



Community Connections

Keeping Nova Scotians Informed about Hepatitis
Fall 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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The Society Turns 10!

On November 23, 1999, the Atlantic Hepatitis C Coalition was incorporated as a charitable organization committed to the wellness and quality of life for all persons living with hepatitis C. The executive committee consisted of Scott Hemming, chairperson; Annalee MacQuaker, treasurer; and Connie Lake, secretary. The first Board of Directors included Dr. Kevork Peltekian, Atlantic Canada’s only hepatologist at the time; Eloise Deering, counsellor and community volunteer; Harold Hamm, community volunteer; Shelley Brown, community volunteer; and Robert Allan, AIDS Coalition of Nova Scotia executive director.

Our name may have changed in 2001 to encompass all forms of hepatitis, but the original goals that were set then are still in place today: to provide information and support to persons infected with, affected by, or at risk of developing hepatitis. We continue to do this through our toll-free phone line, website, awareness campaigns, prevention presentations, and educational workshops.

Former chairperson, current treasurer, and longest standing board member, Wanda MacDonald, commented, “We are proud to have been able to provide these necessary services, and given the range and extent of the needs within Nova Scotia, we hope for more funding with which to expand what we are able to do.”

Being C’een and Heard

By Karen Kittilsen,
Executive Director, Northern AIDS Connection Society (NACS)

We have a golden opportunity in Northern Nova Scotia. Persons living with and individuals affected by the hepatitis C virus are getting their chance to send a clear message and provide a qualitative look into the needs in Northern Nova Scotia. We want to know of any barriers and challenges that you are facing: stigmatization, being marginalized, need for a family doctor, travel to Halifax, adherence treatment, lack of familial support, etc.

Many of these themes and more are coming to the forefront in East Hants, Colchester, Cumberland, and Pictou counties through the Hepatitis C Aware project. All interviews and focus groups are confidential. The results will be sent to the Public Health Agency of Canada which is funding the project.

If you have Hep C in this region, you are not alone. One public health nurse sees many HCV cases on a monthly basis, and she feels epidemic proportions are realistically not far off.

The NS Provincial Exhibition in August provided a good opportunity for NACS to get education and awareness out into the community. We surveyed a number of people and many didn’t know if hep C is a virus or bacteria. There is much confusion amongst hep A, B and C. It’s clear that more work needs to be done in the public education arena.

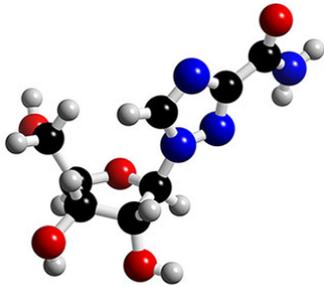
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“The people who make decisions on policy or make the decision on funding and what not, knew very little about us... they know very little about what we need and who we are.” – Man 25

From Silence to Voice: A Qualitative Glimpse into the Lives of People Living with Hep C

Riba Rage – A Firsthand Account of the “I” Syndrome

By “Rose”



Ribavirin
molecular structure

*“I was fine.
I was coping.
I was handling it all
without increased
anti-depressants and
sleeping pills.”*

Christmas 2007 rolled around, and I’d been on treatment for 13 weeks. I was determined to host Christmas dinner because I *always* hosted Christmas dinner: this year was not going to be different just because I was on treatment. The special flatware was brought out, but when a dessert fork was nowhere to be found, I went into a Riba rant. The rant! I was livid, intensely irritated, and obsessed by that missing fork. I knew I was losing it, but I couldn’t stop myself. Mysteriously, a few days later it turned up in the dishwasher in its own quiet way. I happily organized the fork into its storage place in my own Riba world and life was good...until the next rant.

Riba can affect each of us very differently. Prior to beginning treatment I did hear rumours of rage caused by Ribavirin and stories of people (like me) who become the supervisor of everything and everybody. In my case, it all started out with a fork. Throughout the course of treatment the rant became a very familiar friend. I knew I was doing it. I hated myself for doing it. I couldn’t stop myself from doing it.

Prior to beginning treatment, I made the decision to take a minimum dose of an anti-depressant. It was a decision not taken lightly. I was hesitant, however, I figured that 48 weeks of treatment (extended to 72) was going to be a long haul, and I was not coping well with my recent diagnosis of Hep C.

As treatment progressed, sleeplessness and exhaustion increased my agitation. The turning point for me was the Dilly Bar Saga. I had almost no appetite, and when I mentioned I would like to have this treat my husband willingly agreed to go to the DQ. He took advantage of the trip to pick up some guy-things at the hardware store, only to arrive back home with his purchases but no treat. In my Riba crazed mind it was incomprehensible how he could go to town for the one purpose of getting me a Dilly Bar and yet forget it. Even on the “sane” side following treatment I can remember the struggle within to get a grip on myself at the time. I managed to get myself under control because I knew that it was the Ribavirin intensifying the situation.

Jokingly, I referred to the Dilly Bar Saga to my nurse practitioner at my next visit. Our conversation became intense when she insisted that I take sleeping pills because I was not coping well if I were overreacting to minor situations. I couldn’t believe that she was threatening to take me off treatment because of a Dilly Bar! The conversation became negative, and I left her office in a huff. How aggravating to be pushed to take sleeping pills because she thought I had over-reacted. I was fine. I was coping. I was handling it all without increased anti-depressants and sleeping pills. I was indignant. And I was right on all accounts. The empowering drug-induced arrogance of Riba had taken hold and I was in the throes of it.

Immediately following my clinic appointment I was dragging myself around the aisles of a store and a man in a motorized wheelchair rudely raised his voice behind me saying “Watch out!, I’m behind you!”. He snarled “You don’t walk in front of me!” I had left the nurse’s office “oiling for a fight”, and I turned on him. He humbly apologized to me as he scooted by, and I was furious with him for his rudeness and for scaring me. When I calmed down, I realized that my behaviour was shameful. My nurse practitioner was right. I was not coping well with the extensive side effects of treatment. That night I started to take the sleeping pills, and I continued to take them through the remainder of my treatment.

I consider I fared much better than most regarding the rage side effect of Riba, however, you would have to ask my husband to know the real story.

Do you have stories of Riba Rage? Please share them with me by emailing RespondtoRose@gmail.com

“Life can only be understood backwards,
but can only be lived forwards.” – Unknown

How Gary Was Affected By Treatment

By Bette MacAloney

I was on my 60th week of treatment for Hepatitis C when Alton's brother Gary was scheduled to begin his treatment. I still had five months to go and was feeling just about at my worst. Gary's medication was the same as I was taking minus one pill. With him on treatment at the same time, it gave me more incentive to hang in and help him get through by sharing our unique experience. We would do this together. I was kind of excited that I knew someone who was going through treatment and sharing the same experience.

Gary kept a journal each day to record his progress. The following are some lines that he wrote:

I was nervous about my first injection but my NP talked me through it very well. It was about two hours after taking the first three pills that I began to feel aches, pains, chills and feeling nauseated. After the first needle, I had my sister give me the next ones. Dry mouth and nauseated; feeling chills and no energy seemed to take its toll. I had no strength and felt tired all the time. With this pain in my head and a sick stomach, I had to force myself to eat. After twenty days of that, I had my two pills in the morning and before the next pills were due, I felt I had enough. No more treatment for me.

While Alton talked with Gary by phone every night, I remember lying on the sofa listening to Gary's jumbled up words. I could tell he was not doing well. Each day seemed to be worse for Gary. The first few nights were not so bad, but during the second week Gary's wife Marilyn answered the phone to say he was not doing well at all.

It was no surprise that Gary gave up on his treatment. He did the right thing for himself and his family was glad that he did. It took almost three weeks for Gary to start feeling normal again. The same amount of time that he was taking the treatment.

After Gary's recovery, he has had two operations for cancer on his lungs. Gary says this was most likely the reason why he was so tired in the first place. Because of these operations and his age, Gary would not consider treatment for hepatitis C again. However, he is thankful that he has gained knowledge about hepatitis C and can now protect his family and others from contracting the virus from him.

Editor's note: You may contact Bette in confidence at TalkingToBette@gmail.com.

Being C'een and Heard

(cont'd from page 1)

We are looking for more participants for upcoming workshops. A small honorarium will be paid to offset time and travel costs. There will be one workshop held in each county. If individuals are not comfortable in a group setting we are making one-on-one interviews available.

If issues around the perceptions of the general public are to change we have to work together to communicate needs and support to one another as a community. Only you can help to change the perception. Let us help get the information where it needs to be and take one step at a time to change public perception. Together. **Be Heard.**

So how do you contact us? Call Janet, Assistant Program Coordinator or Karen, Executive Director, Northern AIDS Connection Society at 1-866-940-2437 or 902-895-0931 or email hepccordinator@eastlink.ca.



"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has." – Margaret Mead

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

We're on the Web!

Visit us at:

HepatitisOutreach.com

Board of Directors

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Staff

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China Ends Compulsory Hepatitis B Testing

According to a recent report in the *New York Times*, China will end compulsory testing for hepatitis B as a part of the physical examination given to government employees, factory workers, and students applying for college admission. It is estimated that 120 million people in China may be infected, many through contaminated needles during the widespread childhood inoculation campaigns of the 1970s and '80s. Others contracted the disease from their mothers during childbirth. The Health Ministry's new rules mean that infected individuals will no longer be barred from medical school, teaching positions, or jobs in food production.

In announcing the change in policy, officials suggested that they were yielding to pressure from activists who had begun organizing on the internet. In Beijing, Lu Jun, who runs an organization that has been pressuring the government to change its testing policies, proclaimed the new rules both a victory for hepatitis B carriers and for all those attempting to change Chinese society through public advocacy and legal action.

A spokesperson for the Health Ministry commented that the "current social misunderstanding about hepatitis B patients is mainly a result of a lack of understanding. The experts believe that cancelling blood testing for the purpose of employment and students entering schools will not affect the health of others, nor will it cause the disease to spread."

Going Green – Paper vs Email

Community Connections would like to be as green as possible. Not only can we save trees, but we can save 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.

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.

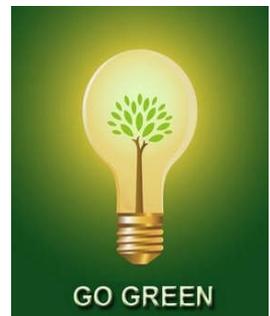
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About The Society

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!