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Canada's Hepatitis C News Bulletin

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LATE-BREAKING NEWS: PEGASYS APPROVED IN THE US!

BC Hep C COLLABORATIVE Circle

Skills, Communication, Education and Support

HEP, HEP, HOORAY!

by Ken Thomson, President of The BC Hepatitis C Collaborative Circle

The BC Hepatitis C Collaborative Circle, held on Sept. 27-29 in Vancouver, was a great success. The workshops and speakers were all rated highly.

We even had a surprise speaker. Durhane Wong-Rieger presented information about the Common Drug Review--a process being quietly pushed forward by the federal government that may entirely cut consumer input out of the drug approval process and base decisions almost exclusively on cost factors. (See the article by Bill Buckels in this issue)

The Positive Forum set priorities for the Circle and the General Assembly worked intently to pass two resolutions demanding that the BC government account for its share of "Care not Cash" money and extend compensation to all people who contracted hepatitis C through the blood system.

The Circle also hammered out recommendations for the Briefing Document, which we hope everyone will use to educate their local politicians, media and health authorities.

The issue of equitable use of the Special Access Program was brought up. Stay tuned for a Circle media release on this subject.

The draft Strategic Plan was introduced. It is a big, important document that needs more input from members. We hope everyone will take a good look at it and suggest changes to help to make it as strong as possible.

The upcoming changes to disability benefits were discussed. A good source for information is the BC Coalition of People with Disabilities and their web site:

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THE COMMON DRUG REVIEW (CDR)

An Advocate's Viewpoint by Bill Buckels

Access to prescription drugs are a major part of public health expense. This especially concerns the Canadian family or individual seeking expensive treatment for Hep C, cancer, and other widespread illnesses. Access to treatment is a national issue which is tremendously important to those with Hep C who are waiting for the new treatments that are "coming down the pipe," and it needs to be given top priority.

The Common Drug Review

In September 2000, at the Annual Conference of Federal-Provincial-Territorial Ministers of Health held in Banff, Alberta, the First Ministers identified pharmaceuticals management as one of their top priorities, including the creation of a common intergovernmental assessment of drugs in publicly funded drug plans called The Common Drug Review (CDR).

In September 2001, federal, provincial and territorial Health Ministers established a single common process for reviewing drugs for potential coverage by public drug benefit plans in Canada. An interim CDR secretariat was established at the Canadian Coordinating Office for Health Technology Assessment (CCOHTA) in March 2002.

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A PROPOSED MECHANISM FOR CHANGE MANAGEMENT FOR THE CANADIAN HEALTH CARE SYSTEM

By Bill Buckels, HepCURE
(Hepatitis C United Resource Exchange)
October 9, 2002

Overview

The Canadian HealthCare System (as Delivered by Health Canada and its partners) apparently provides no standardized direct mechanism for the Health Care Consumer to request a change in a Health Care Delivery Program (especially a program that is already "live" and "up and running"). This lack of a corrective mechanism driven by the consumer is a serious flaw in National Public Health, and can be addressed and corrected by a standard and proven methodology borrowed from the Engineering community.

This proven methodology, used for years in Engineering Change Management and more recently in Software Engineering Change Management, is sometimes known as "Change Control", and consists of three simple documents and a live "round-trip" approach to providing a "Bug Fix" (a defect correction) to an otherwise working deliverable (whether it be product or program).

Assumptions

In any system, accountability to the Customer, User or Consumer is critical for efficiency (and for a variety of other reasons), and deliverables often need to be "hot fixed".

In a commercial "system critical" program or product, if a defect is left in place and no efficient "trouble logging" is provided or responded to, planes can fall out of the sky, and stock markets can crash. It is as important to us all to fix problems in a "system critical" Public Health System, especially to implement fixes requested by the Health Care Consumer who is in dire need

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REPRINTS

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

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

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!!

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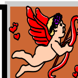
Special thanks to Roche Canada for an unrestricted grant to help publish this newsletter!



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.

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Order Your "Hepper Bear" Now!

$20 CDN each, including postage. This is a GREAT Fundraiser for Support Groups! Call (250) 595-3892 or email info@hepcbc.ca to place your order

HOW I QUIT

by Lisa Harnois

My name is Lisa Harnois and I've had Hep C since 1968. I started smoking when I was 15 yrs old, and I continued smoking for 40 years. Over the past 10 years I have tried several different ways and methods to quit smoking cigarettes. For the past couple of years I figured I was doing good because I was only smoking about 10 cigarettes a day most days, but I knew that it was not good for my health or my pocketbook.

Some of the things I've done to quit include: trying the patch 3 different times, seeing Dr Ron Aspinall an addictions doctor in Victoria specializing in treating nicotine and cocaine addiction for which he prescribed a medication to help cut the cravings, two acupuncture treatments in Vancouver, two acupuncture treatments in Victoria,_hypnosis by three different practitioners, cold turkey more than once, prayer more than once, nicotine stick and Zyban (which is not recommended for people with a history of depression, head injury or seizures).

Every time I tried to quit I almost went crazy with the craving for cigarettes and after one or two weeks I would start smoking again because I couldn't stand the pain of wanting to smoke.

I had almost resigned myself to being a smoker until the day I died but one evening I was watching TV and I saw an ad for a new treatment from "Total Health Laser Therapy Clinics". I called and spoke with the Registered Nurse who is the Certified Laser Therapist and I made an appointment at the Victoria Clinic for July 3rd. She told me to smoke as much as I wanted right up to the door of the clinic but to be prepared to throw out any cigarettes I had left. In my car on the way to the Clinic I finished off the last three cigarettes I had by chain smoking them and finished the last one in the parking lot before going into the Clinic.

The treatment consisted of filling out a brief questionnaire, reclining on a comfortable chair, putting on a pair of dark

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IF IT ITCHES…

BY Joan King

Itching: an unpleasant cutaneous sensation that provokes the desire to rub or scratch the skin to obtain relief. (http://cancerweb.ncl.ac.uk/omd/)

"Doctor, the worst part of this hepatitis thing is the itching."

I have heard this from so many people! It's not the swelling from end-stage liver disease, or the liver pain, or the brain fog that bothers them so much– it's the darn itching. And you don't have to have end-stage disease or be jaundiced (yellow) to suffer from it, either.

Itching in hepatitis patients is because the liver can't remove toxic substances and bile, so they build up in the skin. Doctors would do well to have any of their patients tested for hepatitis C if they are complaining of itching. On the other hand, not all itching may be due to a malfunctioning liver, and even patients with Hep C should go to their doctor to make sure nothing else is going on.

What the heck can you do to make it stop? The first thing to do is to stop putting toxins into your body, and get rid of the ones that are there by drinking plenty of water. We have to remember that anything we put into our bodies or onto our skin has to be filtered out by the liver. By trying to remedy the itching by taking medicines or lathering on cream, we may be harming our livers more, causing still more itching, and creating a vicious circle. Even products from the health food stores with all-natural ingredients may contain herbs like comfrey (allantoin), which are toxic for our sensitive livers. Read the labels!

Having said that, here are some things you can try, depending on how desperate you are:

Internal:

- Treatment with interferon, may get rid of the symptoms by getting rid of their cause.
- Bile acid sequestrants: Cholestyramine
- Antihistamines: Hydroxyzine, Benadryl, Atarax, Chlor-Trimeton
- Ursodeoxycholic Acid
- Rifampicin
- Opoid Receptor Antagonists - Naltrexone orally. (High doses of this drug are toxic to the liver.)

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2nd Annual HepHIVE Health Fair

HepHIVE, the Hepatitis C and HIV Education and Outreach program held their 2nd annual Hep C Awareness Fair on October 11, 2002. HepHIVE is a Health Canada sponsored program, in partnership with Vancouver Native Health Society and BCPWA. We are located at Vancouver Native Health. We built up to this key event, with a series of workshops throughout the year at the Carnegie Community Centre, which has provided a venue for last year's and this year's Health Fair. The location, in the heart of the downtown eastside, is close in proximity to our office and in the thick of a Hep C epidemic affecting the lives of many of the area's people. The fair was a logical extension to some of the materials we have produced, geared toward the Aboriginal and downtown community.

The Health Fair ran from 11:30 AM to 3:30 PM. Aboriginal Elder, Harry Lavallee, truly honoured us with his special prayers and smudge ceremonies, a great beginning to HepHIVE'S Health Fair. We also had a letter from Health Services Minister Colin Hansen, commending us for our hard work, including the low literacy series, Aboriginal booklet and video. He seemed most impressed by the low literacy materials developed by Ken and Will. The first presentation by Ken Winiski, HepHIVE coordinator, was a good Hep C/co-infection overview. He then fielded questions from the audience. Pamela Ferguson, Registered Dietician from the ADAPT (Aboriginal Diabetes Awareness Program) at VNHS, gave an awesome talk about nutrition, and there was definitely a good reception and good interaction with the audience. Next up was Gail Butt, RN, MHSc, Associate Director, BC Hepatitis Services, always an inspiration and a huge asset to the Hep C community, with updates on the BC Hepatitis Strategy. They are working on an advocacy training booklet, full of potential, definitely a step in the right direction. It should be an asset to people in the downtown eastside

We wanted to acknowledge and address that Aboriginals are disproportionately infected with Hep C (up to 8X the rate), with most not even aware they have the virus. Laurie McDonald, from Healing Our Spirit, explained the medicine wheel, some of its symbolism, and the wisdom of trying to maintain a healthy balance. The Native holistic health philosophy is of great value,

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IVUs: TO TREAT OR NOT TO TREAT

It is important to treat active injection drug users (IDUs), because injection drug use is the most common risk factor for infections in the US and Canada in new infections, and by treating the users, transmission could diminish. Many doctors worry that the patients will become re-infected if they are still using drugs, or that they will not comply with the treatment protocol. Treatment is enhanced by linking IVUs to programs that treat drug and alcohol abuse. Methadone treatment (especially oral methadone) can reduce risky behaviour and doesn't affect treatment results. It would be beneficial to have HCV specialists collaborate with specialists in substance-abuse treatment.

The recommendation of the NIH Consensus Conference is the following:

"… it is recommended that treatment of active injection drug use be considered on a case-by-case basis, and that active injection drug use in and of itself not be used to exclude such patients from antiviral therapy."

The Digestive Disease Week presented a talk which included treatment of IDUs, and concluded: "… methadone use …should no longer contraindicate interferon therapy…if it is clinically indicated….The most important aspect of care in this patient group is use of a multidisciplinary team approach. This team would include hepatologists, psychiatrists, psychologists, and social workers."

Sources: NIH Consensus Conference, Final Statement, August 27, 2002
www.medscape.com/Medscape/CNO/2001/DDWCME/Story.cfm?story_id=2283
Digestive Disease Week 2001, Day 2 - May 21, 2001, Understanding Hepatitis C: An Update by David Bernstein, MD
Clinical guidelines on the management of hepatitis C, 2001 Volume 49 Supplement I, 4.1.7, compiled by J C L Booth, J O'Grady, J Neuberger

RETREATING NON-RESPONDERS MAY PREVENT LIVER CANCER

Studies have shown that patients reduce their risk of developing liver cancer (hepatocellular carcinoma) with interferon treatment. This applies especially to responders, but also to non-responders who maintain low ALT levels. The non-responders become more susceptible to cancer again after about 5 years or more. This study of 309 patients looked at the possibility of retreatment to prevent liver cancer in non-responders. The results suggest that retreatment can reduce or delay liver cancer in non-responders.

Source: Hino K, et al, J Viral Hepat 2002 Sep;9(5):370-376, Interferon retreatment reduces or delays the incidence of hepatocellular carcinoma in patients with chronic hepatitis C. PMID: 12225332

IgG AVIDITY ASSAY

By using a test for IgG avidity, researchers may be able to tell the difference between first infection with HCV and chronic infection, which could affect treatment. The test was used in 36 patients who showed antibodies to HCV. The tests showed that the avidity index was low during the acute phase of the disease, and increased as the disease progressed. The researchers believe that the test will be useful in the treatment of people with HCV.

Source: www.reutershealth.com Sept 24, 2002 New assay to distinguish primary vs. chronic infection (Kanno, A, et al, J Med Virol 2002;68:229-233)

AGGRESSIVE TREATMENT NEEDED FOR OLDER PATIENTS

These researchers studied 268 patients who were believed to have acquired HCV from a precisely dated transfusion, and had no other risk factors for hepatitis C. 68% underwent a biopsy and enrolled in the study.

268 (68%) underwent ultrasound-guided liver biopsy and were enrolled in the study, which lasted approximately 18.4 years, after which 20.1% had developed cirrhosis.

Patients aged 21-30 upon transfusion had a 50% probability of developing cirrhosis in 33 years, those aged 31-40 needed 23 years, and patients older than 40 needed only 16 years to have a 50% chance of developing cirrhosis. The researchers believe that those infected at an older age need a more aggressive treatment approach to prevent progression.

Source: Minola, E et al, Blood, 15 June 2002, Vol. 99, No. 12, pp. 4588-4591. Transfusion Medicine, Age at infection affects the long-term outcome of transfusion-associated chronic hepatitis, www.bloodjournal.org

IMMUNOSUPRESSION AND TRANSPLANTS

Lately, efforts have been made to wean patients off immunosuppressant drugs after transplant surgery. These drugs can make the patient more open to infections and can have bad side effects. Stanford Researchers are giving the patients drugs to boost the production of stem cells several weeks before the transplant surgery, and then they give the patients stem cells and other tissues from his/her living donor before the transplant. This procedure seems to block rejection, enabling the patient to stop immunosuppressants within a year. After surgery, the patients were also given 10 radiation treatments on the lymph nodes, spleen and thymus, to weaken the immune response. In order to deplete T cells, they were administered thymoglobulin, followed by the stem cells from the donor.

When rejection occurred, low-dose immunosuppressants were given. The same system is being used in Gujarat, India, with success. The patients are generally off immunosuppressants between 3 and 12 months after surgery. The procedure seems to work with cadaveric donors, as well, by infusing organ tissue from the donor directly into the thymus during the transplant. The Thomas E. Starzl Institute at the University of

Pittsburgh is doing similar treatment. Transplant experts insist that no patient should change his/her regimen without physician approval.

Source: 27elin020.html New techniques may boost tolerance of donor organs by Alicia Ault, 2002-08-27 www.reutershealth.com/archive/2002/08/27/eline/links/200208

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 contraindicated

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

(CDR—Continued from page 1)

Commission" (Commission on the Future of Health Care in Canada) have not yet finished their report which may or may not include a "National Pharmacare Program," on September 6, 2002, the federal, provincial and territorial Health Ministers announced the creation of a common (single) process for reviewing new drugs for potential coverage. The interim CDR secretariat Health Ministers have now approved CCOHTA as the home of the permanent, single CDR. It is expected to begin conducting reviews in early 2003.

It is essential that consumers (patients and public) have adequate input prior to commencement of activity. Moreover, consumers need to be built into every aspect of the review process, including definition of the terms of reference for the CCOHTA, development of the guidelines for conducting reviews, inclusion on the Expert Advisory Committee, and input to the decision-makers of the drug benefits plan.

Currently, there is a single process conducted by Health Canada to review drugs for safety and efficacy prior to licensing them for use in Canada. However, each province or territory conducts its own review to determine which drugs will be listed (paid for) in the public drug plans. Under the Common Drug Review (CDR), CCOHTA will be responsible for conducting all reviews and providing recommendations as to which drugs should be listed for federal, provincial and territorial drug plans, with the exception of Quebec, using clinical and pharmacoeconomic information as a reference.

The CDR could reduce duplication of effort in reviewing submissions for listing drugs on public formularies and provide consistent quality review of drugs. In these respects, it could improve timely access to new medicines and ensure that drugs with therapeutic value are available to appropriate patients. Moreover, the CDR could reduce the inequities in access that currently exist from province to province. However, the process will likely be more time-consuming than the current "two-stage" process, usually involving a recommendation from a provincial expert committee and then approval by the drug plan managers. Indeed, nowhere in the announcement of CDR is the problem of timely access to new medicines discussed; rather, it is the "pressure on governments to maintain access to new drug products…at an affordable cost" that appears to be driving the CDR.

The stated purpose of the proposed CDR is to allow drug plans to focus on the most therapeutically beneficial and cost-effective drugs. But, it is not clear how this assessment will be made and the relative weight that will be placed on "benefit to the patient" and "benefit to the healthcare system" as compared to "cost of medication." Current cost-effectiveness models lack both the validity and sophistication to take into consideration a wide range of factors. The CDR can serve patients only if it is governed by the overriding principle that individual patients must have timely access to medications deemed appropriate by his/her prescribing physician, in consultation with the patient.

And the CDR could result in a further diffusion of responsibility, with the drug plans pointing to the CCOHTA as providing the listing recommendation and the CCOHTA disavowing itself of the final decision, which rests ultimately with the individual plans.

The CDR process will not reduce inequities since each jurisdiction will still make an independent decision as to whether to fund the drug, or not.

Finally, the CDR does not allow for consumer input and this is a key limiting factor. The National Institute for Clinical Excellence (NICE) in the United Kingdom, which has been conducting a common drug review process for a number of years, not only provides for patient and caregiver input, but has just announced the creation of a Citizens Council to provide advice to its decision makers. Transparency and inclusiveness are essential elements if the CDR is to serve the public as both patients and taxpayers.

Consumer Advocare Network Common Drug Review (CDR) Meeting

In Toronto on September 21 and 22, 2002, an 'ad hoc group of concerned Canadians' participated in the "Consumer Advocate Network Education Session on Access To Treatment and Common Drug Review (CDR) Meeting". Marjorie Harris, President of HepCURE (Hepatitis C United Resource Exchange) and Bill Buckels, HepCURE Director, participated.

The participants introduced themselves and gave a brief explanation of why they had come to the meeting. Answers ranged from "Because I want access to treatments for all Canadians", to "I want information on the Common Drug Review" and "I want consumer input on review panels and equal access".

Presentations were made on The Common Drug Review, Access to prescription drugs in Canada, and Consumer Advocacy. A PR and media training seminar was also given on Sunday morning.

Not much is really known about the Common Drug Review (CDR) at this point in time. The group would like to "open it up" and make the process more transparent. The CDR has only introduced another step to getting access to drugs. CCOHTA is known to be an inaccessible organization. The CDR has been put into place without any consultation or input from consumers, professionals, or patients. There is concern that once the CDR is in place, if it does not recommend a drug for inclusion, patients then have no other recourse available to those that need the treatment. Quebec has also opted out of the process. As they have the best access in Canada, what does this mean for the CDR? If this is a money-driven process, "have-not" provinces may drive the selection process, so access will decrease even further. Unfortunately, decisions regarding health care in Canada are made with cost effectiveness as a bottom line. However, what is good for the majority of people, often doesn't work for the individual, i.e., it is often cheaper to let patients die.

Barriers to access were identified. They include: funding, regulatory, coverage, patient/consumer participation, eligibility, co-pays/deductibles, special access/limited use/prior authorization, patent times, end of life costs, "silo" management of health care, waiting times for access to technology, and lack of transparency

It was acknowledged that there could be some positive outcomes related to the CDR. The group will take steps to urge the CDR to develop mechanisms to develop: transparency, accountability, and a permanent and sustainable role for input from patients. The CDR should also strive to provide a mechanism for feedback, and to improve timely and appropriate access for patients. The group further urges the CDR to meet with consumers and patient groups to provide input. To determine how to include patient representation on the CDR, the group will investigate other established areas of patient reps, such as NICE in the UK, the Quebec hospital example, the Cancer Control Strategy, and similar initiatives in Australia.

The Consumer Advocare Network is beginning to move forward with some of the identified "action items" as the result of the CDR meeting, and will be sure to keep the Hep C community informed as events move forward. Groups and individuals who wish to do so can attempt to bring their statement to the attention of decision makers at the Ministerial and MLA level.

Since Colin Hansen, BC's Minister of Health Services, is the Lead Minister responsible for the CDR, you may wish to contact him directly to voice your concerns. Email colin.hansen.mla@leg.bc.ca or Phone (250) 953-3547, Fax (250) 356-9587, or write to PO Box 9050, STN PROV GOVT, Victoria BC V8W 9E2, to insist on a strong consumer voice on the CDR.

Acknowledgements

Dr. Durhane Wong-Rieger, PhD, Psychologist, President and CEO of The Anemia Institute (and who spoke to The BC Hep C Collaborative Circle on Friday, September 27, about the CDR and New Treatment Access under the new National Pharmacare Program) is also head of the Consumer Advocare Network, which includes HepCURE and other Hepatitis C Organizations from across Canada as well as Cancer, Senior, and other Health Based Organizations. Dr. Wong-Rieger is past president of the Canadian Hemophilia Society,

(Continued on page 6)

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: 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.

(CDR—Continued from page 5)

past-director of Canadian Blood Services, executive member of National Blood Safety Council, and a strong consumer advocate for blood safety and alternatives. For more info on the Anemia Institute please visit their website at http://www.anemiainstitute.org/

Dr.Wong-Rieger is gratefully acknowledged for the excellent background material that made this article possible.

Chris Ward, and his organization, Ward Advocacy Communications, facilitated the Consumer Advocare CDR Meeting. Chris has a lengthy involvement in public policy including six years as a lawmaker in Ontario. He served as Parliamentary Assistant to the Minister of Health, in 1985, and had responsibility for carrying the legislation that established the Ontario Drug Benefit Program. In 1987 he was appointed Ontario's Minister of Education and in 1990 became Government House Leader. Chris Ward has participated in public forums, media tours, and advocacy workshops in the United States and Canada. For more info on Ward Advocacy Communications please visit their website at http://www.wardadvocacy.com/

Chris Ward is gratefully acknowledged for supporting Dr. Wong-Rieger in bringing this important information forward.

Bill Buckels, Director
HepCURE (Hepatitis C United Resource Exchange)
Email bbuckels@escape.ca
Website http://hepcure.junction.net/

(PROPOSED MECHANISM—Continued from page 1)

of a responsive working system, and programs that, in many cases, are a matter of life itself.

Therefore, we need to assume that those who are responsible for the Health Care Programs that we access need to be directly accountable, to respond to our change requests swiftly and effectively, using a well-understood standard accountability mechanism.

The Engineered Approach - Trouble Log, PCR and PCN

The Engineered Approach to Change Control is a simple formulated user-driven process consisting of 3 basic forms and a process that supports consumer input and invites tailoring programs that ultimately fit the consumer's needs.

The first form is a "trouble log." In the proposed scenario, the Health Care Consumer phones, faxes, or emails the "help desk" and a "trouble log" (complaint, suggestion) is filled-in by the consumer support staff. This probably should be a function of Health Canada, with national "hot lines", etc., provided for that purpose.

If the problem can be resolved by the "help desk", the trouble log is closed, but available for all to review, including other consumers and the general public. (Matters of confidentiality are details that can be hidden (protected), and are beyond the scope of this document, but can be designed into any such process).

If the problem cannot be resolved to the consumer's satisfaction by the "help desk", the trouble log cannot be closed, and a PCR (Program Change Request) is filled-in and sent to the "Program Review Group" (probably a committee with a consumer voice). The PCR may be rejected, but even if it is, the consumer complaint becomes a matter of record. If the PCR is accepted, the result is to modify or replace ("Bug Fix") the "broken" deliverable (program).

In either case (rejected or accepted), the third form, a PCN (Program Change Notice) is issued, and distributed through a standard distribution list (Media, Internal and External Communications, and of course to the Consumer who made the request in the first place).

If the consumer is satisfied with the "bug fix", the trouble log can be closed. Otherwise, the process starts again, since the fix failed the ultimate Quality Control (i.e., The Health Care Consumer Acceptance Test).

Additions and Conclusions

This proposed change focuses on holding the process accountable. Our Health Care system needs to be self-correcting, and the people who work within it to serve us cannot drive the process. People and Programs can come and go, but the process must be accessible to, and driven by, the consumer, and in "real time".

In a recent workshop initiative entitled "Promoting Health through Organizational Change", Health Canada strongly suggests that their partner organizations develop organizational prototypes based on continuous improvement and adapting through proactive change. Health Canada should and must examine their own process and build-in the very thing that they suggest of their partners, and in doing so provide the ultimate improvement: a strong consumer voice that can access the process and effect Live Change in a system that often means Life itself to those who need it, who need it "now!", and who now have no direct voice in the "day-to-day" programs that they depend on.

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DIAL-A-DIETITIAN

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

(CIRCLE—Continued from page 1)

www.bccpd.bc.ca

Diane Morrissettie was elected as a new Hub team member from the Fraser Health Authority region. We still need one more person from the North.

A new logo for the Circle was approved. All this stuff can be seen in more detail at the Circle web site- www.casper.ca/hepcircle

I'm so proud. We are showing the world that people with Hep C and their supporters can come together, find common ground and work effectively to deal with this awful epidemic.

We will not lie down and die quietly.

ANNUAL ALBERTA HARM REDUCTION CONFERENCE

The conference is being held at the Banff Centre in Banff, Alberta, Canada, March 3 - 4, 2003. Please consider joining us for this important Harm Reduction Conference.

Conference registration and website information will be available soon.

Have a super day,

Jennifer Vanderschaeghe
ACCH Administrative Coordinator
4611 Gaetz Ave., Red Deer, AB T4N 3Z9
Phone: (403) 314-0892
E-Mail: acch@shaw.ca

GoGirlsMusicFest "Get Hip to Hep C" Concert Tour 2002

GoGirlsMusic.com is proud to present the GoGirlsMusicFest "Get Hip to Hep C" concert tour benefiting the American Liver Foundation. We'll have great music and lots of fun at each show and we'll be giving away the official GoGirlsMusicFest 2002 compilation CD! Our goal? To bring you the best local and regional indie women in music while supporting a great cause. See you at the shows!

Tour dates:

November
2 Memphis, TN Hard Rock Cafe
7 Dallas, TX Club Dada
8 Houston, TX Rhythm Room
10 Austin, TX Steamboat
14 San Francisco, CA
14 Boulder, CO Trilogy's
15 Seattle, WA Experience Music Project
16 Phoenix, AZ Minder Binders
16 Raleigh, NC The Berkeley Cafe
19 Chicago, IL Prodigal Son
21 St. Louis, MO Off Broadway
22 Boston, MA The Attic
23 Milwaukee, WI Union Sports Annex Marquette University
30 San Diego, CA Blind Melon's

December
6 Albany, NY Northern Lights
7 Rochester, NY
8 Rochester, NY

Date, time and artists are subject to change. Please call ahead to confirm!

WANTED:

VOLUNTEER BOARD MEMBERS FOR HEPCBC.

Contact: info@hepcbc.ca

(ITCHING—Continued from page 3)

- Colchicine (Has been known to reduce itching, and has been used for Hep B and alcoholic cirrhosis.)
- Bio-Antax (an antioxidant compound) plus Coenzyme Q10 may relieve itching and fatigue.
- Neurontin
- Dyphenhydramine

External:

Keep your skin moisturized. Check the ingredients of anything you put on your skin.

- Phototherapy
- Acupuncture
- Udder cream
- Bath additives:
  Oats: (Put 2 cups of oats into one leg of a nylon stocking and close with a knot. Use like a tea bag, then discard. Soak for 15-20 minutes.)
  Cornstarch

Tips: Keep your fingernails short. Wear all cotton clothes. Stop shaving for a while. Try cold compresses or ice. Eat organic foods. Open the windows at home. Stop smoking. Don't drink alcohol. Reduce stress. Be careful with laundry detergents. Avoid skin products containing alcohol that can be drying. And if it itches, **don't** scratch it.

Sources:
Pruritis in liver disease, http://www.hepnet.com/hkn/c21.html Volume 2 issue 1
Colchecine Peg Intron Long Term Therapy, Nezam Afdhal, MD., Associate Prefessor of Medicine, Harvard University School of Medicine
Skin Care Products and Liver Disease: Read the Label Before You Use, by Annette White
http://www.ucdmc.ucdavis.edu/health/a-z/75Cirrhosis/doc75treat1.html
http://www.bugbear.net/justice/skin.html
http://www.atihealthnet.com/pages/livralcomplex2.html
http://pbcers.org/itching.htm

(HepHIVE FAIR—Continued from page 3)

and pertinent on several levels. The next speaker was Cari Miller, a researcher at the BC Centre for Excellence, who presented some sad statistics that show the young, including Aboriginal women, are affected greatly from induction into the risky behaviour of IV drug use.

HepHIVE volunteer Warren Lewis gave a good relaxed talk about his personal Hep C experience, and what it feels like to be waiting for a clinical trial to start. Carol Dawson gave a passionate speech on Aboriginal advocacy and how Aboriginals may access different avenues to treatment. Lisa McDowell from DERA also spoke on advocacy and the new 21 page disability application and how it will impact people with hepatitis C. Many in the audience expressed anger and frustration about the changes.

Info tables were from organizations such as VNHS, BCPWA, Carnegie Centre, Healing Our Spirit, DERA, DTES Consumer's Board, DEYAS needle exchange. Yasmin of the street nurses kindly provided vaccinations and Hep C testing. Ken Winiski and Will Firby, both part time staff at HEPHIVE, were the producers of the Health Fair. We would like to thank the Carnegie Centre staff, volunteers from the Consumers Board and Vancouver Native Health Society. Together we made this the most successful HepHIVE event thus far, and those who made it so are gratefully acknowledged.

LEXMARK
Passion for printing ideas.™

HepCBC gives special thanks to Lexmark for printing out our Treatment pamphlets!

ISVHLD 2003

INTERNATIONAL SYMPOSIUM OF VIRAL HEPATITIS AND LIVER DISEASE

Sydney Convention & Exhibition Centre

SYDNEY, Australia

6-10 April 2003

Contact:

ISVHLD 2003 Congress Managers
GPO Box 128
Sydney NSW 2001
Tel: + 612 9262 2277
Fax: +612 9262 3135
E-mail: isvhld@tourhosts.com.au
Internet: www.tourhosts.com.au/isvhld

WARNINGS

CAN YOU BELIEVE THIS?!!!

James C. Hill, anesthetist, infected at least 52 people in Oklahoma with hepatitis C when he would put pain medication into IV drips because he reused the needles as many as 25 times per day. Letters have been sent to 1220 patients telling them to get tested.

The same thing happened with 19 patients in Brooklyn last year. An anesthesiologist reused needles and medication. Some practitioners don't realize the danger, since the needles are put into tubes, not under skin, and they don't take into account the back-flow of blood into the IV tube.

Source: Associated Press, Oct 10, 2002, Warning Issued on Reuse of Needles by Nick Trougakos

FISH

Although fish is very good for us, it is also the cause of more cases of food-poisoning than any other food. Some of the organisms responsible are botulism, listeria (in ready-to-eat fish), and ciguatera (in reef fish). Shellfish are especially dangerous because they collect toxic organisms in their bodies. More dangerous still is smoked fish because of the risk of faulty preparation, and also because of retention of toxins. High levels of mercury (found more in shark, swordfish, mackerel) can be very dangerous for pregnant women and young children because they can cause bone defects. Preparing fish: Cook it well. Separate it from other foods. Keep it in the fridge. Report it if you get sick from restaurant fish, so others won't get sick, too.

Source: CNN October 10, 2002 Enjoy but take care: Bad fish can make you sick by Dr. Sanjay Gupta

LUNG PROBLEMS DURING TREATMENT

These researchers studied lung problems linked to the Combo (IFN + ribavirin) treatment. They looked at 4 patients who developed lung problems, which included brodhiolitis obliterans organizing pneumonia in 2 of those patients, and interstitial pneumonitis in the other two. The problems went away upon stopping therapy. One of the patients was on a PEG trial. Lung problems have been reported previously with ribavirin. The problems usually subside, but at least one case needed intervention with long-term sterioids. These problems are rare, and usually mild. Problem cases should probably be investigated.

Source: Kumar KS, et al, Am J Gastroenterol 2002 Sep;97(9):2432-40, Significant pulmonary toxicity associated with interferon and ribavirin therapy for hepatitis C. PMID: 12358269
http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&list_uids=12358269&dopt=Abstract

HCV+ CELEBRITIES

- Pamela Anderson, Bay Watch
- Ed Conroy, former MLA
- Peter Coyote, former digger turned writer, poet, actor and activist
- David Crosby, of Crosby, Stills, Nash & Young
- Freddy Fender, Singer ("Before the Next Teardrop Falls")
- Diamanda Galas, singer/ composer/ pianist/AIDS activist
- Danny Galindo, Thirteenth Floor Elevators bassist
- Larry Hagman , actor
- Florence Henderson, Brady Bunch
- Dusty Hill, ZZ Top bassist
- Tom House, Nashville singer-poet
- Namoi Judd, country singer
- Evel Knievel, dare devil
- Henry Knowles, guitarist, of Agression
- Yohei Kono, Former Foreign Minister-Mel Lastman, Mayor of Toronto
- Phil Lesh, Grateful Dead bassist
- Lance Loud, Eldest Son in Real-Life PBS Series
- Mickey Mantle, baseball player
- David Marks, Beach Boys, Founder: Artists Against Hepatitis
- Joe Moakley, Congressman
- Jim Nabors
- The Hon. Jane Pervis, Minister of Education for Nova Scotia
- Rocco Prestia of Tower of Power
- Rockets Redglare (Michael Morra), actor
- Keray Regan, Country Music singer/songwriter
- Frank Reynolds, TV newsman
- Kenny Rogers, Singer/Entertainer
- Timothea, singer (A Siren to Wail)

glasses and listening to the Therapist speak as she applied low-dose laser therapy to several acupressure points in each ear, on each hand and on each side of my nose. I could feel the pulse which was very similar to a low electric pulse which was totally painless. The Therapist gave me a cassette tape and some printed material to listen to and read if I was experiencing any cravings. She also advised me that I could call their 1-800 number at any time to talk to someone if I needed to. Also included in the original price was the cost of a "booster" within the first 6-8 weeks. Part of the treatment included my going home and following some simple detoxification instructions for the first week, drinking lots of water and agreeing to take three anti-oxidants for at least one month to help overcome withdrawals and cravings. She also gave me several tips and hints to help change my habits and thinking. One thing she really stressed was the importance of not having even one drag off a cigarette as all the old cravings would come back with a vengeance!

When I left the Clinic I was a non-smoker! It was that simple and easy. I could not believe that I was not in agony and craving a smoke. On August 4th I went to Vancouver and was staying with a smoking friend and I thought that I could have "just one".....well, the therapist was not lying to me....the cravings came back twice as strong! I tried for two weeks to overcome with just willpower but I couldn't do it...all I could think about was having a cigarette.

TIP OF THE MONTH:

GET FLU & PNEUMONIA VACCINES NOW!
You can get those and your Hep A & B vaccines free in BC when you have Hep C.

LAB TESTS ON LINE

http://www.bloodbook.com/ranges.html

VOWS?

By Bruce DeVenne

Penny pinching from Crawfords seems to continue as your disease worsens. If and when you reach the stage of transplant and you have to travel your spouse can go too and have her way paid. Thanks to Premier John Hamm and health minister Jamie Muir's dismantling of our liver transplant unit, if you live in Halifax you must go to London, Ontario. Crawfords will pay for your spouse, but there is a catch. They put him/her up in a convent. That's right--a guest house in a convent run by one of the orders of Sisters. If you go there, you better be prepared to take the vows. I spoke with somebody who was there, and was told the accommodations are best described as Spartan. The beds are small and uncomfortable, the meals are simple and small, you get one set of towels and facecloths for the week, it seems, and, if you are out after 10 PM, you have to sign in. I wonder how Crawfords people and the class action lawyers…oops… fund-defending lawyers live out of our fund when they travel. Not like this, I'm sure!

ANNOUNCING:

New Products to Help Raise Money for HepCBC

Metrin is a scientific skin care program formulated by pharmacist motivated by his own skin care concerns. Together with specialists and biochemists, he researched the chemical laws that govern the skin. The result? A synergistic step program that, when used as directed, works with the skin's natural balance systems to cleanse, nourish and protect all skin types - a proven effective skin care program since 1932. For 70 years, Metrin has provided quality skin-care products to women and men around the world. Our customers trust Metrin to help keep their skin clean, healthy and younger-looking.

But healthy skin is only one step towards overall good health. Our health products are designed to promote good health and well-being. With Metrin Life's M3 Nutrient Complex and Herbal BeauTEA, you have health products with the same reliability and proven effectiveness as Metrin Scientific Skin Care.

METRIN Life's M3 Nutrient Complex is an extremely nutritious health supplement designed to help improve your energy level, memory function, skin & physical condition, strength, vitality, appetite, and quality of sleep. Its unique blend of ingredients will help to expedite recovery from illness and prevent the effects of aging. The ingredients in M3 are multi-functional, formulated to bring your internal system into balance.

Your Metrin representative will make a donation of 10% to HepCBC on all products sold to customers through this bulletin. (Please mention this ad!) SUPPORT HEPATITIS C! Call now: (250) 744-3500 or 1-866-375-3500 or e-mail: metrin@shaw.ca

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

DISABILITIES HELP SHEET

The BC Coalition of People with Disabilities has created a 'help sheet' for filling out the new Disability Benefits forms. Please pass this information on to anyone who is having to reapply for benefits. Hopefully it will reduce some of the confusion and anxiety that this process has created for some people. Here is the link, and another useful page:

www.bccpd.bc.ca/commalert/helpsheets/DesignationReview.pdf

http://www.bccdc.org/content.php?item=29

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