



Tainted Blood Product Action Group

Committee Secretary
Standing Committee on Health
PO Box 6021 Parliament House
Canberra ACT 2600 health.reps@aph.gov.au

Inquiry into Hepatitis C in Australia

Term of Reference D: Methods to improve prevention of new Hepatitis C infections, and methods to reduce the stigma associated with a positive diagnosis through:

Dear Committee Secretary,

The stigma experienced by those who acquired Hepatitis C from blood transfusion was well documented by the Senate Community Affairs References Committee's inquiry into 'Hepatitis C and the blood supply in Australia' in 2004. It made life saving recommendations that were designed to reduce the burden of stigmatization. Crucial among them were:

That a national post-transfusion hepatitis C committee be established as a priority with the purpose of:

- *formulating, coordinating and delivering an apology to those who have acquired hepatitis C through the blood supply;*
- *establishing an effective Lookback program; and*
- *improving service delivery through a case management approach that ensures that appropriate medical, counselling and welfare services are provided, sensitive to the needs of people who have acquired hepatitis C through blood and blood products. That membership of the committee include representatives of the Commonwealth, State and Territory Governments, the Australian Red Cross Blood Service, representatives of organisations which support people with hepatitis C acquired through the blood supply and individuals who have acquired hepatitis C through the blood supply. That the committee establish and manage a fund to provide financial assistance for costs not covered through existing services, which could include the costs of visits and transport to general practitioners, prescribed medication and surgical aids, dental, aural, optical, physiotherapy and chiropody treatments, home care and/or home help, and alternative medical treatments, to the people who have acquired hepatitis C through blood and blood products.*

That the committee, and the fund it establishes, be jointly funded by the Commonwealth and State and Territory Governments.

That the committee develop criteria for people to access the fund.

In 2004 victims of the tainted blood tragedy sacrificed their rights to privacy, and told their stories to the Senate. Victims who made submissions to the inquiry included adults, children, pregnant women, haemophiliacs, the sick, the anaemic, accident victims, and those having had elective surgery. Recipients of blood contaminated by Hepatitis C were victims, who went into hospital, received contaminated transfusions, and ended up with this life-changing disease. The inquiry learned that 20,000 Australian hospital patients had fallen victim to Hepatitis C contaminated blood. Alarming, the inquiry also learned that 9000 of them had still not been contacted by authorities and notified of their infections.

The majority of victims told the Senate of a changed life, in which they experienced debilitating symptoms, suffering under stigma, loss of employment, financial hardship, marriage break ups, discrimination, liver failure, and a life of uncertainty. Consequently the inquiry learned that while this was a medical disaster, it was in essence, first and foremost, a human tragedy that destroyed the lives of many men, women and children.

How can the Standing Committee on Health's inquiry help to reduce the burden of stigma on victims of Hepatitis C tainted blood?

By acknowledging and implementing the measures for reducing stigma recommended by the Senate Community References Committee of 2004. It's been over a decade since the inquiry made its determinations with people very literally having died waiting on the Senate's promise of help. Parliament must act to reduce the stigma associated with Hepatitis C and save lives now.

Further stigmatized by the hypocrisy of Hepatitis C groups.

Medical patients contaminated with Hepatitis C suffer due to them being forced into a kind of 'no mans land'. They were not infected by any means other than having been hospital patients. Their psychological trauma made worse by not having access to any kind of proper and truly independent representation. Take the problem of the taxpayer funded Hepatitis NSW (formerly Hepatitis C Council NSW) for example. Their mission statement reads:

'We work in the best interests of people affected by viral hepatitis'

However, their submission to the Senate inquiry into hepatitis C and the Australian blood supply stated:

*"We do not support the view that a particular group of people with hepatitis C should receive ex-gratia payments. If this were to happen, we ask the question what message this would send to ... people who acquired HCV through blood-to-blood contact through sharing injecting equipment when they are not provided fully with the means or the education to protect themselves and others, and when the social and legal context in which HCV infections occur actually encourage infection ...
"Yours sincerely, Stuart Loveday, Executive Officer."*

This view disenfranchised thousands that the Hepatitis NSW purports to represent. And was especially insensitive to the plight of Haemophiliacs, as it was well established that individual legal cases were next to impossible due to the nature of

how their medicines were produced, and the number of blood donors involved.

How did Hepatitis NSW come to the decision to act against the interests of the medically acquired subset of Hepatitis C tragedy?

The various Hepatitis C bodies knew full well what victims wanted. They simply wanted what tainted blood victims in overseas countries had received, specifically that they be spared the torment of court cases and be afforded ex-gratia payments. And yet the Hepatitis C NSW lobbied directly against their needs. **And contributed to their further stigma and alienation.**

In addition to the above, after initially welcoming the Senate's recommendations Hepatitis Australia and its state based counterparts, failed to lobby for the government to implement these much needed recommendations.

The evidence is even clearer now than it was when the Senate Community Affairs References Committee made its recommendations. That a government funded body that specifically works in the interests of victims of one of Australia's worst medical tragedies be established as a matter of priority.

I note below examples of overseas initiatives which would be welcomed in Australia as part of the solution of reducing stigmatism.

Yours sincerely

Charles MacKenzie

Tainted Blood Product Action Group

Email: taintedbloodaction@gmail.com

POSITIVE ACTION

THE SUPPORT GROUP FOR WOMEN INFECTED WITH HEPATITIS C THROUGH
CONTAMINATED ANTI-D IMMUNOGLOBULIN

29th October 2003

Charles MacKenzie The Tainted Blood Product Action Group Australia

Dear Charles,

I write on behalf of Positive Action the Irish support group for women who were “State Infected” with Hepatitis C. We have 750 members who were infected from 1970 onwards. The majority of them were infected in 1977 –79.

As our members are all women who have Rh Negative blood any of those who were blood donors were repeatedly called to donate blood. Therefore from 1970 – 1994 our members were innocently donating infected blood which in turn contaminated others.

As a result of our campaign our members and also members of 3 other support groups who backed our campaign - Transfusion Positive; The Irish Haemophilia Society & The Irish Kidney Association who were subsequently infected as a result of our members have a Statutory Compensation Package which includes:

A Compensation Tribunal where each claim is heard and accessed individually. A Health Care Package which covers : GP visits; All prescribed medication & Surgical Aids. Dental, Aural, Optical, Physiotherapy, & Chiropody treatments.

Counselling services. Alternative treatments ie - Reflexology & Aromatherapy / Massage. Home Nursing service and Home Help (house work) Service.

An Expert Group was set up in 1994 to investigate & report on the contamination of Anti-D with Hepatitis C. A Tribunal of Inquiry sat in 1996 and reported in 1997 A second Tribunal of Inquiry relating to the Haemophiliacs also sat and reported in 2002.

In 2003 A Medical Doctor who was the Chief Medical Consultant, in the Irish Blood Transfusion Service and a Scientist who was a Bio Chemist in the Irish Blood Transfusion Service were arrested and criminally charged with causing Grievous Bodily Harm to named persons by administering to them infected Anti-D. They will re-appear on Friday 31st October in the Circuit Criminal Court to set a Trial Date.

We believe than any victims of contaminated blood products deserve support, compensation and a Health Care system to meet their needs. It is our belief that those persons who have been State Infected are in a different category to those who have acquired Hepatitis C from IV drug use and the sharing of needles. State Infected persons have Hepatitis C through no fault of their own whilst the other group have a self inflicted illness.

Detta Warnock

FROM : PHONE NO. : DATE: 11 2002 05:45PM PZ

	HEPATITIS C RESOURCE CENTRE Liston House, 54 Patricia Square, P O Box 50 843, AUCKLAND. Freephone: 0800 22hpc (0800 224 372), Phone/Fax: (09) 377 8500. E-mail: administration@hpc.org.nz, Web Page: www.hpc.org.nz
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11 June 2002

Charles McKenzie
Tainted Blood Product Action Group
Facsimile Number: 061 2 9552 6293
AUSTRALIA

Dear Charles

We were delighted to hear that the *Tainted Blood Product Action Group* was in the process of formalising its status as a charitable organisation, possibly under the umbrella of the Exodus Foundation, which has done so much good work on behalf of marginalised groups in Australia.

We support the avowed intention of your group to work and advocate on behalf of the whole community of hepatitis C affected people. We also support your short-term priority of seeking justice and support from government for the significant minority unwittingly infected through unscreened blood and blood products, within the public health system.

Go well.

Yours sincerely

Robyn Brown
COORDINATOR/SECRETARY

Quality information, support & advocacy for those infected with and affected by hepatitis C.



Hepatitis C Society of Canada (HeCSC)
Société de l'Hépatite C du Canada (SHéCC)

February 15th 2002

To the Editor:

The Hepatitis C Society of Canada offers its support to all Australians who have suffered or who have lost loved ones because of tainted blood and blood products. In the last decade Canadians have listened to discussions about our nation's blood supply, its problems and its future. Under the leadership of Justice Horace Krever, we had an extensive public inquiry about our blood system including court hearings (at which the Hepatitis C Society of Canada obtained the right to cross-examine). The final result was the Krever Report to which we were invited to contribute, and into which many of our recommendations were incorporated. We have been represented in Court by legal counsel and the final award made by the federal government was \$1.2 billion. Regrettably, for legal purposes, a temporal window was identified so that only those affected from 1986-1990 are eligible for compensation from this package. However, due to political pressure which we have continued to apply, the provinces of Ontario, Québec and Manitoba are now compensating victims infected outside this window.

In addition to this, through our advocacy the Canadian Red Cross has offered compensation of \$75,000,000 to the "forgotten" victims as a condition of their negotiations to avoid bankruptcy and to withdraw as operators of the blood delivery system.

Canada's blood system, as supervised by the Canadian Red Cross, neglected to use all of the protocols available in the 1980s for testing for the presence of Hepatitis C (then known as non-A, non-B hepatitis), even though American and European centres had alerted them to such tests. We understand Australia's blood banks have also chosen to disregard the use of readily available tests. As a result, like Canada, Australia has lost many lives and has witnessed many lives ruined because of loss of earning capacity and serious damage to family structures. However, unlike Canada, Australia has not established a compensation relief package. A relief package offers much needed support to all those individuals who *through absolutely no fault of their own* have become infected or affected by tainted blood.

We sincerely hope that surviving victims of Hepatitis C tainted blood and blood products in Australia can be compensated in a similar way to Canadians.

National Office: 3950 Confederation Parkway, Suite 301-B, Mississauga, ON L5B 3Z8
Ph. (905) 276-1110 Fax. (905) 270-1277 www.hepatitisociety.com 1-800-652-4373 (HCP)

