

Hepatitis C Compassion Umbrella



Groups come together to seek help for excluded victims.

by Jo Dunaway

Thousands of people across Canada were infected with Hepatitis C through transfusions of tainted blood supplied by the Canadian Red Cross. One group of these victims has been deliberately excluded from receiving assistance from the federal government's compensation program.

This program established in 1998 by the federal and provincial governments, put aside \$1.2 billion for Canadians who had been infected with Hepatitis C through blood transfusions—but only if the victims received the tainted blood between January 1, 1986 and July 1, 1990. Anyone who received tainted blood transfusions before January 1, 1986 or after July 1, 1990 would not have access to the fund. The federal government's rationale for what is known as the "86/90" group was that, during this period, screening tests to detect the Hepatitis C virus (HCV) were available but not used in Canada. It therefore became the federal government's view that it was not responsible for compensating anyone who was infected with Hepatitis C through a blood transfusion received before January 1, 1986 or after July 1, 1990 (the pre-86/post-90 group).

Lack of compassion for pre-86/post-90 victims

The 1998 compensation program ignored the recommendation of Justice Horace Krever's report, issued after a four-year public inquiry into Canada's blood system: "Compensating some needy sufferers and not others cannot, in my opinion, be justified."

But that is exactly what the government did. No other victims of Canada's tainted blood supply are subjected to an arbitrary inclusion period. For example, people who contracted the AIDS virus from transfusions are compensated by the federal government regardless of when they were infected.

The Canadian Red Cross filed for bankruptcy protection in 1998 and, after two years of negotiations, Hepatitis C victims in the 86/90 group received a partial settlement of class action law suits. A \$63 million trust fund was set up. Four provinces also established small compensation programs for pre-86/post-90 Hepatitis C victims.

In September 1998, then Health Minister Alan Rock committed \$300 million to a *Care not Cash* program. These funds were to be transferred to the provinces and distributed to ensure that pre-86/post-90 victims did not have to pay out-of-pocket expenses for treatment. To date, there is almost no evidence of distribution of this money to Hepatitis C victims.

However, there *is* ample evidence of Hepatitis C victims who are unable to afford needed medication or care for themselves and their families. Those infected before 1986 have had the disease the longest and are among the sickest. As their health continues to worsen, many have been forced to declare bankruptcy and have lost their jobs and their homes.

HCCUC advocates for excluded victims

This was the situation when the Hepatitis C Compassion Umbrella of Canada (HCCUC) was formed in 2004.

Hepatitis C victims in the pre-86/post-90 group had been asking for assistance from their government for seven long years. Their only recourse has been to pursue claims in the courts. HCCUC is working on this endeavour with the law firm Klein Lyons in BC, and others in Ontario and Quebec who have undertaken class actions on behalf of pre-86/post-90 Hepatitis C victims.

HCCUC is a coalition of groups, including BCCPD, that work on issues important to people with disabilities. As of the beginning of May 2005, more than 345 community groups had endorsed the HCCUC recommendation that the pre-86/post-90 excluded group be given immediate access to the existing federal government 86/90 fund.

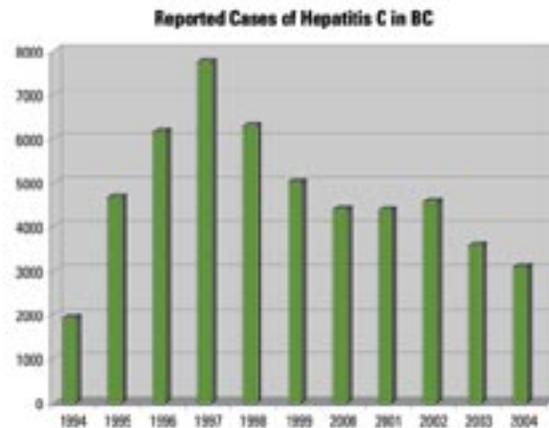
HCCUC writes letters on a regular basis to all MPs, including the Minister of Health and the Prime Minister, and includes updated lists of the community groups that have endorsed the recommendation. HCCUC representatives have also met with individual MPs and the Minister of Health. It also distributed a brief entitled *Compassion for all Hepatitis C victims* and conducted a financial analysis showing that there is more than enough money in the 86/90 fund to include all Hepatitis C victims who received tainted blood, including those in the pre-86/post-90 excluded group.

Hundreds and hundreds of ill and discouraged pre-86/post-90 Hepatitis C victims and their families have written letters to their Member of Parliament describing how they contracted the

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Hepatitis C Statistics

An estimated 5,000 Canadians are infected with Hepatitis C each year. 300,000 in Canada are believed to be infected. "This means that up to one in every one hundred people in Canada have Hepatitis C. Most of these people have not been tested and do not know they have the disease." <http://www.bccdc.org/topic.php?item=60>



"...the BC rate has remained twice that of Canada, due to a high prevalence of injecting drug use. The rate of Hepatitis C diagnosed in BC males exceeds females in all age groups except in the 10-14 and 15-19 age groups. The Hepatitis C rate was above 100 per 100,000 in all three Health Service Delivery Areas of Vancouver Island, Vancouver and Fraser East." (p. 44)

From: p. 44

BC Centre for Disease Control
2003 British Columbia Annual Summary of Reportable Diseases
http://www.bccdc.org/downloads/pdf/epid/reports/2003_BCAnnualSummary_ReportableDiseases.pdf

2004 statistic from:

Cumulative Health Service Delivery Areas Reports
December 2004 showing total Hepatitis C cases reported for 2003 and 2004 <http://www.bccdc.org/download.php?item=1867>

More recently, on April 20, 2005, MPs voted unanimous support for a motion brought by the Conservative Party of Canada to extend compensation to the excluded Hepatitis C victims.

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Hepatitis C virus through blood transfusions during a medical procedure and what it is like to live with the illness: how they have lost their health, their jobs, and in many cases their marriages and their homes.

Progress...but victims still waiting

It's undeniable there has been progress: MPs from all parties have spoken out in support of the pre-86/post-90 excluded victims and in November 2004 Minister of Health Ujjal Dosanjh directed lawyers for the Department of Justice to immediately begin negotiations on all options regarding the pre-86/post-90 group, including the "potential actuarial surplus."

More recently, on April 20, 2005, MPs voted unanimous support for a motion brought by the Conservative Party of Canada Health Critic Stephen Fletcher to extend compensation to the excluded Hepatitis C victims. Celebration of this important step forward was tempered by the knowledge that no completion date has been given by the Health Minister for the government review now underway and no date has been set for when Hepatitis C victims will begin receiving financial assistance.

Time is a crucial issue for desperately ill people. For them, justice delayed is justice denied. The Hepatitis C Compassion Umbrella of Canada is urging community groups and MPs to press Health Minister Dosanjh for firm dates for the completion of the review and commencement of financial assistance. ■

resources

Here are some resources for more information about Hepatitis C.

Hepatitis Information Network–Hepatitis C, The Hepatitis Knowledge Newsletter
<http://www.hepnet.com/hepc.html>

Public Health Agency of Canada Hepatitis C http://www.phac-aspc.gc.ca/hepc/hepatitis_c/drhepc.html
Hepatitis C Resource Library
http://www.phac-aspc.gc.ca/hepc/hepatitis_c/library.html

Hepatitis C Society of Canada
<http://www.hepatitiscsociety.com/english/HepCHome.htm>

BC Centre for Disease Control Hepatitis C <http://www.bccdc.org/topic.php?item=60>

Canadian Hepatitis Information Network, Hepatitis C InfoCentre
<http://www.hepnet.com/hepc.html>

Canadian Liver Foundation Hepatitis C http://www.liver.ca/english/liverdisease/hepatitis_c.html

HepC BC
<http://www.hepcbc.ca/>

Multicultural Hepatitis C Prevention Project Tel: 604-709-6538
E-mail: bcmhss@yahoo.ca