WE'RE NOT ALL ROCK STARS

Most people living with hepatitis C
are actually quite shy
and, frankly, a little boring…

Acknowledgements

- To those who have bravely stepped into the public eye to say, “I have hepatitis C and here is my true story.”
- To those who remind us to expect - and insist others respect - our human rights.
- To those don’t have hepatitis C listed as their Cause of Death, though it was.

- To those many friends whose pictures you won’t find in this slideshow because they feel forced to keep hepatitis C secret in order to…
  - find or keep a job,
  - find or keep a relationship,
  - be treated respectfully in a hospital or other place of vulnerability,
  - protect their families from shame or ostracism.

How do normal people respond…

- When they find out they have been infected with a deadly new disease
- That no one has heard of yet?
- And there is no known cure?

They get mad! They try to find out who gave it to them! And they sue!

With signs, music, candles, hope…they demonstrate in front of parliament.

Sometimes it is hard to know what to ask for when problems are complex.

Disease and poverty often go hand-in-hand. Like chickens and eggs, what comes first?

How much is the government responsible for helping those with hepatitis C? What is the Red Cross' responsibility?

HCV+ people and their friends and families kept trying to publicize the issue because no one else was!

They formed groups with LOGOS!
HepCBC was incorporated in 1996.

SANDI'S CRUSADE AGAINST HEPATITIS C

HEPHIVE

HeCSC
HCV

HepC BC
HCV

THE HEPATITIS WEBRING

HepC BC

HepC BC
HCV

Hepatitis C
The Silent
KILLER

HepC BC

They did whatever they could to raise funds.

May Daze Gala

a dazzling musical event in support of

HepCBC

an evening of
music and entertainment
Sunday May 6, 2001
(Doors open at 7/concert begins at 8)

at

The Church of Our Lord
626 Blanshard Street at Humbolt

hosted by
Victoria's own award winning poet
Linda Rogers

Door Prizes

performances by:
Pablo Diemecke
Tango Argenta
Mandolirium
The Ragtime Robins
and more.....

Silent and not-so-silent auctions
with auctioneer
Mr. Howie Siegel
(auction purchases by **cash or cheque** only)

A light snack provided by several of Victoria's finest restaurants will be served.

Tickets $15 available at:
Ward Music, Ivy's Bookstore and Munro's Books

for more information phone: 361-4808
Hepatitis C Education and Prevention Society

Local art, including even “the Queen” herself got auctioned off to raise money to fight the new Silent Killer.

Victoria’s vibrant music community played a major role in these fundraisers.

Patients felt an urgent need to protect others from the tragedy that had befallen them. HepCBC put the first Hepatitis C transit ad on a Canadian bus (in Victoria):

However, HepCBC was also starting to emphasize the importance of TESTING, not only to protect individuals, but to protect the public's future BLOOD SUPPLY.

Who is the Editor?

- Since 2000, one persistent individual got “Peppermint Patti’s FAQs” updated regularly.
- She also made sure the monthly *hepc.bull* newsletter (which started in 1996!) came out regularly with accurate and timely HCV news.
- Since 2002, when www.hepcbc.ca went online, she has done the same with it.

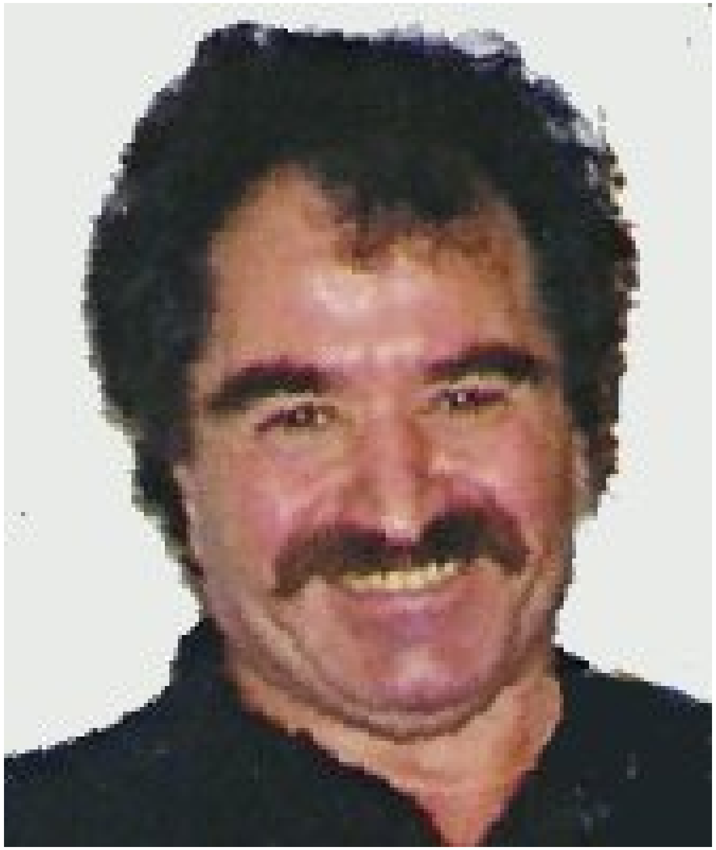
THANKS,
JOAN!

The 2006 cross-Canada Caravan gave them hope, confidence, and energy. It also helped establish friendships and working relationships that continue to this day.

Hepatitis C
Caravan of Hope

There have been lots of tearful goodbyes. Here is just a sampling of colleagues/friends lost to hepatitis C…

Artur de Torres



William Loeppky

The smiles of these lovely ladies are sadly missed by so many.

Dianne Morrissettie

Doreen Stalker

Two fighters…

Brad Cummings

Brian Brownrigg

Two who were very inspirational to those in Canada’s HCV+ community.

Neil van Dusen

Priscilla Udall Ekman

Two guys we lost way too soon…

Bruce DeVenne

Dave Fitzgerald

Two women greatly missed by their communities and families

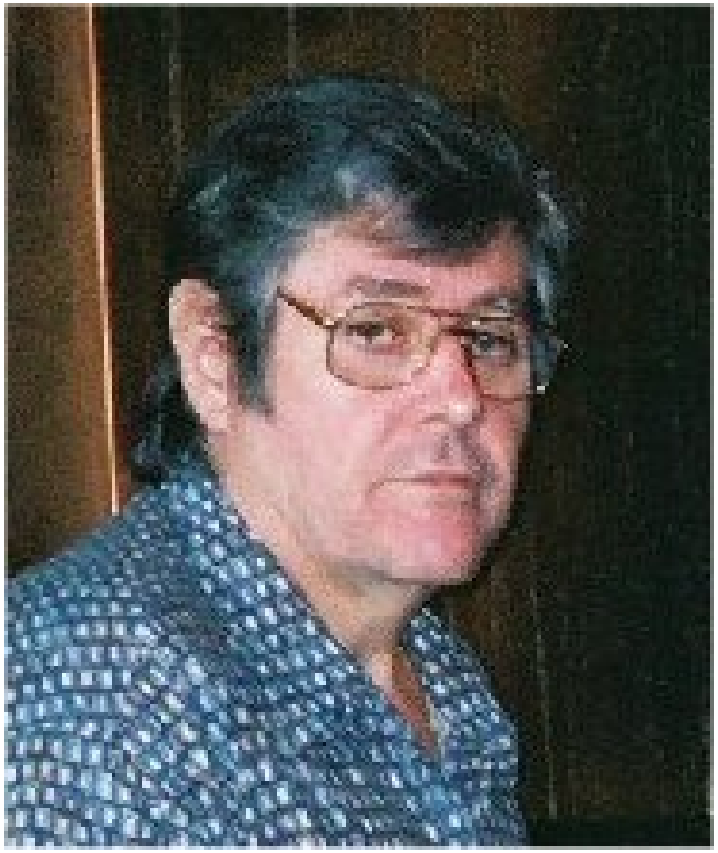
Ramona Rondeau

Sharon Grant

Two more great fighters; so sorry to say goodbye.

Ron Thiel

Rudy Lang, hemophiliac



These two women had so much energy – it was very hard to say goodbye to them!

Jean Anne Day

Kelly O'Dell (and Pepper)

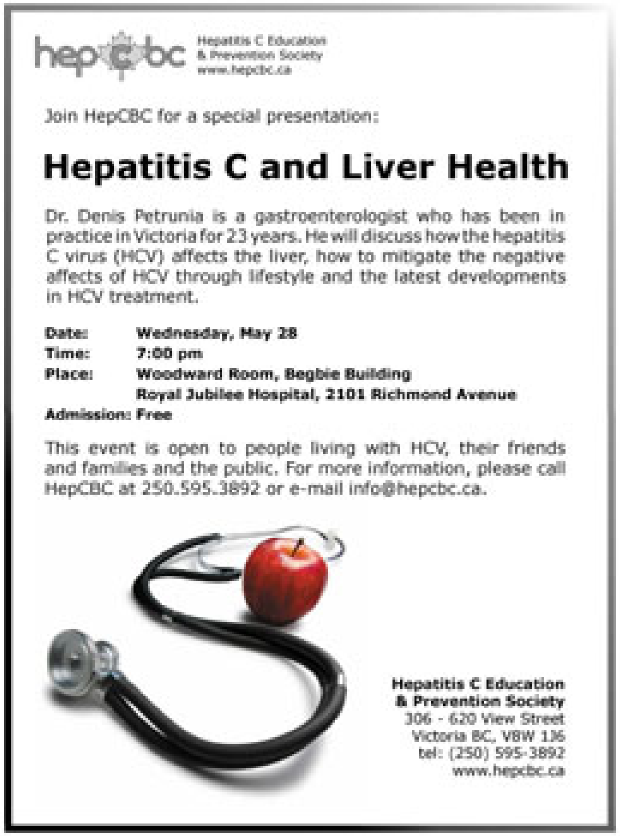
These men greatly helped community members also living with hepatitis C.

Howard Langlois

“ Until we meet again ”

Gordon McClure

In 2007, HepCBC held public presentations to inform the Victoria community about hepatitis C.



hepcbc Hepatitis C Education
& Prevention Society
www.hepcbc.ca

Join HepCBC for a special presentation:

Hepatitis C and Liver Health

Dr. Denis Petrunia is a gastroenterologist who has been in practice in Victoria for 23 years. He will discuss how the hepatitis C virus (HCV) affects the liver, how to mitigate the negative affects of HCV through lifestyle and the latest developments in HCV treatment.

Date: **Wednesday, May 28**
Time: **7:00 pm**
Place: **Woodward Room, Begbie Building**
Royal Jubilee Hospital, 2101 Richmond Avenue
Admission: Free

This event is open to people living with HCV, their friends and families and the public. For more information, please call HepCBC at 250.595.3892 or e-mail info@hepcbc.ca.

Hepatitis C Education
& Prevention Society
306 - 620 View Street
Victoria BC, V8W 1J6
tel: (250) 595-3892
www.hepcbc.ca

Working Together Against HCV

HepCBC March 31, 2007

LAIR
CENTRE

Natalie Rock RN, BSN

Hepatology Nurse

Clinic Director LAIR Centre

www.laircentre.com

And Natalie Rock…well, she did!

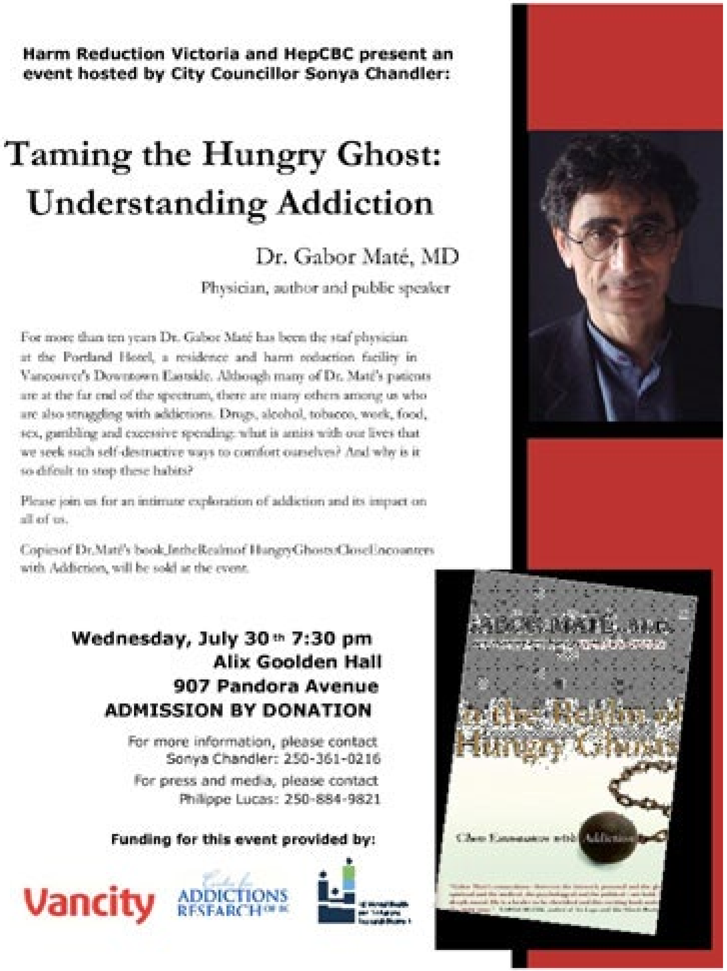
LIGHT SIDE

"If you remember, I did mention possible side-effects."

In 2007 we teamed up with the Canadian Liver Foundation on their Liver Walk around Elk Lake. Walking is great for our liver health!

Mary Lucas and Alana Kronstall, two wonderful HepCBC Executive Directors (not at same time), helped us focus. We likely drove them crazy, however.

In 2007, Harm Reduction Victoria & HepCBC co-hosted Dr. Gabor Maté who helped us see relationships between addiction, illness, and family life/love.



Harm Reduction Victoria and HepCBC present an event hosted by City Councillor Sonya Chandler:

Taming the Hungry Ghost: Understanding Addiction

Dr. Gabor Maté, MD

Physician, author and public speaker

For more than ten years Dr. Gabor Maté has been the staf physician at the Portland Hotel, a residence and harm reduction facility in Vancouver's Downtown Eastside. Although many of Dr. Maté's patients are at the far end of the spectrum, there are many others among us who are also struggling with addictions. Drugs, alcohol, tobacco, work, food, sex, gambling and excessive spending: what is amiss with our lives that we seek such self-destructive ways to comfort ourselves? And why is it so difcult to stop these habits?

Please join us for an intimate exploration of addiction and its impact on all of us.

Copiesof Dr.Maté's book,IntheRealmof HungryGhosts:CloseEncounters with *Addiction*, will be sold at the event.

Wednesday, July 30th 7:30 pm
Alix Goolden Hall
907 Pandora Avenue
ADMISSION BY DONATION

For more information, please contact
Sonya Chandler: 250-361-0216

For press and media, please contact
Philippe Lucas: 250-884-9821

Funding for this event provided by:

BIG QUESTION: What is HepCBC's relationship with Harm Reduction?

- HepCBC's mission is HCV education, support, and prevention.

- Now that the nation's blood supply is much better protected, Harm Reduction education, techniques, and supplies have become the primary means of preventing the spread of HCV into the nation's "Blood Pool".

Why doesn’t HepCBC “Do” Harm Reduction?

- Harm reduction that prevents HIV and STDs *generally* prevents HCV as well*
- Why duplicate other groups’ efforts and compete for Harm Reduction funding?
- We concentrate on what we can do well.
- *****Some differences exist – we point them out.*

SUMMARY OF FACTS:

- Harm Reduction helps prevent individuals from getting HCV and has led to a significant decrease in incidence of new HCV infections in British Columbia.
- Harm Reduction helps limit the spread of HCV into the nation’s “Blood Pool”.
- Harm Reduction SAVES LIVES.
- Therefore, HepCBC supports Harm Reduction.

Steve, Cheryl, Mary in our former (Volunteer Victoria) office.

Kids, dogs, balloons, smiles, a roller-blading escort, candy (back in 2008 giving candy was ok)! Former Office Manager Andrea Sunderland, far left.

This was the first time many of us had identified publicly with a hepatitis C group. Confronting stigma in oneself…

HeCSC and HepCBC

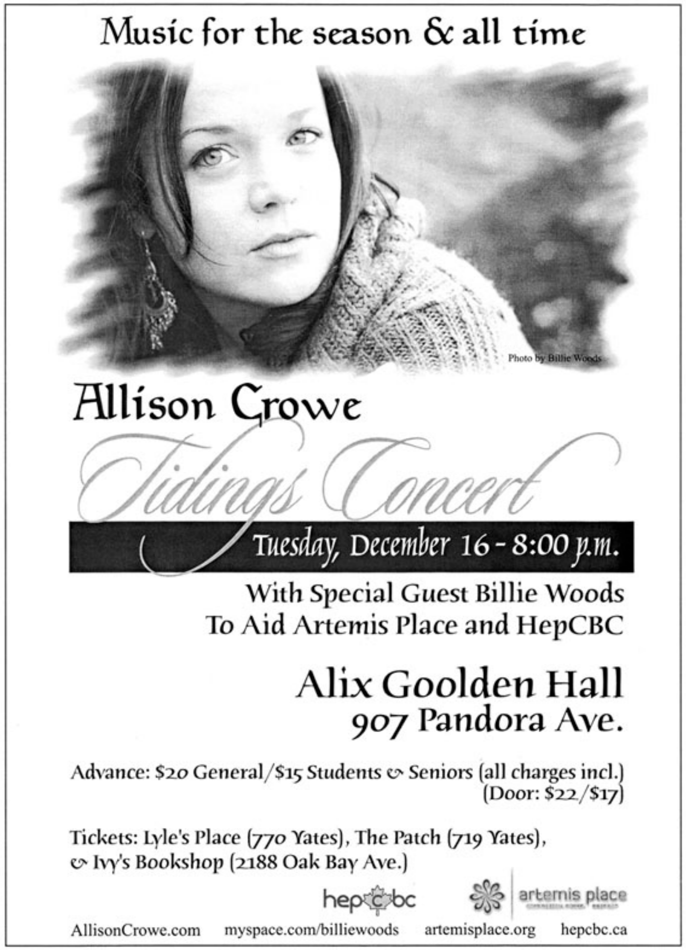
- Hepatitis C Society of Canada (HeCSC) was the first society to focus only on HCV.
- Some of the members of the Victoria and Vancouver HeCSC groups joined Darlene Morrow's HepC BC in 1999, to promote it as a sister group with a provincial focus, so that we could apply for certain funding not available to HeCSC, which was a national society.
- HepCBC became a provincially-registered society that same year, and a registered charity in 2001.

HepCBC, Hep C Circle, & PHCN

- HepCBC applied for Health Canada funding to organize the “Hep C Circle” and was its “Agency of Record” until it became a registered charity in 2008. It is now called the Pacific Hepatitis C Network (PHCN) and is an ‘umbrella organization’ for various groups in BC and the Yukon.
- HepCBC is a member of PHCN and enjoys working with them on regional and Canadian HCV issues. (Thanks, Deb!)

Gordon McClure of HepLife in Vernon, and Cheryl of HepCBC, at PHCN conference, Victoria, 2008

HepCBC has benefited from local musician Allison Crowe's faithful Christmas generosity over the years.



Music for the season & all time

Photo by Billie Woods

Allison Crowe

Tidings Concert

Tuesday, December 16 – 8:00 p.m.

With Special Guest Billie Woods
To Aid Artemis Place and HepCBC

Alix Goolden Hall
907 Pandora Ave.

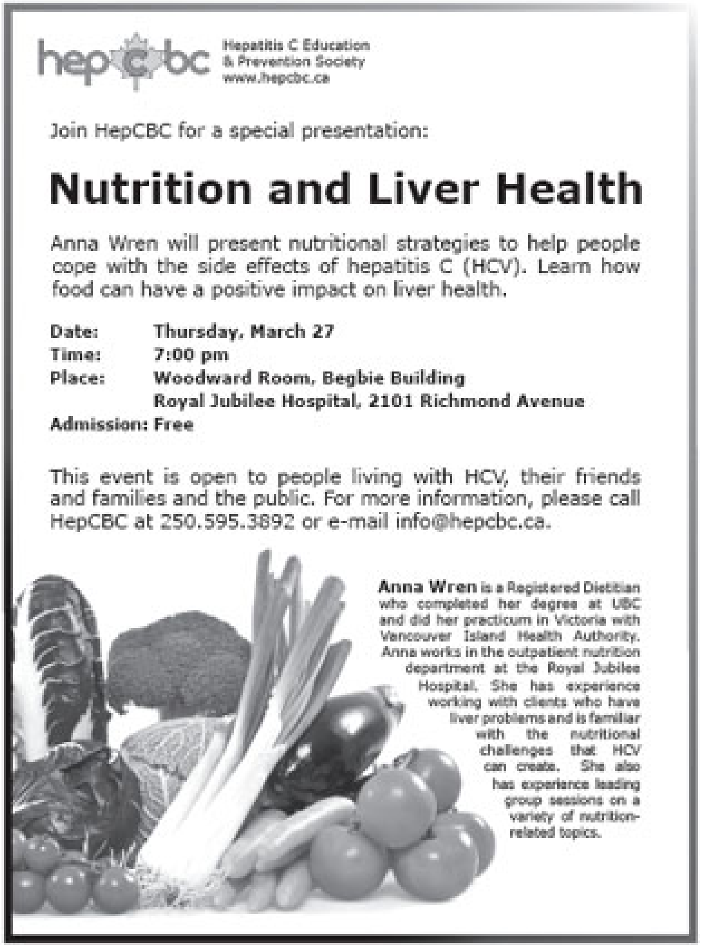
Advance: $20 General/$15 Students & Seniors (all charges incl.)
(Door: $22/$17)

Tickets: Lyle's Place (770 Yates), The Patch (719 Yates),
& Ivy's Bookshop (2188 Oak Bay Ave.)

hepcbc artemis place

AllisonCrowe.com myspace.com/billiewoods artemisplace.org hepcbc.ca

Everyone enjoyed Anna Wren's presentation about food, of course!



hepcbc
Hepatitis C Education
& Prevention Society
www.hepcbc.ca

Join HepCBC for a special presentation:

Nutrition and Liver Health

Anna Wren will present nutritional strategies to help people cope with the side effects of hepatitis C (HCV). Learn how food can have a positive impact on liver health.

Date: **Thursday, March 27**
Time: **7:00 pm**
Place: **Woodward Room, Begbie Building**
Royal Jubilee Hospital, 2101 Richmond Avenue
Admission: Free

This event is open to people living with HCV, their friends and families and the public. For more information, please call HepCBC at 250.595.3892 or e-mail info@hepcbc.ca.

Anna Wren is a Registered Dietitian who completed her degree at UBC and did her practicum in Victoria with Vancouver Island Health Authority. Anna works in the outpatient nutrition department at the Royal Jubilee Hospital. She has experience working with clients who have liver problems and is familiar with the nutritional challenges that HCV can create. She also has experience leading group sessions on a variety of nutrition-related topics.

HepCBC & AVI co-hosted WHD, 2009.

May 19, 2009
Legislative Buildings
12:00pm - 2:00pm

Philippe Lucas
Philippe is an elected city council member and the Executive Director of the Vancouver Island Compassion Society. He has also worked with a countless number of organizations including HepCBC and Harm Reduction Victoria.

Dr. John Farley
Dr. Farley is an Internal Medicine specialist from Vancouver, BC. He is an outspoken advocate for the hepatitis C community and has been featured in many articles for several newspapers and media outlets including CBC.

Fran Falconer
Fran is a hepatology nurse advocate who has won several awards for her services. Her most recent award was the Clinical Practice Award for her excellence in hepatology care.

AIDS Vancouver Island and HepCBC present:
2009 World Hepatitis Day with guest speakers from the community

Am I Number 12?

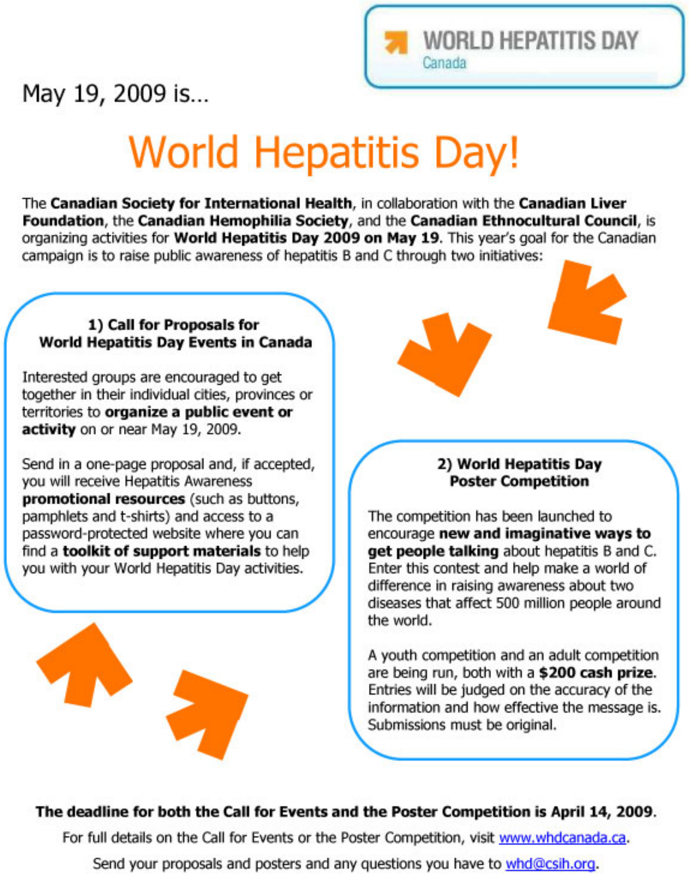
1 in 12 people world-wide have hepatitis B or C. The problem is that many people don't even know it.

Are *you* number 12?

Join us **May 19th** from **12:00pm - 2:00pm** at the **Victoria Legislative Buildings** to help bring awareness to this silent epidemic.

Brought to you by: AIDS Vancouver Island hep c bc

AVI's community education is funded by the **Vancouver Island Health Authority** and HepCBC is sponsored by **United Way** and the **generous public**!



WORLD HEPATITIS DAY
Canada

May 19, 2009 is…

World Hepatitis Day!

The **Canadian Society for International Health**, in collaboration with the **Canadian Liver Foundation**, the **Canadian Hemophilia Society**, and the **Canadian Ethnocultural Council**, is organizing activities for **World Hepatitis Day 2009 on May 19**. This year's goal for the Canadian campaign is to raise public awareness of hepatitis B and C through two initiatives:

1) Call for Proposals for World Hepatitis Day Events in Canada

Interested groups are encouraged to get together in their individual cities, provinces or territories to **organize a public event or activity** on or near May 19, 2009.

Send in a one-page proposal and, if accepted, you will receive Hepatitis Awareness **promotional resources** (such as buttons, pamphlets and t-shirts) and access to a password-protected website where you can find a **toolkit of support materials** to help you with your World Hepatitis Day activities.

2) World Hepatitis Day Poster Competition

The competition has been launched to encourage **new and imaginative ways to get people talking** about hepatitis B and C. Enter this contest and help make a world of difference in raising awareness about two diseases that affect 500 million people around the world.

A youth competition and an adult competition are being run, both with a **$200 cash prize**. Entries will be judged on the accuracy of the information and how effective the message is. Submissions must be original.

The deadline for both the Call for Events and the Poster Competition is April 14, 2009.

For full details on the Call for Events or the Poster Competition, visit www.whdcanada.ca.

Send your proposals and posters and any questions you have to whd@csih.org.

Groups in Vancouver & Victoria had loads of fun celebrating “Hepatitis Day”!

In fact, we had such fun we decided it was time to remind Victoria: "May is World Hepatitis Month"! The Mayor agreed.

HepCBC's annual participation in the Victoria Day Parade in Victoria has become one of our main anti-stigma and public health education activities.

Beginning of the parade route – still slightly disorganized and awaiting instructions from the Marshall.

An elegant lady rode in the car. HepCBC won 2nd prize in category.

Blood-to-blood contact is a new idea for many people who think of HCV as an STI.

Groups joined forces at a 2010 Health Fair to speak with one strong voice about hepatitis C and healthcare justice for all.

Thanks, Fran.

Thanks to our Health Fair Volunteers!

Thanks, Steve.

What’s Number 12, anyway? Sounds like a gastroenterologist’s euphemism for something quite awful.

Thanks, Philippe.

Some people were fascinated with our pamphlets, and happy we were there.

Thanks, David.

Big smiles but a very serious message. (HepCBC's current Office Manager is Anamaria Medina, far left.)

Celebrating a success; we assured a few more people they're not alone, and that support is there if/when they need it.

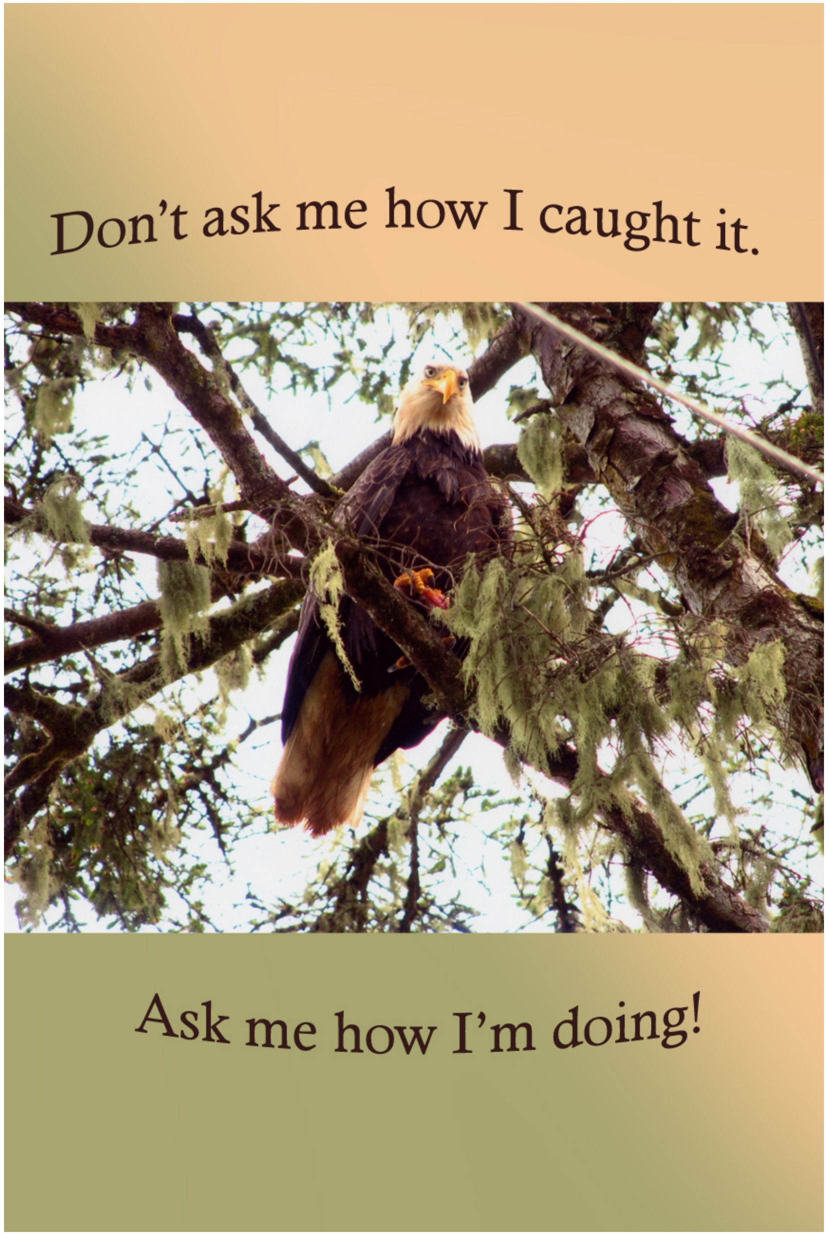
Former Executive Director Jessica Chan and friend at a Christmas luncheon

Cheryl & Gary Stieman (counselor from Chilcotin/Williams Lk. Area) at PHCN conference, Surrey, Nov. 2010. Recently he reported 10% HCV+ population in the remote northern villages where he serves.

HepCBC is happy to offer a monthly support group for HCV+ people & friends/relatives.

It meets every 4th Tuesday at 7 pm at the VIHA Health Unit, 1947 Cook St. in Victoria.

It's confidential, so we have no photos.



Is anyone with HCV welcome? (Yes, but…)

- We are peer volunteers, and not trained to handle special problems.
- We don’t have counseling, medical, or legal skills.
- Those co-infected with HIV are encouraged to go to AVI. The treatment protocols are very different from those mono-infected with HCV.
- Those currently battling mental illness or addiction are encouraged to seek help from Cool Aid Clinic or another agency who can give them the special help they need. We wish them all success and hope to see them healthy soon!

Allison Crowe continues to do benefit concerts for HepCBC (& Artemis Place) every December. Thanks, Allison!

Victoria Day Parade is big in Victoria – a great opportunity for us to put a human face to HCV and fight stigma.

Our Pres., Steve, practices the "C" sign. Unfortunately this campaign does not look promising. His real passion, shown on his T Shirt, is TRANSPLANT.

It was an honour to have Kelly O’Dell from Hep C Canada join our parade.

Kelly and “Pepper”

Kelly and Cheryl try “C” signs.

"#12" Pepper was a big draw…

Shared laughter with friends is precious. Every day we're alive with HCV is a gift we don't take for granted.

Cheryl, Steve, Joan

Kelly's "Pepper" with volunteer Grasi

June comes from NW BC. She is not HCV+, but knows many people who are. Stigma in small communities can be awful. June wants to let people know it's ok to talk about HCV. Thanks, June!

June & Cheryl tried to show a positive face to people while encouraging them to confront painful truths about hepatitis C.

Joan, Kelly, Grasi, June, & Cheryl, with Pepper in the lead, have made it to the end of the 2011 Parade.

We were awarded 1st place in our category. But those who had participated in the 2011 Victoria Day Parade were badly shaken to hear of Kelly's sudden death a few weeks later. Below, Bev and Joan at Kelly's Memorial in Vancouver.

World Hepatitis Day Forum at “Positive Haven” in Surrey, with Fran Falconer.

The 1st HepCBC “Liver Warriors” team poses half-way through the 2011 Goodlife Fitness Royal Victoria 22.5 km Half-Marathon.

We wanted to get in shape and have fun. We chose to walk, not run. (Good decision!)

HepCBC has been chosen one of 20 official charities of the 2012 Marathon!

This year we hope to demonstrate benefits of distance walking to people with HCV & other liver diseases.

We want to raise money so HepCBC can re-open its Victoria office.

Mostly, we hope the Liver Warriors team will help combat stigma and the public's fear of HCV+ people.

In early 2012 we attended a Pacific AIDS Network conference where we learned a lot about HIV/HCV co-infection, and why HCV is a major STI among gay males, while within the general population, it is not. Thanks for your honesty and humour, PAN!

Fran doesn't look like a very Happy Camper here, does she? Maybe it's because she fears funding for her tiny, sparsely-outfitted office space will soon be cut. Let's hope her fears are groundless, and that she'll get computer access there soon. Unfortunately, Vancouver Island desperately needs expanded HCV services.

Proof that Hepatitis C doesn’t have to be a Death Sentence. The 5 friends below share 150+ years of hepatitis C!

All of us have been HCV+ for a long time: between 20 and 45 years (except Fran). Try the treatment, and if it works, great! If not, don't despair -- take good care of yourself! You're in good company.

Who does HepCBC serve?

Earliest members were…

- Those who got HCV via contaminated blood transfusions or blood products.
- Hemophiliacs who got HCV through contaminated clotting Factor VIII.

NOW, in addition, many of us..

- Got HCV via recreational drug use, often just once, many decades past.
- Aren’t sure how we got HCV-possibly via tattoos, or even a dental procedure.
- Are immigrants who got HCV via re-used needles in childhood vaccinations or unsafe medical procedures.

What does HepCBC do?

In the Beginning we…

- Did research to educate ourselves.
- Started publications to educate others.
- Publicized the plight of those with HCV to policy-makers.
- Sought compensation.
- Did basic fundraising.

NOW, in addition, we…

- Provide regular support groups & health-promotion activities
- Cooperate actively with other local, BC, Cdn, & international groups
- Arrange public forums
- Get some funds from pharmaceuticals (but we stay independent!)

What are HepCBC's future plans?

- Keep doing what we do right; but try to improve.
- Cooperate with other organizations to be more effective in combating this awful disease.
- New, more interactive website!
- Outreach into the baby-boomer and senior communities, encouraging them to test for HCV.
- New anti-stigma activities; continue prison visits.
- Increase public's understanding of HCV transmission methods, especially among youth.
- Research HCV chronic and end-of-life protocols.
- WE WELCOME YOUR INPUT & PARTICIPATION!

More acknowledgements

- Photos by various people. Just ask and we'll try to get all the info. or credits for you. We have permissions for everything; it's just that some are from a long time ago.
- This slideshow prepared for lunchtime presentation at HepCBC Hepatitis C Education & Prevention Society's public forum on upcoming hepatitis C management guidelines in Victoria, BC, on March 2nd, 2012.
- **And if you actually see this, it's thanks to the AV Gods!**