 90% of infected individuals will probably live normal life spans without symptomatic liver disease.

Can HCV Infection be Treated?

The goal of anti-hepatitis C therapy is to ameliorate symptoms and halt the progression of disease to cirrhosis and possible liver cancer. Alpha 2b-Interferon was licensed for the treatment of chronic hepatitis C in 1991. It is the only agent which has shown efficacy against the virus. Although 40 - 50% of patients respond to a 6 month course of treatment with normalization of liver enzyme levels, the relapse rate after therapy is at least 50% and as high as 80%. Unfortunately, three to four years after successful interferon treatment only 8 - 15% remain free of virus and have normal liver function tests.

Interferon therapy is associated with considerable morbidity. It must be administered subcutaneously. At the beginning of therapy 60 - 80% of patients have a flu-like illness which resolves within three weeks. Additional side-effects include irritability, fatigue, depression, anorexia, nausea, rashes and hair loss. Migraine headaches may increase in severity and frequency. A history of anxiety or depressive illness is a relative contraindication to interferon treatment.

At current Food and Drug Administration approved dosing 85 - 92% of treated patients will not ultimately benefit from interferon treatment. Since the best current estimates are that clinically significant disease will occur in only 5 - 15% of infected individuals, the vast majority of infected individuals will not benefit from interferon therapy. Assuming a "cure" rate of 8 - 15% in the 5 - 15% who would potentially benefit from treatment, one comes to an estimated improvement in outcome in only 0.4 - 2.25% of patients. Even this higher number is doubtful since the group with the most aggressive disease tends to have the lowest response to interferon.

Recent studies indicate that a mere six months of treatment at three million units may be suboptimal. Treatment with high doses (up to 30 million units per week) for 12 - 18 months have produced "cures" in 22 - 45%. To get sustained remission in over 50% of patients on a consistent basis may require several years of interferon therapy.

Summary:

In summary HCV infection is a serious viral epidemic affecting 1.5% of the United States population. Health-care personnel are at risk for occupational exposure, especially those exposed to blood products on a regular basis such as dialysis and operating room nurses. Although treatment is available it is associated with considerable expense and morbidity and fails to cure the disease in up to 90%. The infection can lead to liver failure and liver cancer in a substantial minority of infected individuals. The disease is becoming an important issue in workers compensation for health-care employees. Extensive research is underway in an attempt to develop more effective therapies.

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MEDICATION RESEARCH - Why does it take so long?

When a pharmacist fills your prescription, you get more than a medication... you get years of accumulated scientific knowledge.

The Drug Discovery Process -- From Ideas to Marketing

PHASE	NUMBER OF YEARS	NUMBER OF DRUGS IN EACH PHASE *
Discovery	3 - 11 years Searching for an experimental drug.	[redacted]
Pre-clinical Testing	1yr Lab and safety testing.	10 - 15
Phase 1 *Is it safe?*	1yr Drug used in a small number of healthy volunteers to test safety and to determine dosage.	5
Phase 2 *Does it work?*	2 - 3 years Drug used in 100 - 300 patients to study its effectiveness and side effects.	4
Phase 3 *Are there side effects?*	3 - 4 years Drug used in 3,000 - 10,000 patients to learn how it works long-term, to determine proper dosage and identify side effects.	1
Federal Review	2 - 4 years Federal Government regulators analyze data from the laboratory and clinical tests to determine whether a drug is safe and effective.	1
# of years	1 2 3 4 5 6 7 8 9 10 11 12 13 14 15	

*Out of thousands of compounds synthesized, and millions of tests, only a handful make it past the lab.