



# Community Connections

*Keeping Nova Scotians Informed about Hepatitis*

August 2009

- Do you have questions or seek information about hepatitis?
- Are you newly diagnosed and want support?
- Feeling alone and need to talk to someone who understands?

**CALL US**

**WE'RE HERE FOR YOU!**

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## Another Successful Hepatitis Awareness Month

“Shockingly one in 12 people worldwide is living with either chronic hepatitis B or hepatitis C. While this is far higher than the prevalence of HIV or any cancer, awareness is inexplicably low and the majority of those infected are unaware.”

-- World Hepatitis Alliance [www.aminumber12.org](http://www.aminumber12.org)

May was Hepatitis Awareness Month in Canada, and the Hepatitis Outreach Society marked the occasion in three ways.



“Hepatitis 101” and “Safer Tattooing and Piercing” presentations were made to various groups in arrangement with community partners such as Metro Turning Point, Mainline Needle Exchange and Youth Pathways.



With the generous software loan from RealDecoy and all the wonderful items donated by our supporters, the second Annual Art/Etc Online Auction raised over \$1600 for the Society.



In conjunction with the Public Health Agency of Canada, the Canadian Society for International Health, the Canadian Liver Foundation, the Canadian Haemophilia Society, the Canadian Ethnocultural Council, and other national, provincial and local organizations, the Hepatitis Outreach Society orchestrated a province-wide awareness campaign with members, volunteers, community-based organizations, students, inmates, medical professionals and other concerned Nova Scotians. Details and photos can be found on page 3.

## Using the Internet for Support

By “Rose”

Upon being diagnosed with a melanoma in 2004, I raced to my computer and looked up every bit of information on the net regarding this cancer. Anyone who has access to a computer is guilty of doing this fact-finding mission if they or a family member is diagnosed with some disease or illness. Unfortunately as a result of this research we can scare ourselves with information overload.

Two years later, when I was diagnosed with hepatitis C, I set out on another internet search and succeeded in dwelling on the worst case scenarios that could happen to me. I became a sponge for information on how to help myself, comparing my symptoms to the published lists of symptoms, and living in dread of what might happen to me. As time went by I realized that I was overloading myself with unnecessary fears. I was suffering from “self-induced cyberchondria”.

Cont'd on page 5

"You must be the change you wish to see in the world."  
-- Mahatma Ghandi

## My Secret is Out!

By Bette MacAloney

After eight months of appointments with several specialists about my hepatitis C (HCV), my husband Alton and I felt it was time for a vacation. This was a vacation before the unknown of treatment and how it might affect us. In September we went to Ontario to visit Alton's brother, Gary, and family.

Before our holiday I still had not let our daughters know about the many medical appointments over the past several months. They already knew about the hepatitis C, but they didn't know I was getting ready for treatment. I needed to know myself what would be happening before I was able to share it. I felt my secret was safe for now and I knew I would be too emotional talking about everything.

During a phone conversation in June, Gary told us the surprising news that he was diagnosed with hepatitis C. He had been to the doctor with complaints of tiredness and no energy. When the nurse explained the facts and risks of HCV to Gary along with possible treatment, he learned a great deal.

My decision to keep my secret to myself became even tougher when we visited. Gary was very open about himself and his hepatitis C. He mentioned how he had feelings that he shouldn't be kissing or hugging his grandchildren, although he knew the virus is only spread through blood. He was devastated to think that he could have passed the virus on to his son after years of sharing the same shaving tools and fingernail clippers. Gary worried that other family members could have contracted the virus from him. He was relieved when his wife and son both tested negative for HCV.

I felt so bad for Gary and I knew exactly what he was going through, but I couldn't let him know my feelings. I remained quiet about myself and listened. I remembered back to 1974 when our second child was born and everything that happened then, the blood transfusions after haemorrhaging; and two months later I was diagnosed with hepatitis. I remembered the year of anguish that I went through and finally getting better. That part of my life was buried deep inside and it was definitely not easy revisiting it. Even in 1998 when I first learned that I had HCV, I couldn't believe how difficult it was for me to talk about it with Alton. I was too emotional remembering the past and I just wanted to shut it out. I remember saying to him, "Whatever it is that I have, it's been in me for 25 years. There's no sense in bringing it out now."

By November 2005 I had my first appointment with Carla Burgess and Dr. Peltekian. My treatment date was scheduled for January 2006. That day, when Alton and I left the hospital, we had a great deal more information. I felt it was time to share my secret but our daughters had to come first. They were both upset with me and concerned for me. They couldn't believe I had not said anything before. Gary and family were very surprised, but they understood. I explained to some of my family that I was being treated for cirrhosis of the liver. The result of my biopsy was first grade cirrhosis, so I didn't feel it was a complete lie. Before the end of my 72 weeks of treatment my secret was out.

A good friend once told me that every day is a new beginning. I kept a diary of my thoughts and how I was feeling each day. Sharing my feelings about treatment has helped me to be more open about hepatitis C. With all the thinking time that I had, I realized that the most important thing in life is to do the things you want to do the most, be happy and keep a positive attitude.

I am thankful for an understanding family and for the support of my husband and our girls. Knowledge is power. Stay informed. Be well. We're not alone.

Editor's note: You may contact Bette in confidence at [TalkingToBette@gmail.com](mailto:TalkingToBette@gmail.com).




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*"Gary worried that other family members could have contracted the virus from him."*

"Although the world is full of suffering, it is also filled with the overcoming of it." -- Helen Keller

Below: Staff from the Halifax Sexual Health Centre on Quinpool Rd.



The Gottingen Gang!  
 Left: Premier Darrell Dexter, Society Treasurer Wanda MacDonald, and Megan Leslie, MP Halifax.  
 Above: Angus Campbell, Megan Leslie and volunteers

World Hepatitis Day 2009 was a huge success. This year's campaign was called THATTS Nova Scotia – Taking Hepatitis Awareness To The Streets of Nova Scotia – and we did! Members and supporters of the Society, especially public health nurses, could be found all over Nova Scotia raising awareness and providing information. Thank you everyone.



Above: Students from Hants North Rural High School in Kennetcook raised awareness and a surprise donation for the Society. Thanks! Unphotographed: Students from Sir John A. Macdonald High School in Upper Tantallon also distributed information in their school.



Left: Students from Dalhousie University School of Medicine.



Left: The staff from the QEII Liver Clinic and Infectious Diseases Clinic.



Left: The Scotia Square 12 (actually 13 with Larry) included volunteers from the AIDS Coalition of Nova Scotia, and staff from the Nova Scotia Advisory Commission on AIDS and the Public Health Agency of Canada. A special mention to a member in Cape Breton whose camera and photos went missing.

## Program Coordinator's Message

It's been a busy few months at the Society. The support for the auction and success of World Hepatitis Day were thrilling. We received very good feedback from bidders on the auction. They found RealDecoy's RealAuction software easy to use. People especially enjoyed the proxy bidding feature, knowing that their bids would continue to a maximum preset amount.

In June we held our Annual General Meeting. Dr. Kevork Peltekian was the guest speaker and gave a superb presentation on hepatitis, including historical information (the discovery of a 5,000 year old mummy with hepatitis B) and the latest updates regarding treatment therapies.

Starting in September, two fourth year students from the Dalhousie School of Nursing will be working in the office on Thursdays. I've prepared a stimulating work plan for them, including attending the Hepatology Nurses' Workshop in Halifax.

We owe much of our success to our volunteers. If you're thinking of volunteering, we're very flexible with your time and we have a variety of things that you could do that would really help us out. Give us a call.

On behalf of the Board of Directors, I would like to thank the following people and organizations for making our auction so successful with their generous donations:

Baidu Traditional Chinese Medicine	Beth Lenco
Chintzy's	Ciao Bella Esthetics
Ciao Bella Hair Studio	Glenora Distillery
Halifax Dance	Humphrey's Landscape and Construction
Java Blend	Juanita MacPhee
Kent - Mic Mac Mall	Kristin Muntz Massage Therapy
Local Jo Café & Market	Margot Metcalfe
Natural Means Massage Therapy	Nova Scotia Tattoo
Palooka's Boxing Club	Park Place Hotel & Conference Centre
RealDecoy	Shambhala Sun
Stan Rogers Folk Festival	Tattletales
The Chickenburger	The Four Points Sheraton Halifax
The Medicine Shoppe	The Naturopathic Way
The Westin Nova Scotian	Victor's Bar & Grill
Doug Williams	World Trade Centre

Sincerely,  
Angus

## Genetic Test Predicts HCV Treatment Responders

The standard therapy to treat hepatitis C is pegylated interferon and ribavirin, and more medications are in development and being tested in trials. On August 16, 2009, Nature magazine published an online report that researchers have identified a gene that may predict how a person with the hepatitis C virus (HCV) genotype 1 will respond to standard therapy.

The study by Dr. Dongliang Ge et al, titled "Genetic variation in IL28B predicts hepatitis C treatment-induced viral clearance" is welcome news. Not only is type 1 the toughest strain to treat, but the presence of the gene could double the chances of standard therapy being effective on people with African and/or Hispanic descent.

In addition to treatment response, the gene also appears to be connected with natural clearance of HCV, as 10 – 15% of people do clear the virus without any treatment. The researchers agree that further studies are needed to see if the IL28B gene plays a role with other HCV genotypes, other medications in development, and people who are co-infected with HIV.

## Study Participants Needed

The NS Advisory Commission on AIDS is funding a study investigating implications for policy and practice regarding HIV testing and counselling. Specifically they are interested in hearing about people's experiences of HIV testing in the province. If you HAVE or HAVE NOT been tested for HIV in Nova Scotia in the past 12 months (whether your test result was HIV+ or not), and are between 15 and 65 years of age, you may be able to take part in a private and confidential one-on-one interview with a member of the research team.

The interview will take approximately 1.5 hours and a \$15 honorarium will be provided. Please contact Janice Fuller, Research Coordinator, at 902-494-6620 or Janice.Fuller@dal.ca to participate or for more information.



Capital Health



## Using the Internet for Support

(cont'd from page 1)

I am not implying that educating yourself is a negative thing to do. I went into treatment armed with knowledge and ready for the battle ahead. I had to learn to separate the truth from fiction and I am very sure that I became a challenge for my nurse practitioner as I questioned many aspects of my diagnosis and treatment.

Following 72 weeks of treatment and now in a "detoxing" stage I have realized that I may have been looking for answers on the net, but most of all, I was looking for someone like me. I was looking for someone newly diagnosed, someone who was considering treatment, someone going through treatment or someone who had the entire experience. I was looking for a "kindred spirit", so to speak. None of the websites I was visiting was fulfilling that need until I discovered an online forum for people diagnosed with hepatitis C. I searched for more online HCV forums and was rewarded with many options.

Living in "Smallville, Nova Scotia" I am isolated regarding my diagnosis. Having hepatitis C is not something I wanted to shout from the rooftops because I became aware very quickly that most people would not understand and would become fearful of me. Misinformation, especially from news media, has labelled hepatitis C with a negative fear-mongering stigma. Finding internet forums for people diagnosed with HCV was a gift because I found what I was looking for at a time I really needed it.

Choosing the right site for support is an individual journey. I visited several forums and chat rooms, and took part in three during my quest to find a comfortable place. There are many great Hepatitis C forums out there and you do have to read through many of them to find the right forum culture for you. [Yes, there will always be "wing nuts" with personal issues, however, I stayed out of the battles that can occur with the different personalities, but it was great reading entertainment on the long days of treatment.]

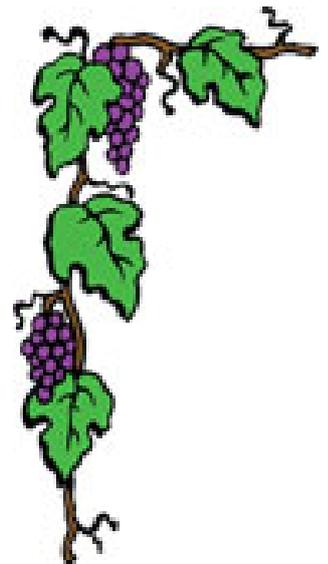
Of course, you should practice safety on the internet and keep your personal life private. The main focus is to find a group of people that support you and walk you through your journey no matter what you choose to do regarding your diagnosis.

I am very sure I wouldn't have made it through treatment if I hadn't investigated hepatitis by using the internet. The forum I chose has been a wealth of support to me. It was a long build-up from the diagnosis to the actual treatment and a long 72 weeks to get through by myself. Sure, I had my husband and children, but the forum carried the brunt of my angst. The forum held me upright until I made it to the very last injection and the very last pill. My journey was filled with battles and triumphs and forum members were there for me through each and every one of those days.

To quote singer-songwriter James Taylor, "I've seen fire and I've seen rain. I've seen sunny days that I thought would never end. I've seen lonely times when I could not find a friend." However, I did find a friend. I found many who share a common bond: Hepatitis C.

Editor's Note: You may contact Rose in confidence at [RespondToRose@gmail.com](mailto:RespondToRose@gmail.com).

A latin phrase: "Uva Uvam Vivendo Varia Fit  
– Diverse grapes, through time, grow together."



## Hepatitis Outreach Society

2973 Oxford Street  
Halifax, NS  
B3L 2W3

PHONE:  
902-420-1767  
1-800-521-0572

FAX:  
902-463-6725

E-MAIL:  
info@  
HepatitisOutreach.com

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We're on the Web!

Visit us at:

**HepatitisOutreach.com**

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### Board of Directors

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## Annual Walk for Life

It's that time of year again to put on your best walking shoes and gather with friends to support the various AIDS Service Organizations throughout Nova Scotia. This is the Canadian AIDS Society's most important fundraising and awareness event.

This year you are able to support both the AIDS Coalition of Nova Scotia and the Hepatitis Outreach Society concurrently by making a pledge to Team Hepatitis Outreach at the Halifax Walk for Life. Better yet, why not join our team or form a hepatitis awareness team at one of the other walks?

To make a donation, join or create a team, or for further information, please visit:

[www.aidswalkforlife.ca](http://www.aidswalkforlife.ca).



## Going Green – Paper Versus Email

*Community Connections* would like to be as green as possible. Not only would we save a tree, but we could be saving precious dollars – money that could be put towards important programming. If you are receiving a paper edition of this issue and would like to have it sent electronically instead, please email [Info@HepatitisOutreach.com](mailto:Info@HepatitisOutreach.com).

If you receive a paper edition, please ensure we have your correct mailing address. If you would like more than one copy for your office or waiting room, we'll be happy to send them to you. And remember, we always have a full colour version on our website.

Thanks for helping us to be more environmentally friendly and cost effective. And please recycle the paper copies whenever possible.



## About The Society

The Hepatitis Outreach Society is a charitable organization committed to community capacity and development, health promotion, public awareness, and implementation of social support networks throughout Nova Scotia for those infected, affected and at-risk of developing hepatitis.

Working with volunteers and community partners since 1999, the Society strives to educate Nova Scotians about hepatitis and its prevention, reduce social stigmatization and isolation, and prevent the spread of hepatitis.

Our work would not be possible without the commitment and dedication of our volunteers, members and donors. Please contact us to discuss how you can make a difference.

**Get Involved! Get Connected! Volunteer!**