

### RESEARCH STATS: HCV IN YOUTH

According to the Public Health Agency of Canada, the prevalence of hepatitis C virus (HCV) in the total youth aged 15 to 24 population is low at 0.02%.

However, among street youth the rate is 4.5% and among street youth who use injection drugs, 34.7% tested positive for HCV.

The percentage of youth using injection drugs who were HIV positive was 5.1%, and of these, 81.8% also tested positive for HCV antibodies.

For more see:

**Epi-Update HCV in youth aged 15 to 24 years**  
<http://www.phac-aspc.gc.ca/sti-its-surv-epi/hepcyouth-jeunes-eng.php>

### Dr Baruch Blumberg July 28, 1925 – April 5, 2011

Dr Baruch S. Blumberg, who shared the 1976 Nobel Prize in physiology or medicine for his discovery of the hepatitis B virus, died at age 85.

Blumberg shared the 1976 Nobel Prize with D. Carleton Gajdusek for their "discoveries concerning new mechanisms for the origin and dissemination of infectious diseases". Gajdusek, who died in 2008, shared the prize for his work on so-called slow viruses, infectious agents, including one implicated in mad-cow disease.

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### WORLD HEPATITIS ALLIANCE: WORLD HEPATITIS DAY

As stated in the resolution, and as agreed by all 193 World Health Organization Member States, World Hepatitis Day will be celebrated on the 28<sup>th</sup> of July this year (in honor of Nobel Laureate Prof. Blumberg, discoverer of the hepatitis B virus, who celebrated his birthday on that date).

Although the Alliance was very keen to keep May 19<sup>th</sup> as the date since we have all worked so hard over the last three years to establish it, many of the Member States argued that it was not very convenient because it always falls during the World Health Assembly when many Ministers of Health are therefore in Geneva. They wanted it changed so they could be in their own countries to attend events, hold press conferences or support the day in other ways.

"This is hepatitis..." was chosen as the theme for this year's World Hepatitis Day. This theme is a development of our 'Am I number 12?' concept, in recognition of the fact that we need to move beyond simply the size of the issue and the fact that one in 12 people worldwide is living with either chronic hepatitis B or C. The Alliance began this process last year with the introduction of 'This is hepatitis ...' which allows us to focus on the many different aspects of these diseases and their human impact.



All of those 193 Member States which agreed on July 28<sup>th</sup> are expected to be involved in the Day and we believe that this is an excellent opportunity for the community to approach them and work with them in order to coordinate actions which will ultimately bring improvements in prevention, diagnosis, treatment and awareness of viral hepatitis.

### COMMUNITY PLACEMENT: NURSING STUDENTS AT HepNS

In the fall of 2010, we began work with HepNS, as part of our fourth year community-nursing course in the Dalhousie nursing program. Our mission was to learn and understand the experiences of individuals who have Hepatitis, primarily Hepatitis C. The plan was to utilize this information in developing a presentation for health care providers, about living with Hepatitis. Engaging in a variety of experiences in the community allowed us to accomplish our mission and enact our plan.

One of the most significant experiences was an interview with a member of the Hepatitis community living in rural Nova Scotia. She discussed her personal challenges and stigma faced, from diagnosis through treatment. This first hand information shed light on a major issue regarding the lack of support in the community, due in part to insufficient information and education. These negative experiences have encouraged her volunteer work in helping and supporting those at risk for and living with Hepatitis.

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## FIRST PERSON: FINDING COMFORT WITH SOFI

During treatment it's a great feeling to have someone to count on for support. Not just the kind of support that you get from people who say "hey how ya doing?" or "you're looking good." I mean the kind of support that goes much deeper, the kind that sees you everyday, when you're at your worst and knows how bad you're really feeling. The support that lives the treatment with you and truly knows what you're going through. Although my husband Alton was a great help throughout treatment, my dog Sophie was my rock.

It was early in August of 96 when we brought Sophie home in the midst of building our house and doing the work ourselves. I didn't want another dog and I didn't want her; I even said I didn't like her. Alton was the dog person, and so we got her anyway. I didn't like her so much that I tried to give her away to my brother Bob. He said "How could you not like her, just look at her!" Sophie was a very lovable puppy, a blonde cocker spaniel with black eyes, droopy and sad looking. She had soft curly hair, long floppy ears and girly eyelashes. It wasn't long till she became my little girl, my baby.

My treatment for Hepatitis-C began in January 2006. In the first month I was able to attend a scrap-book class although I wasn't full of energy as usual. I was so glad when Alton came to bring me home after being there for just an hour. I felt exhausted and had little concentration and no interest of being there. When I got home Sophie was waiting for me at the door. I knelt down hugging her and said "Oh Sophie, it's so good to be home where you can act like you feel." She followed me to the room where I relaxed in my blue rocking chair. Wherever I went, she followed. I could tell that she knew I wasn't well and she always stayed by my side. I spent many hours in that old rocking chair with my homemade quilt wrapped around me. Sophie pawed at the leftover quilt around my feet until she got enough to lie on. She stayed close to me giving me her warmth and her loving dog kisses whenever she could. She gently nudged me when she needed to go out, if I didn't get up then, she'd patiently wait a while longer and nudge again. When I was lying down, she would lay with me, comfortable and quiet.



At week seven, middle of February, just before bed Sophie was out for a quick run. Although we taught her not to talk to strangers, she found her first skunk that night. Alton brought her in to see if I could smell skunk. He could not tell since the air outside was so strong. That awful odour was on her alright and wafted all through the house, the smell was so strong we could hardly breathe. We phoned our daughter Anne, Sophie's favourite groomer to ask what to do. Anne said "As soon as possible, get her bathed in a solution of 1 cup of blue liquid dish soap, 1cup of peroxide, then fill the bucket with water, don't let her get cold." After finding the ingredients, Alton took Sophie outside for the bath. I stayed inside and got towels ready, warm water and vinegar in the tub for the rinse. After being on our way to bed and already exhausted, I was amazed of where the extra energy comes from. It had been fairly mild that night but the wind was howling fierce and the temperature dropping quickly to -20. Sophie was made comfortable in the bathroom for the night.

At 2:00 am all the windows were wide open with the breeze screaming through. I was tucked in bed with a heap of blankets to keep warm. My tension was so high I felt stiff like a board teeth clenched and fists tight. In the morning the skunk smell had diminished considerably, only a slight smell lingered. Sophie was well rested and ready for play; she'd bring her squeaker toys and toss them into the air. My energy was still exhausted and I didn't regain it for a few days. There were many hurtles such as this one and we made it through them all.

Even after my treatment was over, and I had been feeling better Sophie continued to stay close to me, she was not well herself. Then came the day that she didn't eat or drink, she was very sick. The veterinary said it could be dementia and they could try a number of things, too many for an old dog of eleven years. Although we knew it was coming for some time it was then we had to make that painful decision to let her go. Wrapped in her quilt, I held her all the way home; I couldn't help from crying and wishing she was back. My heart was heavy, the tears didn't stop that day and I'll never forget her. Sophie was the love in our life, our little girl dog, our best friend with an undying love.

Dogs bring so much comfort to someone who is ill and Sophie was no exception. I never felt alone when she was beside me. She gave love unconditional with warmth, comfort and so much to smile about.

**Bette**

See what's new at HepNS by checking out our [Facebook](#) link



on our website [www.HepatitisOutreach.com](http://www.HepatitisOutreach.com)

## ASK AN EXPERT: TREATMENT—DO WE SEE A PROMISED LAND?

Since the first discoveries in the treatment of chronic hepatitis C (CHC), individuals living with the infection have looked to the horizon, seeking better, easier treatment for their disease. The year 2010 was pivotal for the treatment of hepatitis C. From new treatment options to a better understanding of patient factors that impact therapy, 2010 has exhilarated physicians and nurses specialized in hepatitis C and offered new hope to the people living with the disease.

At the American Association for the Study of Liver Disease conference in Boston last fall, it was standing room only as results of large clinical trials on new therapies were revealed. These long-anticipated new treatments seem to deliver on their promise of greater efficacy and shorter treatment courses.

For decades now, the main treatment for CHC has been weekly injections of pegylated interferon (PEG) with daily ribavirin (RBV) oral therapy for 48 weeks in infections with genotype 1 HCV. With conventional therapy, 50% of patients respond to treatment. The new therapy combines PEG/RBV with a third oral medication taken for the first 8 to 12 weeks of treatment. These add-on medications are called Proteinase Inhibitors (PIs) and work by blocking a key enzyme the hepatitis C virus uses to reproduce.

When used alone without PEG/RBV, PIs are able to briskly bring down the quantity of virus circulating in the bloodstream, and patients can achieve undetectable levels of virus in days. However, the virus quickly becomes resistant to the medication and its effect is short-lived. PIs alone cannot cure HCV. New studies reported in Boston last year found that combining PIs to PEG/RBV neutralizes the problem of resistance and the number of patients reaching a sustained virological response (SVR) – or long term cure— is higher, nearing 65-75% of patients with genotype 1. Beyond the improved response to treatment, PIs allowed 45-60% of individuals to have their treatment shortened from 48 weeks down to 24-28 weeks without sacrificing efficacy.

The true benefit of PIs, however, is what they can do for patients who previously tried treatment but did not respond to treatment at all or relapsed less than 6 months after the end of therapy. This population grows with each passing year with at least 40% of patients who try therapy falling into this category. With ongoing HCV infection, these individuals are still at risk of developing cirrhosis, and having it progress to liver failure or liver cancer. Progression to cirrhosis is halted in CHC patients once the infection is cured and their risk of developing liver cancer diminished.

Currently, the only option for people who do not have a lasting response to treatment is retreatment with the same medication which offers only a 20% chance of cure the second time around. Trials looking at these specific patients show that adding a PI to PEG/RBV retreatment increases the percentage of patients cured of CHC from 20% to 66%. These numbers are nothing short of astonishing.

The role of PIs in the treatment of HCV is likely to be in the treatment of individuals infected with genotype 1 hepatitis C who do not respond to treatment or those who, for various reasons, are unlikely to respond to standard therapy. This is because of the very substantial cost of PIs and the added side-effects they may cause in some. These medications are likely to be on the Canadian market as early as 2012 and promise to change the landscape of CHC treatment forever.

If what we hoped for was quick, easily-tolerated, 100 percent effective treatment for hepatitis C, then the advent of PIs is not the long sought-after answer. If, however, curing HCV is the goal, then we do indeed see the Promised Land and PIs will allow many more to reach it.

**Submitted by – Dr Marie Laryea**

Dr Laryea is a HepNS Board Member, attending physician in Hepatology and Assistant Professor of Medicine at Dalhousie University

*If you have questions that you would like answered, please submit them to [Newsletter@HepatitisOutreach.com](mailto:Newsletter@HepatitisOutreach.com)*

**Thank You! Thank You! Thank You!**

The HepNS Lucky Duck campaign raised just over \$1000. Thank you ticket seller volunteers and Recreation Nova Scotia for allowing us to participate in this annual event.



## ABOUT US

HepNS is a charitable organization that reduces the impact of hepatitis through support, information and education.

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Community Connections is a quarterly informative publication of the Hepatitis Outreach Society of Nova Scotia. We welcome your comments and contributions.

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## NURSING STUDENTS CONT'D

A visit to the Hepatology clinic at the Victoria General Hospital in Halifax, allowed us to gather vital information about maintenance of health and living with Hepatitis. This was our first interaction with the Hepatitis community at large, and helped us visualize and understand the diversity in the Hepatitis population. People from all walks of life have to deal with the struggles and stigma associated with the virus.

At Highland Park Junior High, Halifax, we focused on educating a high risk group for contracting Hepatitis. We gave a presentation, previously developed by nursing students working with HepNS, on safer tattooing and piercing. The students (ages 12-14) showed a high level of interest, sharing their desires for and experiences with tattoos and piercing, while displaying a general knowledge of needle safety. Many were aware of Hepatitis C and the risk of contracting it through needles but there was a low understanding of the lifelong affects of the virus.



The director at Mainline Needle Exchange, Halifax, provided insight on the high rate of Hepatitis C in the drug use population, averaging at about 85%. This high rate of illness, coupled with the diversity of the drug use population, presented the difficulty in educating and supporting individuals who engage in drug use.

The nurses from Public Health, in the department of Communicable Disease Prevention and Control explained their role in the Hepatitis community. Hepatitis reports are only a small part of the influx of communicable diseases that come through their office, which provides insufficient time for these nurses to provide education and information for those who are inflicted with Hepatitis. Another concern is reporting and following up with individuals who test positive but have no fixed address.

A rewarding experience was the opportunity to visit Springhill Institution and participate in the annual health fair for the inmates. We recognized a high level of interest in both HepNS and Hepatitis. It became evident that there was a lack of readily available education and support for inmates at risk of contracting the virus and those diagnosed and enduring treatment.

Each of these experiences and opportunities provided us with a variety of information to develop a presentation aimed at educating health care providers in providing high quality care to individuals living with Hepatitis. Our hope is that through similar work, health care providers can establish a role in recognizing and supporting the unique needs of the diverse Hepatitis population.

*Katie & Kaitlyn*

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