Witness Name: Charles MacKenzie
Statement No: WIT3939001
Exhibits: WITN3939002- WITN3939060
Dated: 15 May 2020

INFECTED BLOOD INQUIRY

EXHIBIT WITN3939052

P1040

11th February 2020

Timeline of government funded Hepatitis C groups discriminating against infected blood victims: Before and during the senate inquiry into hepatitis C and blood supply in Australia 2004.

Compiled by

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1. Timeline of government funded hepatitis C groups lobbying against infected blood victims

(A)

12 June 2002 meeting of tainted blood victims at the Ashfield Uniting Church Sydney (video available)

Stuart Loveday came from the United Kingdom to found the government funded national hepatitis body, Australian Hepatitis Council (now known as Hepatitis Australia) in 1994 and subsequently became executive officer of the Hepatitis C Council NSW (now known as Hepatitis NSW).

Loveday attended a meeting of tainted blood victims held in June of 2002, whereby he refused to support calls for special assistance for them.

In view of the government funded hepatitis groups refusing to advocate for financial assistance for contaminated blood victims, the host of the meeting, the Reverend Bill Crews, asked Mr Loveday if he and his organisation would have any issue with victims continuing with a group of their own so that they could lobby for themselves. Stuart Loveday responded by saying:

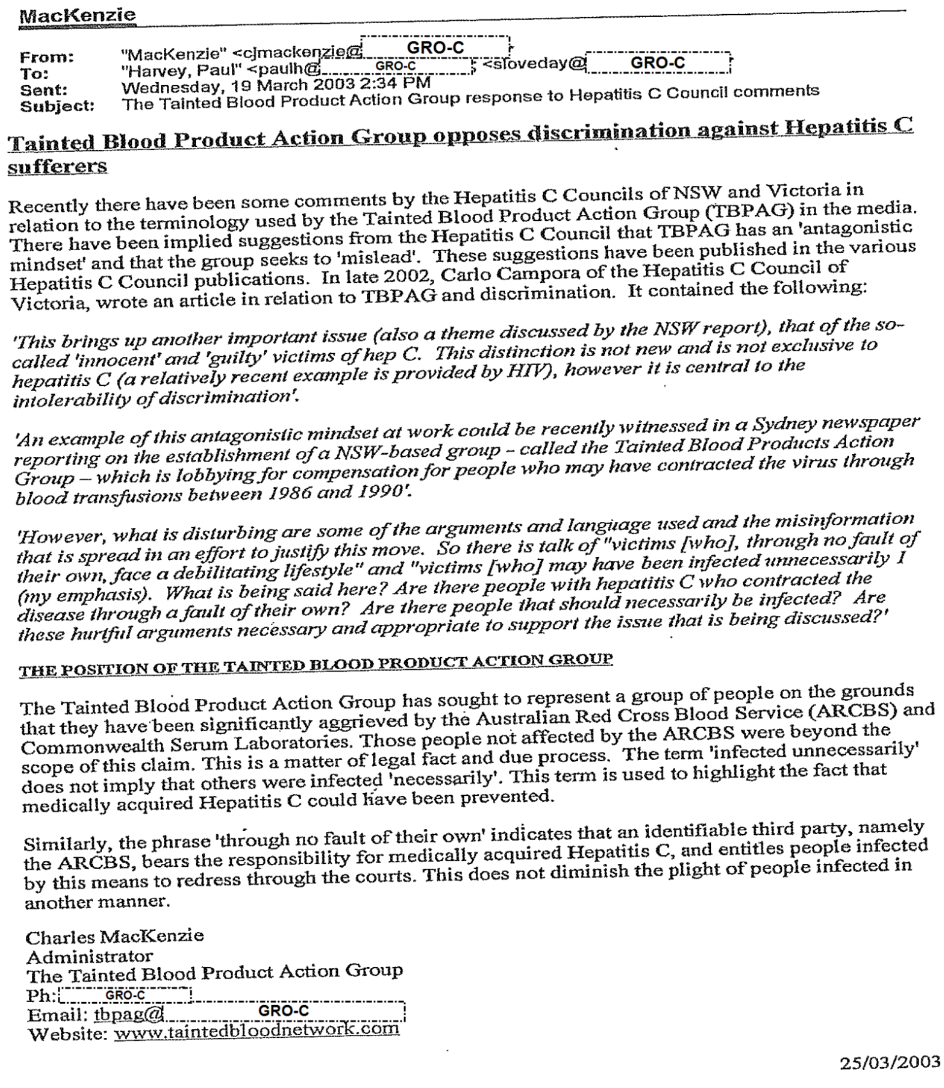
"We fully respect the right of this group to do that, but because of the negligent nature or the alleged negligent nature, which may or may not be the case, it probably is the case, I don't know, because it's such a complex issue, we see it as something that we can't judge on, we would support the individuals within it, we would support groups within it, as we have done already, but we would see it as being a legal issue."

A four-minute video of Stuart Loveday's response at the meeting can be seen here:

https://www.youtube.com/watch?v=DZblu5Rh7zg&feature=youtu.be

(B) 19 MARCH 2003:

Email from Tainted Blood Action Group to Stuart Loveday of Hepatitis C Council NSW stating our opposition to discrimination against hepatitis C sufferers



MacKenzie

From: "MacKenzie" <cjmackenzie@GRO-C>
To: "Harvey, Paul" <paulh@GRO-C> <sloveday@GRO-C>
Sent: Wednesday, 19 March 2003 2:34 PM
Subject: The Tainted Blood Product Action Group response to Hepatitis C Council comments

Tainted Blood Product Action Group opposes discrimination against Hepatitis C sufferers

Recently there have been some comments by the Hepatitis C Councils of NSW and Victoria in relation to the terminology used by the Tainted Blood Product Action Group (TBPAG) in the media. There have been implied suggestions from the Hepatitis C Council that TBPAG has an 'antagonistic mindset' and that the group seeks to 'mislead'. These suggestions have been published in the various Hepatitis C Council publications. In late 2002, Carlo Campora of the Hepatitis C Council of Victoria, wrote an article in relation to TBPAG and discrimination. It contained the following:

'This brings up another important issue (also a theme discussed by the NSW report), that of the so-called 'innocent' and 'guilty' victims of hep C. This distinction is not new and is not exclusive to hepatitis C (a relatively recent example is provided by HIV), however it is central to the intolerability of discrimination'.

'An example of this antagonistic mindset at work could be recently witnessed in a Sydney newspaper reporting on the establishment of a NSW-based group – called the Tainted Blood Products Action Group – which is lobbying for compensation for people who may have contracted the virus through blood transfusions between 1986 and 1990'.

'However, what is disturbing are some of the arguments and language used and the misinformation that is spread in an effort to justify this move. So there is talk of "victims [who], through no fault of their own, face a debilitating lifestyle" and "victims [who] may have been infected unnecessarily I (my emphasis). What is being said here? Are there people with hepatitis C who contracted the disease through a fault of their own? Are there people that should necessarily be infected? Are these hurtful arguments necessary and appropriate to support the issue that is being discussed?'

THE POSITION OF THE TAINTED BLOOD PRODUCT ACTION GROUP

The Tainted Blood Product Action Group has sought to represent a group of people on the grounds that they have been significantly aggrieved by the Australian Red Cross Blood Service (ARCBS) and Commonwealth Serum Laboratories. Those people not affected by the ARCBS were beyond the scope of this claim. This is a matter of legal fact and due process. The term 'infected unnecessarily' does not imply that others were infected 'necessarily'. This term is used to highlight the fact that medically acquired Hepatitis C could have been prevented.

Similarly, the phrase 'through no fault of their own' indicates that an identifiable third party, namely the ARCBS, bears the responsibility for medically acquired Hepatitis C, and entitles people infected by this means to redress through the courts. This does not diminish the plight of people infected in another manner.

Charles MacKenzie
Administrator
The Tainted Blood Product Action Group
Ph: GRO-C
Email: tbpag@GRO-C
Website: www.taintedbloodnetwork.com

25/03/2003

(C) 30th January 2004

Following the ousting of the original instigator of the inquiry, Senator Steve Hutchins, as chair, of the Senate investigation, victims were appalled when the government funded hepatitis groups and Stuart Loveday were all of a sudden not only included into an inquiry they had not lobbied for, but also were given one of the more prominent roles under its replacement chair Senator Jan McLucas.

Haemophiliacs from our group were not invited to give evidence but these government funded hepatitis C organisations were, and bizaarely they opposed financial assistance for infected blood victims at an inquiry that was formerly set up by Senator Hutchins as a way to bring about ex-gratia payments like the British achieved in 2004 and possibly also for compensation.

We felt profoundly misled, because even though Stuart Loveday and his organisation, had told us they would not advocate for financial assistance for contaminated blood victims, they had stated that they respected our right to do so for ourselves. We were not governent funded, they were, and so this was without a doubt a most unhelpful act designed to sabotage victims chances at the inquiry. It also infuriated us as they were using government funds which were provided under the terms that they would represent the best interests of all people with viral hepatitis, were instead being used to lobby against haemophiliacs, who at the time were predominately infected with hepatitis C.

Stuart Loveday and the Hepatitis C Council of NSW made their first written submission to the Australian Senate inquiry into hepatitis C and the blood supply in Australia on the 30th January 2004

In their submission they state: *'we have not specifically addressed the terms of reference, as we do not have the expertise or capacity to do so.'*

However, they did make the additional points in the submission:

'Much has been said in the popular media about Australia's failure to introduce surrogate testing (via liver function tests - LFTs) in order to screen out those donors who potentially had non-A, non-B hepatitis (NANB, later called hepatitis C when the virus was formally identified in 1989.) While, of course, with hindsight, we regret this was not done, we note that not much attention has been paid to the reasons why the decision not to introduce surrogate testing was made'.

And …

'However, we understand that the decision by the ARCBS not to use those surrogate tests to screen the blood supply was taken for well considered reasons - whether one agrees with them or not - and using the best available evidence at the time'.

*'Like the Australian Hepatitis Council (***Stuart Loveday was the founder and a board member***),we believe that where compensation to be paid, negligence needs to be proven. For this to happen, it needs a legal investigation, and we are not in a position to judge that. If negligence on behalf of anyone or any organisation were proven, we would strongly support compensation payments to the aggrieved parties'.*

'But we understand the decision not to surrogate-test was taken using best available evidence at the time, and it was a calculated decision based on weighing up known and estimated risks at the time using best medical and scientific expertise available then.

With hindsight, we wish surrogate testing had been introduced. It would have prevented many infections. But we believe we should not be making judgements and payments now based on hindsight unless it is shown that negligence occurred'.

In terms of ex-gratia payments, as have happened in some countries abroad where the situation may be very different from the Australian context, we would also be very concerned about the perceived inequality if payments were made to some but not to other people with hepatitis C.

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:

- *those many people from countries overseas who acquired hepatitis C infection through blood transfusions or other medical means in their countries of origin (eg Egypt, South-East Asian countries, Europe) and who are now Australians*
- *health care and other workers who acquired HCV through needle stick injuries where the legal judgement against them has not been in their favour*
- *children who acquired HCV infection from their HCV positive mothers*
- *people who acquired HCV infection through unsterile tattooing or body piercing*
- *other people who contracted HCV through a range of means: people who acquired HCV through blood-to-blood contact through sharing injecting*

equipment when there was no knowledge that NANB / HCV could be transmitted that way

- *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.*

We question why these other people with hepatitis C also not be given some sort of recompense for their hardship and reduced quality of life now endured.

We also ask what impact any payments would have on the availability of public funding for general hepatitis C service improvement.

We believe that support, management treatment services for people with hepatitis C should be improved - but these need to apply to all people with hepatitis C - we do not support particular benefits accruing to a particular groups.

If ex-gratia payments are made to a few who can prove their infection was at a particular time via a particular means, what message does that send to the many hundreds of thousands of Australians who do not fit those particular criteria? We do not consider that to be an equitable situation.

<u>(D) 6 April 2004</u>

Senate inquiry Hepatitis C and blood supply in Australia . Committee met at 9.05am. Public evidence of Stuart Loveday and Hepatitis C Council NSW

Tuesday, 6 April 2004 Senate—References CA 3

"Our understanding is that, during the 1970s and the first half of the 1980s, there were no real means available to carry out surrogate testing of the blood supply that might have excluded as far as possible the possibility of contracting non-A, non-B hepatitis through the blood supply."

"We understand that it is the latter part of the 1980s that is of primary interest to this inquiry. It is known that, at that time, a nationally constituted committee took the decision—based on best available evidence and also best available beliefs and understandings at the time—not to introduce surrogate testing that might have excluded that donated blood which showed elevated liver function test results. We note this distinction because we feel it is important to point out what would happen if Australia were to follow the examples of the UK, Canada, Ireland and possibly other countries and pay blanket recompense on compassionate grounds to all people who acquired hepatitis C in Australia through the blood supply at whatever period. That would provide some financial benefit to a particular group of people but would perhaps not consider the plight of many other people who contracted hepatitis C through similar means—say, in their countries of origin or through other means in Australia, when they did not have the knowledge that infections were occurring or the means to prevent those infections."

Mr Loveday—"Yes, the evidence is clear. The beliefs were that non-A, non-B was possibly not a serious health condition—that it possibly would not lead in many circumstances to serious liver disease. They knew that non-A, non-B was a virus that infected the liver. I lived in the UK at the time—throughout the 1980s—and I first heard about non-A, non-B in 1981. In the sexual health clinic where I heard about this concept, the view was that it was not that serious—that it was nothing to worry about. I understand that that view continued throughout the 1980s. It was only very much later in the 1980s, just prior to the introduction of antibody testing to the blood service, that natural history studies were able to be carried out over a period of time and that the true nature of hepatitis C infection and its long-term effects were seen to be a whole lot more serious than previously thought. That is what I meant by the beliefs at the time. They were that hepatitis C perhaps was not as serious as it is now known to be."

"My understanding is that in the 1970s, when a lot of people with haemophilia would have received hepatitis C—and likewise in the 1980s—nothing could be done at that time. Our understanding is that there was no knowledge, no expertise and no possibility of excluding hepatitis C from the blood supply through surrogate testing. I think it is up to this inquiry to establish whether the process and the systems in place at the time of the decision when the knowledge became available were the right ones. If they are shown to be the wrong ones then I think a special case needs to be made, but if they were the right ones then I would strongly suggest that this inquiry look more broadly—even though the terms of reference are very specific at this stage—at the overall situation for all people affected by hepatitis C and not at a particular group."

<u>(E) 27 May 2004</u>

AUSTRALIAN RED CROSS BLOOD SUPPLY STAKEHOLDER MEETING with facilitator Sir Laurence Street former chief justice of NSW

Held in the Jubilee Room Parliament House Macquarie Street
Sydney, Thursday, 27 May 2004 at 10.00 a.m.

Page 25.

Stuart Loveday:

"I would like to note and welcome the fact that the Senate inquiry is actually happening because I think this will get to a lot of the - certainly it allows a forum for expression of need, of hurt, of anger. It also allows a very formal way forward because it is a Federal Government inquiry, one which has national implications, and we certainly welcome that".

(F) 31 May 2004

The Hepatitis C Council of NSW made an additional submission to the inquiry four days after the Australian Red Cross blood supply stakeholder meeting that was facilitated by Sir Laurence Street. This was highly unusual in that even by their own admission from the outset of their evidence they had not met the terms of reference. Something had changed between the mediation meeting of days before for Stuart Loveday to make determinations that he had stated months before in his evidence *that they did not have the expertise to do so.* **He was using parliamentary privilege to put the final nail in the argument against haemophiliacs in Australia achieving anything like financial assistance.**

1. *In verbal evidence on 6 April, Mr Charles Mackenzie, Administrator of the Tainted Blood Products Action Group (TBPAG) implied, when describing the role of the Hepatitis C Councils across Australia, that the Hepatitis C Councils are "[community] groups where people got it [hepatitis C] through sharing needles." The implication that Hepatitis C Councils are in existence solely for and on behalf of people who acquired hepatitis C through illicit drug using means is incorrect. All Hepatitis Councils in Australia, including the Hepatitis C Council of NSW, have always provided information, support, referral and advocacy services for all people with hepatitis C, whatever the route of transmission. This can be evidenced from all our published reports, media, resources, websites and other information sources that describe our work since 1991, and confirmed in our submissions to this Inquiry.*
2. *We reject the assertion made by Mr Mackenzie that the reason the Hepatitis C Council of NSW differs from the position taken by the TBPAG with regard to recompense for people with blood transfusion acquired hepatitis C is because we are funded primarily by the NSW government. The Council is a fully independent, community based, non-government organisation with a membership, at 31 May 2004, of 942 individuals and organisations, and with a Management Committee responsible for overall policy and direction, elected from that membership. Many of our members are people who acquired hepatitis C through blood transfusion or blood products receipt, and many members are people who acquired hepatitis C through other means, including injecting drug use. We are funded by the NSW Health Department to perform a range of services, but this in no way impinges on our independence as an organisation or on the views of the organisation.*

11.*It is inconceivable to suggest, in the absence of further evidence, (alluded to by the Tainted Blood Products Action Group in the hearings on 6 April but not seen by us) that there was any malicious wrongdoing at the time. We would have great concern if this were shown to be the case.*

12.*Likewise we would have great concern if allegations of cover-ups and medical record destruction alleged by the Medical Error Action Group were shown to be true. We are not aware if any further evidence supporting these allegations has been presented to the Inquiry.*

13.*In hindsight, it is simple to say that the decision taken then should have been to introduce surrogate testing. However we note that an award-winning research review by Harvey J Alter (Nature Medicine 6(10): 1082-6,2000) of surrogate screening over three decades, concluded that despite its conceptual appeal, ALT screening had never been substantiated as a routine measure to prevent post-transfusion NANB hepatitis, and its introduction was driven by concern about the emerging problems in recipients rather than evidence of its efficacy.*

16.*We note the majority view of clinicians and epidemiologists in the 1980s was that non-A non-B hepatitis was frequently asymptomatic or mild and that there had been insufficient natural history studies at that point to provide the now well-known finding that hepatitis C causes a much more serious disease state over a long period of time, with significant impairment of quality of life.*

17. *We repeat our assertion, made in our verbal evidence on 6 April, that in the case of people with haemophilia, were the current inquiry to find that people involved in the decision not to surrogate test in the 1980s were at fault, then we would support the view that that group of people should have their situation viewed differently and that financial recompense be provided.*

19.*We note the comments of Professor Geoff McCaughan, who had concerns that if financial recompense were to be paid to a particular group of people with hepatitis C who acquired hepatitis through blood transfusion, that this might endanger the overall funding available, within current limited health budgets, which would enable the health care response for the broader group of all people with hepatitis C to be improved. We share his concerns that were recompense to be paid that consideration should be given to ensuring it does not affect ongoing (or future) funding for the current overall hepatitis C response.*

21.It is our summary view that this inquiry has considered all available and relevant evidence that led to the decision not to introduce surrogate testing. On balance while we regret, in the strongest possible terms, that hepatitis C infections arose as a result of this decision, we do not believe that negligence or at fault activities occurred.

2

Responses from infected blood victims: to the government funded hepatitis groups position that offering ex-gratia payments would be unfair or discriminatory against others can be found here:

(A)

Submission to the Senate inquiry into Hepatitis C and Bloody Supply in Australia number GRO-A

TRANSCRIBED FROM HAND-WRITTEN ORIGINAL
10 – 6 - 2004

GRO-A

The Secretary
Senate Community Affairs References Committee

Dear Sir / Madam

It has been brought to my attention that offering compensation to people with medically acquired Hepatitis "C", specifically via a transfusion of blood or blood products may constitute unfair discrimination against people who have acquired the Hepatitis "C" virus by other means, i.e. substance abuse and in particular intravenous drug use and abuse by the sharing of needles.

As a former member of the management committee of the Hepatitis "C" Council of Queensland and the Co-Chairman of that committee for one year, I do not believe this to be the case. During my time on the management committee, I dealt with many people from all walks of life, who had become infected with Hepatitis C . It became very evident to me that the needs, support, counseling of those with medically acquired Hep."C" were entirely different to those who had acquired the virus by other means. Injecting drug users by and large were accepting of their fate and still continued in many cases to continue to use drugs with a somewhat couldn't care less attitude. I found this to be quite disturbing and very alarming, while those with medically acquired/transfused Hepatitis "C", were absolutely crushed when they learnt of their affliction.

Marriages, seemingly good marriages, were suddenly put under tremendous strain, mothers and fathers were so devastated they could not bring themselves to tell their children and families of their illness, some faced dismissal from their employment, some had already been dismissed, many simply could not bring themselves to cope with the knowledge of their infection and became suicidal.

With this in mind I elected in the year 2000 to start a support group here on the Gold

Coast for those who had medically acquired Hepatitis “C”. I was encouraged but not supported in this endeavor, the reason being it was made known to me was that the subject of compensation would arise and this may not be a path to pursue, also it was pointed out that the support group should be open to all – I had no intention of turning anyway away in any case.
To have the terms of the support group dictated to me was in my opinion an act of discrimination of itself. I and the group were being discriminated against before we had even started, consequently the group never came to fruition, sadly.

Have you ever been to a dinner, where a “special” place had been set for you? Been refused life assurance? Had personal files marked in RED and underlined HEPATITIS “C”? Had a doctor refer you to his nurse to draw blood for a test? These and many other similar instances have become the lot of people with transfused Hepatitis “C”. Many, many of us have suffered in silence over many years for fear of discrimination should our dark secret become public knowledge. We have become pariahs living in a situation not of our choosing — We are the innocent victims trapped in a world not of our choice. In closing I have the greatest sympathy and compassion for those who carry this virus, however compensation for medically acquired/transfused sufferers of Hepatitis “C” does not constitute discrimination in any way shape or form in any circumstances.

For reasons of privacy I have not named the persons pertinent to my story. I can assure you however they are the absolute truth.

Yours sincerely

GRO-A

Mr GRO-A
GRO-A

14 June 2004

Charles MacKenzie
Independent Blood Council
GRO-C

Dear Charles,

Please find below the letter I sent to the Senate Community Affairs References Committee as requested.

"I am writing in support of those who are victims of receiving infected tainted blood and how there needs differ from those who received Hepatitis C through means other than blood transfusion. I strongly believe that there is no cause or case to support claims that when the Senate inquiry declares its finding that it constitutes discrimination against those who received it any other way than through receipt of tainted blood.

The definition of discrimination changes upon the perception of the person making the judgment. A person that has received Hepatitis C through no fault of their own still has to bear the discrimination that is associated with Hepatitis C. The misperceptions that they are drug users and needle shares are but to name of few. They are forced to deal with discrimination on a daily basis. Yet they did nothing to warrant this discrimination. They were in situations that through different medical conditions required blood transfusions in hospitals. Places were they thought were safe, where they were to be healed not to be subjected to further pain and suffering. Yet because of inappropriate screening methods they have become alienated from their previous lives and family. Opening the way for them to suffer the most humiliating discrimination of all. To be associated with those who contract the disease in other way.

To say that all Hepatitis C suffers have all of the same needs and suffer the same persecutions and discrimination is to say that all people who suffer from cancer require the same treatment. We know that this is false. The way a disease is contracted brings it own emotions and coping mechanisms. To treat them all the same irrespectively of the way contracted shows ignorance not understanding.

By trying not to be discriminative towards any suffers of Hepatitis C you become a contributor to the horrible discrimination of those who caught Hepatitis C through blood transfusions. In a world were we are constantly trying not to discriminate against minority or at risk groups we can easily fall into the category we are trying so hard to protect. And become on who discriminates against the people who need the assistance the most.

Try and imagine yourself in my shoes, imagine a loving and young family, three small children, a wonderful wife, a working career and then in one moment that was out of your control have it all taken from you. Your family doesn't look at you the same way, your friends draw away from you and due to the illness your work career has gone. Try and support a family while dealing with all of the emotions of accepting what has happened. All you can do is accept and try to move on and rebuild your life. But it is so difficult you can't, finally when you think that there may be some closure, a peace offering, an organization taking ownership for the horror you have been living, only to find that it might be discrimination to others who carry the same disease but contracted it through there own choices. Tattoo's, needle sharing. They are not the same. And should be treated differently.

I believe that all groups of Hepatitis C carries deserve to have an inquiry into their situations. I would offer my full support if they passed a judgment that benefited other carriers of Hepatitis C I would rejoice with them. It would inspire me to continue to fight for recognition of our needs. I would not feel that I had been disadvantaged or discriminated against. It is their right to have state their case and be heard. Just as it is my right to be heard. That is what we are asking. Hear the cries of the people who have been in receipt of tainted blood. Don't add to the discrimination that we already have been subjected to. You never know when the same thing could possibly happen to you or someone that you love. Help stop this before it is too late.

If you require any additional information or clarification of the views I have expressed them please feel free to contact me on the above mentioned details."

Thanking you,

GRO-A

Sub 28.

GRO-C

The Senate of Community Affairs Reference Committee, Canberra

Dear Sir,

In response to the issue of discrimination I would like to clarify the issue. This is not about discriminating against others who are suffering from this disease. But rather in our case it's a matter of medical negligence by the Red Cross.

It's about the organization which gave us this infected blood through medical transfusion and blood products. This disease has had a profound effect on my life and lives of others who have gone to get life threatening illnesses operated on etc and have been infected with tainted blood.

We should be compensated and this should be urgent because of the years of suffering and disabilities we have had to endure from this tragedy. With most of us a bleak future because of limited treatment cures available.

Yours sincerely,

GRO-A

GRO-A

RECEIVED
16 JUN 2004
Senate Community Affairs Committee

Sub 44

10 June, 2004

GRO-C
Telephone: GRO-C

The Secretary
Senate Community Affairs References Committee
Suite S1 59
Parliament House
CANBERRA ACT 2600

RECEIVED
15 JUN 2004
Senate Community Affairs Committee

Dear Sir/Madam

Re: GRO-A – Victim of Hepatitis C

As a victim of medically acquired Hepatitis C I made a submission for compensation to the recent Senate Inquiry into Hepatitis C and the Australian blood supply, dated 3 December, 2003.

I now understand through the Independent Blood Council that this Senate Inquiry believes offering compensation to victims of medically acquired Hepatitis C constitutes discrimination against other Hepatitis C sufferers.

I wish to protest most strongly against this finding. How can blood transfusion recipients be grouped together with IV drug users? These latter know the risks they take every time they share needles.

I would also like to draw your attention to a newspaper article dated 20 August, 1998 (copy enclosed) reporting compensation of up to $100,000.00 each to be paid to victims of Hepatitis C from contaminated blood, resident in the ACT. Why should ACT residents be treated differently to NSW residents? The discrimination issue didn't apply to them.

Some of us have had to endure over 20 years of anxiety over possible long-term effects of the disease and discrimination in the workplace. The discrimination issues in the Senate Inquiry findings are unfounded and grossly unfair.

Yours sincerely,

GRO-A

GRO-A

Sub 35

THE SECRETARY.
SENATE COMMUNITY AFFAIRS REFERENCES COMMITTEE
SUITE S1 59.
PARLIAMENT HOUSE
CANBERRA - ACT. 2600

RECEIVED
15 JUN 2004
Senate Community Affairs Committee

GRO-A

GRO-A

9th JUNE 2004.

MR. SECRETARY;

THIS LETTER IS FACT NOR FICTION!

THAT OFFERING COMPENSATION TO VICTIMS OF TAINTED BLOOD, CONSTITUTES UNFAIR DISCRIMINATION AGAINST PEOPLE WHO ACQUIRED THE VIRUS THROUGH OTHER MEANS, SUCH AS ILLEGAL IV DRUG USE.

① FIRST OF ALL; HOW CAN YOU SAY THAT A "ILLEGAL IV DRUG USER" AND A "HAEMOPHILIAC" ARE THE SAME.

A DRUG USER IS LOOKING FOR A HIGH THAT WENT WRONG.

A HAEMOPHILIAC NEEDS BLOOD PRODUCTS TO LIFE OR WE WILL DIE.

②

BY THE WAY, THIS SENATE INQUIRY HAS NOTHING TO DO WITH DRUG USERS! SOMEONE THOUGHT IT WAS A GOOD IDEA TO DRAG THEM ALONG I GUESS.

THIS IS ABOUT MEN WHO RECEIVED A DEATH SENTENCE THROUGH BLOOD BANKS BAD HANDLING OF BLOOD PRODUCTS AND NOTHING ELSE!

③

IN 2002 I THINK; MY MEMORYS NOT WHAT IT USE TO BE; I WAS SENT PAPER WORK FROM CANBERRA; SAYING THAT IF "A HAEMOPHILICA" WAS TREATED IN AN A.C.T. HOSPITAL IN

P.T.O.

(3)

1989 OR SOME YEAR LIKE THAT, WHO RECEIVED HEP "C" FROM BLOOD PRODUCTS WAS OFFERED COMPENSATION FOR THAT.

④

SO YOUR DISCRIMINATION AGAINST ME AND OTHER HAEMOPHILIACS THAT WERE NOT TREATED IN THE A.C.T. THAT YEAR I GUESS, AM I RIGHT?

SO SOME GET COMPENSATION AND SOME DON'T.

⑤

I AM AN HAEMOPHILIAC WITH HEP "C" THROUGH BAD BLOOD FROM BLOOD BANK; SO IF YOU PEOPLE WISH TO PLAY GOD; GO AHEAD! IT ONLY PROVES TO ME THAT THIS WHOLE SENATE INQUIRY IS NOTHING BUT A FAST.

YOURS, GRO-A

GRO-A

PS.
NOT HAPPY JANE!

(D) The following is a letter received from a victim called GRO-A in late 2004 highlighting the unfair treatment of the government funded hepatitis groups toward infected blood victims.

GRO-A

3 November 2004

Mr Charles McKenzie
President,
Independent Blood Council

Dear Charles

In March of this year I made contact with the Hepatitis C Council of South Australia, as I was keen to become a volunteer with the Council My experience was initially positive but took a sudden 360-degree turn around. At the time I thought that it was perhaps because the Chairperson/Co-coordinator of the group felt threatened by my work and life experience but now on reflection, and after again reading the Senate Committee Report (e.g. clause 5.24) I have become cynical of the whole process

On the 26th March I telephoned the Council offering my services. The lady on the phone discussed my working background and gave me the impression that they would be keen to meet me, as there was a shortfall in people to provide their telephone service to individuals. She made an appointment for me to go out to the Council on Monday 29th March and meet with Jeanette at 2.00 p.m.

I received a warm reception and we talked for sometime about how I had worked for 12 years at the Institute of Medical and Veterinary Science (pathologists), had a break to have three children, and then joined the Health Insurance Commission in 1983 before retiring on invalidity in January 2002. I had spent most of my time at HIC in management roles.

Jeanetta indicated that all of this was fantastic and that my timing could not have been better because they were conducting a three days course for two other ladies on 5 & 6 April and a final day on 19 April. I checked my diary and all dates were free.

She then took me on a tour of the building and to meet everyone, except the Chairperson/Co-coordinator who was busy. Everyone was most congenial. I met two gentlemen who were volunteers and who were preparing pamphlets and literature for mailing. One man asked me when and how I contracted Hepatitis and I told him 'as a result of a blood transfusion in 1979'. He proudly showed the caricature drawings of all the staff and volunteers that he had done and asked me if I would let him draw me when I came to work, and I agreed.

A man wandered in and I was told he had been coming every day for the last few weeks – he had only recently been diagnosed. I had a general conversation with him and he went on his way quite happy. Jeanetta remarked," that was great!"

Limited in what I am able to and not able to do, I was enthusiastic about the course and the prospect of being able to utilise my skills on a voluntary basis.

How mistaken I was.

On the Tuesday an obviously embarrassed Jeanetta telephoned me to advise that she was sorry, but I could not do the course. While stunned I was able to question her.

Why the change?

"Wendy who was apparently 'the boss' had said that I did not have the skills that the others had and would not be able to do the course"

That is strange – she has not even met me. What skills don't I have I asked?

"Telephone skills."

I can't see why, one of my roles was to manage the HIC call centre in this state and to oversee that the appropriate training was given to all operators.

"You haven't had counselling experience"

I had approximately 100 staff and a day rarely went by that I did not have to counsel staff on personal or work issues. I had a number of certificates in counselling, including those from the University of Adelaide. I had attended and conducted counselling workshops.

"The other two ladies have done a course"

She was unable to explain what course or where I could do a similar course. I certainly had broad experience in the health sector.

GRO-D

Given that I was infected in 1979 I doubted that there were large numbers volunteering to help who had the infection longer than me.

I asked to speak to Wendy as I thought it unjust that she seemed to be the one having the power to either let me or let me not do the course, but she wasn't available. Wendy would however be happy for me to work in the order room sending out pamphlets. I did not think this would be the stimulation I was looking for so I said I would think about that and call back.

Clearly I was angry, and as stated initially my initial reaction was she might have thought I was a threat – I certainly wasn't, my health would not let me threaten anyone's job.

On 1 April I telephoned the Council and advised that I was not interested in sending out pamphlets – I wanted something that would be a challenge. I was still not able to talk to the elusive Wendy.

I did ask if the Council was aware that a new Hepatitis group had been set up to help victims infected by tainted blood or blood products. The response was "That's great" – to which I replied – "It depends if you look outside of the square because clearly the new group will be also drawing on the fund that the government provides for group associated with all victims of Hepatitis C"

GRO-D

Yours sincerely

GRO-A

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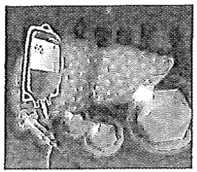
Inquiry into Hepatitis C in Australia 2015

https://www.aph.gov.au/Parliamentary_Business/Committees/House/Health/Hepatitis_C_in_Australia

Submission 102 Tainted Blood Product Action Group



Tainted Blood Product Action Group

Committee Secretary

Standing Committee on Health

PO Box 6021 Parliament House

Canberra ACT 2600 health.reps@ GRO-C

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. Alarmingly, 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

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Stuart Loveday Background

Mr Stuart Kinnoch Loveday (Originally from the UK) - *B Com*

Former CEO of Hepatitis NSW since 1994 (retired November 2019) Australia's first and largest community based organisation and health promotion charity working for and on behalf of people with viral hepatitis.

He is a former President and was a founder and continuous executive board member of Hepatitis Australia from 1997 to 2013.

Having served on a range of national Australian hepatitis committees and working parties since 1994, Stuart represents Hepatitis NSW on the NSW Ministry of Health's Hepatitis B and Hepatitis C Strategies Implementation Committee, serves on the Board of the NSW Justice Health and Forensic Mental Health Network and on a range of other national and NSW hepatitis advisory, governance and research committees.

Mr Loveday is a key figure in the Hepatitis C landscape in Australia. In his submissions he refers to the role of the Hepatitis C Council as to help improve the quality of the lives of people in New South Wales living with hepatitis C and to advocate on their behalf and contribute to the improvement of all information, treatment, support, management and care services for all people affected by hepatitis C. While he acknowledges the burden of chronic hepatitis C infection and even a diagnosis of hepatitis C, can be great for many people for a range of reasons because of the stigma surrounding hepatitis C, because of the symptomatic illness that many people with hepatitis C endure and through the reduced quality of life that occurs as a result of their diagnosis or their infection. He states , in relation to medically acquired hepatitis C, they do not support the view that a particular group of people with hepatitis C should receive ex-gratia payments,or particular benefits and their concerns of the impact of any payments on the availability of public funding for hep c service improvement..

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(A)

30 January 2004

Mr Elton Humphrey
Secretary
Inquiry into Hepatitis C and Blood Supply in Australia
Parliament House
Canberra ACT 2600

Dear Mr Humphrey

Inquiry into hepatitis C and the blood supply in Australia

We write to provide our submission to the Senate Community Affairs References Committee Inquiry into Hepatitis C and the Bloody Supply in Australia.

We support fully and endorse the views expressed by the Australian Hepatitis Council in their submission dated 29 January 2004. Given the level of detail provided in that submission, we do not intend to duplicate any of that information, but rather provide an additional perspective that we hope will serve to contribute positively to the Committee's deliberations.

Please note that at any time we would be more than happy to provide any additional information, further evidence or assistance with the committee's work.

About the Council

The Hepatitis C Council of NSW is the independent, community-based non-government organisation funded by the NSW Health Department to provide information, support, referral, education, prevention and advocacy services for all people in NSW affected by hepatitis C.

We strive to be representative of, supportive and accessible to people affected by chronic viral hepatitis, especially hepatitis C. Working actively in partnership with other organisations and the affected communities, we work to bring about improvement in the quality of life, information, support and treatment for the affected communities and to prevent hepatitis C virus (HCV) transmission.

We integrate principles of quality within all aspects of our operations and are accredited by the Quality Improvement Council of Australia (QIC) in recognition of our successful assessment against the Australian Health and Community Services Standards.

Having developed from a support group established in 1991 by members of the communities directly affected by hepatitis C, we employ a team of ten paid staff, casual workers and involve teams of volunteer workers to carry out our day-to-day operations.

A voluntary management committee, drawn from the membership and other members of the community, has responsibility for overall strategic direction and policy.

In addition to being an association incorporated under the Associations Incorporation Act, the Council is a not-for-profit membership organisation, and has full income tax exempt charitable status as well as Deductible Gift Recipient tax status.

Information and resources

We produce detailed HCV information booklets, brochures and factsheets. *The Hep C Review*, our quarterly magazine, provides up to date information on clinical developments, political and legal issues, support services, membership information and other HCV-related news. *The Hep C Review* is also an important source of peer support, and is widely circulated in NSW correctional centres as well as within the broader communities affected.

Our website www.hepatitisc.org.au provides a range of general and detailed hepatitis C related information.

We operate a library loan service of hepatitis C information videos, cassettes and books. These cover general and specific information about living with hepatitis C, clinical treatments, complementary therapies and how HCV affects the liver.

Our Medical Research & Advisory Panel, comprising of eminent clinicians, researchers and public health specialists, provides guidance and advice both in our resource development and in our education work.

Our resources are endorsed by the NSW Health Department and reviewed and updated regularly. They are distributed to people affected by HCV and to a wide range of health, welfare and education services.

***NSW* Hep C Helpline**

The *Hep C Helpline* is the free statewide, confidential and non-judgmental telephone information, support and referral service for people in NSW affected by hepatitis C, health workers and the general community. The *Prisons Hep C Helpline* is an extension of the service for NSW prisoners, their families and corrections staff.

Staffed by full time workers and a dedicated group of volunteers, the service takes over 4,000 calls each year.

People can call the *Hep C Helpline* and *Prisons Hep C Helpline* for information, free written resources and video loans, emotional support, and referrals to GPs and specialist services.

Access to translation services is available through the *Hep C Helpline*.

Hep C Helpline

9332 1599	(Sydney callers)
1800 803 990	(other NSW callers)

Prisoners use the freecall service.

Education & Development

The Education & Development team aims to support and build the capacity of health care and community organisations and workers who address hepatitis C care and prevention. We do this through:

- **Education**
  We provide free educational and workforce development services to health care, community and youth workers, and others who work with people affected by or at risk of hepatitis C. Our services include developing and delivering customised educational workshops or planning sessions and services for groups or whole organisations.
- ***C-een & Heard* Speakers Service**
  C-een & Heard speakers share their experiences of hepatitis C with audiences of health care or other workers with the aim of increasing understanding and awareness of hepatitis C, dispelling myths and misconceptions, and reducing related stigma and discrimination.
- **Capacity Building, Partnerships and Networks**
  We provide input and feedback on hepatitis C strategic plans, submissions, resource development, and educational planning. We also represent people affected by hepatitis C through participation on advisory committees, steering groups or reference groups for hepatitis C projects or programs.
- ***HepLink***
  HepLink is the statewide network comprised of various health care workers and others who address issues relating to hepatitis C in their work. The aim of *HepLink* is to share information, resources and support. The Council serves as the secretariat for *HepLink*.

Advocacy

The Council strives to represent and promote the interests of all those in New South Wales affected by hepatitis C at the local, state and national level by taking action on broader community issues.

Services for all people affected by hepatitis C

The Hepatitis C Council of NSW provides non-judgmental and non-discriminatory services for all people affected by hepatitis C.

Given the subject matter of this inquiry, we consider it vitally important to stress that all people either with, affected by or at risk from hepatitis C infection are able to and do access our services. The route of transmission of one's infection is generally not a concern for us, unless of course it is raised by a client seeking help from us. We will then work with and support that client in regard to that particular issue, providing information, support, referral and advocacy services as required.

Our membership, service users and communities of interest comprise of people who contracted hepatitis C through all transmission routes. Our management committee has on it people who acquired hepatitis C through blood transfusion and blood products receipt, through sharing equipment used to inject illicit drugs and through other means.

We consider it vital that no one group of people with hepatitis C are either advantaged or disadvantaged over another group of people with hepatitis C.

Our national peak organisation, the Australian Hepatitis Council, made it very clear in its submission to this inquiry that there is an urgent need to improve services for *all* people affected by hepatitis C, and that currently scarce resourcing needs to be enhanced in order to provide these much needed improvements for all people with and affected by hepatitis C, whatever the route of transmission.

Introduction of screening tests

Australia was, in February 1990, among the first countries in the world to introduce the HCV antibody test in order to screen the blood supply. This effectively stopped, by and large, the transmission of HCV through the blood supply.

Additionally, Australia has also introduced in June 2000, at great and continuing expense, NAT (nucleic acid testing) in order to further ensure the safety of the blood supply.

Much has been said in the popular media about Australia's failure to introduce surrogate testing (via liver function tests - LFTs) in order to screen out those donors who potentially had non-A, non-B hepatitis (NANB, later called hepatitis C when the virus was formally identified in 1989.)

While, of course, with hindsight, we regret this was not done, we note that not much attention has been paid to the reasons why the decision not to introduce surrogate testing was made.

We understand that during the 1980s, a national group of experts, including scientists, experts from the medical profession and public servants was established to weigh up all the factors and evidence and arguments for and against surrogate testing. We understand this group was convened by the Australian Red Cross Blood Service working with government health departments of the day.

We understand that the surrogate tests that could have been used at the time were LFTs - particularly ALTs (alanine aminotransferase, a protein or enzyme which, when found in the blood in elevated quantities, generally indicates the liver damage), and hepatitis B markers.

However we understand that the decision by the ARCBS not to use those surrogate tests to screen the blood supply was taken for well considered reasons - whether one agrees with them or not - and using the best available evidence at the time.

In summary – the decision was taken, we understand, because experts did not believe at the time that NANB posed a major health risk (we all know differently now) and that they were very concerned that if they did screen out all people with raised LFTs (for whatever reason) then they stood the danger of not having enough blood stocks for the emergency and other needs of the day.

Compensation or ex gratia payments

Like the Australian Hepatitis Council, we believe that where compensation to be paid, negligence needs to be proven.

For this to happen, it needs a legal investigation, and we are not in a position to judge that. If negligence on behalf of anyone or any organisation were proven, we would strongly support compensation payments to the aggrieved parties.

But we understand the decision not to surrogate-test was taken using best available evidence at the time, and it was a calculated decision based on weighing up known and estimated risks at the time using best medical and scientific expertise available then.

With hindsight, we wish surrogate testing had been introduced. It would have prevented many infections. But we believe we should not be making judgements and payments now based on hindsight unless it is shown that negligence occurred.

In terms of ex-gratia payments, as have happened in some countries abroad where the situation may be very different from the Australian context, we would also be very concerned about the perceived inequality if payments were made to some but not to other people with hepatitis C.

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:

- those many people from countries overseas who acquired hepatitis C infection through blood transfusions or other medical means in their countries of origin (eg Egypt, South-East Asian countries, Europe) and who are now Australians
- health care and other workers who acquired HCV through needle stick injuries where the legal judgement against them has not been in their favour
- children who acquired HCV infection from their HCV positive mothers
- people who acquired HCV infection through unsterile tattooing or body piercing
- other people who contracted HCV through a range of means: people who acquired HCV through blood-to-blood contact through sharing injecting equipment when there was no knowledge that NANB / HCV could be transmitted that way
- 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.

We question why these other people with hepatitis C also not be given some sort of recompense for their hardship and reduced quality of life now endured.

We also ask what impact any payments would have on the availability of public funding for general hepatitis C service improvement.

We believe that support, management treatment services for people with hepatitis C should be improved - but these need to apply to all people with hepatitis C - we do not support particular benefits accruing to a particular groups.

If ex-gratia payments are made to a few who can prove their infection was at a particular time via a particular means, what message does that send to the many hundreds of thousands of Australians who do not fit those particular criteria? We do not consider that to be an equitable situation.

Conclusion

We have not specifically addressed the terms of reference, as we do not have the expertise or capacity to do so. Instead we have provided a general submission to this inquiry wherein we have described our mission and services and approach, as well as describe our understanding and opinions about a matter that is very sensitive and of great concern to many people in Australia affected by hepatitis C, as well as to the Hepatitis C Council of NSW.

We provide a link to a Council factsheet that describes the natural history, or course of disease progression, associated with chronic hepatitis C infection.

http://www.hepatitisc.org.au/factsheets/documents/HepatitisCoutcomesnaturalhistory_001.pdf

Hepatitis C can cause great hardship and severe illness for many people. It has a major personal, social and economic impact on individuals, families and on the healthcare system. Systems and strategies are in place to help address this epidemic. We firmly believe that what is required is major investment in evidence-based prevention services, and in improving significantly the care and support services for all people living with hepatitis C.

Thank you for the opportunity to make a submission to your Inquiry. Please do not hesitate to contact us if we can provide any further information.

Yours sincerely

Stuart Loveday
Executive Officer

(B)

Evidence from Stuart Loveday at the public hearings of the Senate inquiry into Hepatitis C and Australian blood supply

Tuesday, 6 April 2004 Senate—References CA 1
COMMUNITY AFFAIRS
Committee met at 9.05 a.m.
LOVEDAY, Mr Stuart Kinnoch, Executive Officer, Hepatitis C Council of New South Wales

CHAIR—I declare open this public hearing and welcome everyone who is here today. The Senate Community Affairs References Committee is continuing its inquiry into hepatitis C and the blood supply in Australia. There has been a high level of interest in this inquiry, as seen by the large number of people who have attended our hearings. I welcome the representative of the Hepatitis C Council of New South Wales. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you. The committee prefers evidence to be heard in public but evidence may also be taken in camera if you consider such evidence to be of a confidential nature. The committee has before it your submission, and we thank you for that. I now invite you to make an opening presentation, to be followed by questions from the committee.

Mr Loveday—I thank the committee for the invitation to the Hepatitis C Council of New South Wales to give evidence to this inquiry. Having already made a written submission, for my opening presentation I wish to highlight a number of key summary points from the submission as well as make statements pertaining to terms of reference (f), (m), (n) and (o). The Hepatitis C Council of New South Wales is the independent community based non-government organisation funded by the New South Wales health department to provide information and support and referral services for all people in New South Wales affected by hepatitis C. We are one of the eight state and territory hepatitis councils that comprise the predominant membership of the Australian Hepatitis Council, our national peak agency. I note and fully support the views and information given by Ms Kerry Paterson, Acting Executive Officer of the Australian Hepatitis Council, in her evidence in Canberra on 1 April.

We are a small organisation, having developed from a support group established in 1991 by members of the communities affected by hepatitis C. I am happy to provide further information that may be required concerning the type and range of services we provide, as well as the broad range of people who use and contribute to our services. The basis of our existence comes from the fact that the communities in New South Wales who are affected by hepatitis C see it as essential that there is a representative voice advocating on their behalf. It is part of our mission to help improve the quality of the lives of the many thousands of people in New South Wales living with hepatitis C.

It is estimated that there are around 100,000 people in New South Wales who have been exposed to the hepatitis C virus by a variety of transmission routes. This comprises some

40 percent of the national estimates of some 240,000 people who have been exposed to December 2003. As we noted in our submission, approximately 75 per cent of those people will go on to develop a chronic or a long-term hepatitis C infection.

The physical effects of hepatitis C usually take a long time to manifest. Symptoms may take between 10 and 15 years to present themselves. Natural history studies have been collated by Australia's National Centre in HIV Epidemiology and Clinical Research to show that after a long period of time with hepatitis C infection—that is, 40 years—it is estimated that out of 100 people with chronic hepatitis C who remain untreated, 45 may not develop any liver damage, 31 may develop mild to moderate liver damage, 20 may develop cirrhosis of the liver and four may develop liver failure or liver cancer. It is in this last case where four per cent of people with chronic hepatitis C who remain untreated will be facing, or might be facing, a life-threatening condition. The burden of chronic hepatitis C infection and even a diagnosis of hepatitis C, as we have pointed out, can be great for many people for a range of reasons because of the stigma surrounding hepatitis C, because of the symptomatic illness that many people with hepatitis C endure and through the reduced quality of life that occurs as a result of their diagnosis or their infection.

Among the services the council operates are the New South Wales-wide hep C helpline and the prisoners hep C helpline. This is a free, confidential and non-judgmental service for all people in New South Wales affected by hepatitis C. Additionally, the council publishes Australia's most widely read regular magazine journal on hepatitis C, the Hep C Review. The helpline is an avenue for people to find out information, receive support and provide to the council an idea of the issues they or their loved ones face in their day-to-day lives in relation to their hepatitis C infection. Likewise members of the affected communities write in to the Hep C Review with their stories and letters to the editor, in which they talk of their personal experiences. We act also, therefore, as a conduit for expressing the views and needs of the communities affected by hepatitis C.

We have been consistently conscious, since our formation in 1991, of the potential divide that could exist when the fact of the transmission route of hepatitis C is taken into account. We know from the epidemiological research that approximately 83 per cent of all people with hep C contracted it through blood-to-blood transmission when injecting drugs. Approximately five per cent contracted hepatitis C through the contaminated blood in the blood supply prior to February1990 when antibody testing commenced in Australia. The remaining 12 per cent contracted hepatitis C through a miscellany of transmission routes. Probably all of them contracted it from blood-to-blood contact through the following means: unsterile tattooing and unsterile body piercing; vertical transmission from a hepatitis C positive mother to her baby; needlestick injuries; medical procedures; and a substantial proportion of people, now Australians, who have contracted hepatitis C through unsterile medical procedures, including mass vaccination programs, in their countries of birth.

Hepatitis C is not classified as a sexually transmitted infection. Where it is feasible to be transmitted in a sexual context, it is where there is blood-to-blood contact during sex with a person who has hepatitis C. All hepatitis councils in Australia, including that in New South Wales, as well as the Australian Hepatitis Council, provide services in a non-discriminatory manner for all people with hepatitis C, whatever their route of transmission.

We are fully conscious of the community anger over the fact that hepatitis C was or could be acquired through Australia's blood supply. We receive calls from and work with people who acquired hepatitis C in that way. It is not the role of the council to judge whether the decisions taken in the period between 1985 and 1990 were the right or the wrong ones. We do not have the expertise to do so. It is certainly our view, however, that were negligence to have occurred in any circumstances, and that negligence led to hepatitis C infections within the medical setting, then compensation should be paid to those who were infected with hepatitis C in those circumstances.

I wish to provide some statistics on the number of callers to the hep C helpline in two financial year periods which may give some indication to the committee about the number of people approaching the council on the subject of medically acquired hepatitis C. In 2002-03, out of a total of 2,782 calls to a helpline worker, 136 people advised they contracted hepatitis C through the medical system at some stage in the past. Please note: these would not necessarily have been through the blood supply but, for example, through possible medical or dental infection control breaches—that is, not only through the blood supply. Of those, 17 people discussed litigation and we referred 13 of those people to the Tainted Blood Product Action Group, with whom we have been in contact over the last few years. More recently, in the nine months of 2003-04, we have received 2,175 calls. Eighty-seven people advised they had contracted hepatitis C through the medical system at some stage. Nine callers discussed litigation and five were referred to the Tainted Blood Product Action Group and other sources. Please note: within the calls people may discuss the fact that they received hepatitis C from a blood transfusion, but it may not be the focus of their call or they may not discuss or be seeking compensation. If they are, we provide the relevant support and information, and we refer those callers on to the relevant legal services and the Tainted Blood Product Action Group as well. One of the council's primary aims is to advocate for and contribute to the improvement of all information, treatment, support, management and care services for all people affected by hepatitis C.

I wish now to refer to a matter which is necessary for the consideration of potential liability of governments or the Australian Red Cross Blood Service in relation to hepatitis C acquired through Australia's blood supply. We note the differences in terminology that have been applied to date. There is the term 'compensation', which in our understanding implies financial payment in response to negligence shown to have been the fault of agencies or individuals. We also note the term 'recompense', which in our estimation might imply financial payment not in response to negligence but in response to the existence of a set of circumstances.

The broad implication we draw from the latter—that is, financial recompense—is that it provides a financial benefit for events which occurred at some stage in the past.

Within this consideration we wish to draw the committee's attention to the various periods in question: prior to February 1990, when hepatitis C was relatively commonly transmitted through the blood supply. We all know that, before the identification of hepatitis C, it was known as non-A, non-B hepatitis. Our understanding is that, during the 1970s and the first half of the 1980s, there were no real means available to carry out surrogate testing of the blood supply that might have excluded as far as possible the possibility of contracting non-A, non-B hepatitis through the blood supply.

We understand that it is the latter part of the 1980s that is of primary interest to this inquiry. It is known that, at that time, a nationally constituted committee took the decision—based on best available evidence and also best available beliefs and understandings at the time—not to introduce surrogate testing that might have excluded that donated blood which showed elevated liver function test results. We note this distinction because we feel it is important to point out what would happen if Australia were to follow the examples of the UK, Canada, Ireland and possibly other countries and pay blanket recompense on compassionate grounds to all people who acquired hepatitis C in Australia through the blood supply at whatever period. That would provide some financial benefit to a particular group of people but would perhaps not consider the plight of many other people who contracted hepatitis C through similar means—say, in their countries of origin or through other means in Australia, when they did not have the knowledge that infections were occurring or the means to prevent those infections.

CHAIR—Let us start by discussing that point. I just want to clarify something there. You said that the National Blood Transfusion Committee made a decision not to implement surrogatetesting in the latter part of the 1980s.

Mr Loveday—That is our understanding.

CHAIR—You said that that decision was based on evidence and beliefs. Evidence is clear. Could you explain what you meant by beliefs?

Mr Loveday—Yes, the evidence is clear. The beliefs were that non-A, non-B was possibly not a serious health condition—that it possibly would not lead in many circumstances to serious liver disease. They knew that non-A, non-B was a virus that infected the liver. I lived in the UK at the time—throughout the 1980s—and I first heard about non-A, non-B in 1981. In the sexual health clinic where I heard about this concept, the view was that it was not that serious—that it was nothing to worry about. I understand that that view continued throughout the 1980s. It was only very much later in the 1980s, just prior to the introduction of antibody testing to the blood service, that natural history studies were able to be carried out over a period of time and that the true nature of hepatitis C infection and its long-term effects were seen to be a whole lot more serious than previously thought. That is what I meant by the beliefs at the time. They were that hepatitis C perhaps was not as serious as it is now known to be.

CHAIR—That is because of the delay between the point of infection and when the disease starts to manifest itself and truly affect people's lives?

Mr Loveday—That is correct, yes. The normal course of progression of hepatitis C infection is that, in the vast majority of cases, when you get infected you know absolutely nothing about it. Acute, early-stage symptoms might present themselves in only up to 20 per cent of cases. In the vast majority of cases—80 per cent of cases—people will not notice that they have been infected. It is only in the relatively long term—10, 15 or 20 years later—that people start to notice an impact on their physical health. Often, with information and with a relevant knowledge of risk behaviour in the past, people might then put two and two together, go for a test, find that they have hepatitis C and so have their disease situation explained to them. But it is a very longterm health condition for the majority of people.

CHAIR—We knew very early that blood-to-blood transfer was the way that hepatitis was transferred. In your recollection, when were the campaigns developed to advise intravenous drug users that their behaviour risked their infection with hepatitis C? When did we really start trying to talk to that group of people who were engaging in risky behaviour?

Mr Loveday—My experience with the Hepatitis C Council started in October 1994. Before then, I do not know when campaigns amongst that particular client group started. It became very clear from the early days that the broader communities affected by hepatitis C included those people whose drug taking risk behaviours put them at risk of infection. That was certainly known in the UK in the late eighties. In Australia the first hepatitis C information resources for the general community—that includes all people affected by hepatitis C as well as the general public—were formulated in 1991 and 1992. We have in our archives the records of the development of the first hep C information resource. That process was led by members of the affected communities and was contributed to by Professor Geoffrey Farrell of Westmead Hospital. Those were the first information resources.

In terms of campaigns it was a very long and hard slog to get governments to realise the importance and impact of hepatitis C. It was only in 1994, in the New South Wales parliament, when there was a parliamentary briefing by the Hepatitis C Council of New South Wales—and this was prior to the formation of any national representative voice of the affected communities—that awareness among politicians was raised as to the seriousness of the situation.

The Hepatitis C Council of New South Wales received public funding for the first time only in mid-1994. So it was a very long time before the need for any formal health department response was recognised and funded and before the need for any community response was acknowledged and funded. So, to my recollection and knowledge, there were no campaigns, if you like, before the community groups started making a noise about raising awareness of hepatitis C.

CHAIR—That is in comparison with what we did with HIV-AIDS nationally. I think it is well regarded that Australia's campaign to do with HIV-AIDS was one of the best in the world.

Mr Loveday—Absolutely.

CHAIR—But the comparison is so obvious.

Mr Loveday—There is a massive gulf between the response to HIV-AIDS—which was excellent and needs to continue—and the response to hepatitis C. It has been a piecemeal, hard slog. The first real impetus, I feel, came in New South Wales when the New South Wales upperhouse, the Legislative Council, carried out an inquiry into hepatitis C in 1997 and handed down their report in 1998. That report was entitled Hepatitis C: the neglected epidemic. It was an extremely hard-hitting report which made recommendations for New South Wales but alsofederally, via the New South Wales health minister at the time, and that led in part to the recognition that hep C was a lot more serious than was originally thought. That led to a substantial financial response in New South Wales, but as always these things are subject to the criticism of being too little and very late in the day. At a federal level, attempts to form a national peak body of the then existing state and territory based groups which formed, as I said, in the early 1990s, fell on deaf ears until the Australian Hepatitis Council was funded and set up in 1997. So that was a very long time after the identification of hepatitis C.

Senator LEES—I have a question about prevention and whether or not we really would have seen some improvement. I am just looking at some evidence from the health department. They are arguing that the number of infections prevented would have been very small indeed had we moved. I would just like you to comment, given what you have said on page 5, where you said that many infections would have been able to have been prevented if there had been earlier testing.

Mr Loveday—That is certainly our understanding, that infections would have been able to have been prevented with the introduction of this additional screening. How many, we do not know. I would defer to the experts on that matter, perhaps to the epidemiological experts at the National Centre in HIV Epidemiology and Clinical Research. Given the number of people who have hepatitis C and given the fact that approximately five per cent of them acquired hepatitis C through the blood supply, we did a rough calculation—and I must admit it was a back-of-the envelope calculation—just to get some idea of the numbers. It was not a scientific attempt, because we are not epidemiologists, but in the Hep C Review of September 2002 we estimated the number of people we believed might have contracted hepatitis C through the blood supply in that five-year period from 1986 to 1990. Background notes and assumptions to the article headed 'Council Comment: Financial compensation for blood supply-acquired hepatitis C' state:

Based on estimates from the latest and as yet unpublished 2002 report of the ANCAHRD HCV Estimates and Projections Working Group, we estimate that there are 5% of 210,00 people = 10,500 people who acquired HCV—that is, hepatitis C—through medical means in Australia.

These figures have changed now because it is five per cent of a bigger number. The notes continue:Around 75% (7,875 people) developed chronic HCV infection. Around one quarter of those (2,000 people—and those are the 2,000 people we have very crudely calculated were infected during that particular period—

Senator LEES—When the surrogate testing was known but not used?

Mr Loveday—Correct—1986 to 1990, those five years. The background notes and assumptions continue:... may be eligible for compensation were it to be paid. Clearly, not all of those people would be facing ill health as a result of their HCV infection. A minority would be facing debilitating symptomatic illness because of their hepatitis C. Around 5% would be facing a life threatening situation as a result of their HCV infection.Just to explain the basis of those calculations:
For the sake of arithmetical simplicity, to calculate the numbers of people who contracted HCV through medical means in Australian in the period 1986-1990, we have assumed 4 time periods 1970-1975, 1976-1980, 1981-1985 and 1986-1990. I must emphasise that this is not scientific; it is a very crude arithmetical means of assessing roughly how many people would have been exposed through that route and who might be facing health problems.

Senator LEES—So, as people come into contact with your organisation and start seeking support, you can get some idea of when they were infected in that period? You can take their evidence into account?

Mr Loveday—Only if they choose to disclose that information. We act as a responsive service, so we will accept calls from people affected, the general public et cetera, and we will meet their needs according to what they raise in the subject matter of the conversation. We do not specifically ask people how they contracted hepatitis C, so those figures that I read out in the evidence this morning were based on only those people who identify—

Senator LEES—Who wish to talk about it.

Mr Loveday—Who wish to talk about their route of transmission.

Senator MOORE—I asked the national body of the organisation about the discrimination that people who have hepatitis C face, and we received some information there. I am interested specifically in the cost and impact of the treatment for hepatitis C. We do not have evidence on record yet about the impact of the treatment, how long it takes and its expense for people who have been diagnosed.

Mr Loveday—First of all, the impact of treatment varies for people who go on to treatment, and not many Australians who have hepatitis C have been through the treatment course. Probably between four and six per cent of people—possibly more now; perhaps seven per cent—with chronic hepatitis C have been through the treatment regime. In Australia today we have the best available pharmaceutical treatment that the world has to offer, so it is currently the world gold standard. That treatment is a combination of a drug called pegylated interferon and a drug called ribavirin. The pegylation molecule is a slow released molecule and it slows down the release of the interferon drug so that one injection a week is required, as opposed to the previous regime of three injections per week. So pegylated interferon makes the drug easier to take, and that in turn leads to better adherence to the treatment regime.

When that is combined with ribavirin, which is an orally taken pill, the combined success rate can be measured. Success is measured in terms of sustained viral response, which for many people is a cure for their hepatitis C infection. It is total viral clearance. In all the studies done to date, in the case of people who undergo successful treatment—if they have not had cirrhosis in the first instance—it is not known for them to get hepatitis C again. So it is clear that people who have a sustained viral response, if they do not have cirrhosis to start with, are in fact cured. Those people who have cirrhosis and who have successful treatment can go on to develop liver cancer or liver failure, even though the virus is not present in their bloodstream, but that is in a small percentage of cases. So we are confident as a community organisation in talking about cure for people with hepatitis C in certain circumstances.

The success rates for the majority of people now with pegylated interferon and ribavirin average around 50 per cent, which is much higher than we have ever had before. The result differs depending on what genotype you have. The genotypes of hepatitis C have different subtypes in Australia. The more common genotypes include, on the one hand, genotype 1. That responds less well to hepatitis C treatment—around the 40 per cent mark. There are also genotypes 2 and 3 in a group. They respond much better to combination therapy. There the success rate is around the 60 per cent, 70 per cent or 80 per cent mark. That averages out to between 50 per cent and 60 per cent sustained viral response.

Senator HUTCHINS—Yesterday or on Thursday we heard that most of the Australian sufferers have genotype 1. Is that correct, Mr Loveday?

Mr Loveday—No, not most. I will finish my answer and get back to you on that one. I do have the data here.

Senator HUTCHINS—I have just been reminded that it might be haemophiliacs.

Mr Loveday—It could be; I will check. Many people are scared, and perhaps quite rightly so, by the side effects of hepatitis C treatment. It can knock people around. In many instances the side effects quite perversely mirror the symptoms of hepatitis C infection—lethargy, tiredness and depression—but in quite a large percentage of cases there are additional side effects such as rapid mood swings for no apparent reason. There are other side effects as well: with Interferon as a chemotherapy there might be hair loss and dry mouth.

There are many side effects of hepatitis C treatment, but it is very rare that people need to come off treatment because of the side effects. Most people can live with them. They tend to be worse in the early days of treatment and they tend to improve as people work with their clinical nurse consultant and with their treatment provider to stabilise the treatment. First the body gets used to treatment and then they can amend the treatment regime slightly so that the side effects are lessened. But most people do go through treatment and I have mentioned the success rates once treatment is over. Side effects can last after treatment ceases, up to six months in cases. There are good information resources available for people who go through treatment. You also asked about the cost of treatment.

Senator MOORE—And the duration. I heard it is up to 72 weeks.

Mr Loveday—The funded therapy—and this is where treatment is available free of charge except for a small Medicare administration charge for each prescription, which happens on a monthly basis—lasts in the cases of people with genotypes 2 and 3 for six months, so 24 weeks. In the cases of people with genotype 1 it lasts a year or 48 weeks.

Senator MOORE—Of weekly treatments?

Mr Loveday—Of weekly injections—and those are self-administered—and oral pills taken I think three times a week. I am not sure about that though.

Senator MOORE—And the cost?

Mr Loveday—It is free to the person with hepatitis C if they meet the Pharmaceutical Benefits Scheme highly specialised drug section 100 criteria which require people before they commence treatment to go through a regime of tests and show a certain level of liver damage on one of those tests—on the liver biopsy—which is not necessary for people with haemophilia. They need to have a fibrosis score of one. There are four scores—F1 through to F4, where F4 is cirrhosis. They need to have at least a fibrosis score of one or a fibrosis score of zero with substantial inflammation of the liver, and that can be measured on biopsy. Right now biopsy is the only means of assessing that as accurately as is required.

Senator MOORE—You said there was a significantly high success rate—60 per cent balanced across the genotypes?

Mr Loveday—Between 50 and 60 per cent, yes.

Senator MOORE—Is there any evidence that if someone goes through a year of treatment with the level 1 condition and it does not work then they can go back and do it again and again? Is that a possibility?

Mr Loveday—I would need to defer to my clinical colleagues on that. I am not aware of that. There will be studies which show that, but I am not aware of those studies.

CHAIR—Senator Knowles, do you have any further questions?

Senator KNOWLES—No. Thank you very much, Mr Loveday, for a very comprehensive submission and also for the information that you have provided about the council's view of surrogate testing. I think that is a very balanced view and an understanding view given what you have said on page 4 about the decision being based on the best available evidence at the time.

Mr Loveday—There was the question earlier about genotypes across Australia and I have that information now. It is estimated that in Australia approximately 35 per cent of people with hepatitis C have subtype 3, mostly 3a; seven per cent have genotype 2; 35 per cent have genotype 1a and 15 per cent have genotype 1b. So 50 per cent of people have genotype 1 and 42 per cent have genotype 2 or genotype 3. So you were right that the majority of people in Australia with hepatitis C have genotype 1.

CHAIR—The council's view about compensation or recompense is very clear in your documentation, and I thank you for that. You make it clear that if negligence is proven then compensation should be applied under common law. We heard evidence yesterday from the Haemophilia Foundation Australia. They said very clearly that, because of the nature of the way they have become infected, it is very hard to prove negligence. Is there a special case for that cohort of the community? The principle you are basing your position on is that negligence needs to be proved so that compensation can be paid. Given that those people with haemophilia who have hepatitis C cannot prove that they received hepatitis C through medically acquired means, is there another case for that group?

Mr Loveday—I would suggest that we need to look at the full decision making process—and perhaps this inquiry is a way to do that—that led to the decision not to surrogate test. My understanding is that in the 1970s, when a lot of people with haemophilia would have received hepatitis C—and likewise in the 1980s—nothing could be done at that time. Our understanding is that there was no knowledge, no expertise and no possibility of excluding hepatitis C from the blood supply through surrogate testing. I think it is up to this inquiry to establish whether the process and the systems in place at the time of the decision when the knowledge became available were the right ones.

If they are shown to be the wrong ones then I think a special case needs to be made, but if they were the right ones then I would strongly suggest that this inquiry look more broadly—even though the terms of reference are very specific at this stage—at the overall situation for all people affected by hepatitis C and not at a particular group.

It is our firm belief that services for people with hepatitis C certainly need to be improved, but they need to be improved for everybody, and they need to be vastly improved for everybody.

Where we found our frustrations occurring is in the stoush that goes on between the Commonwealth and the states about funding for the services on the ground. One blames the other, and it is community health and it is public health that suffers.

CHAIR—If we had time, we would have been able to talk about the review.

Senator MOORE—Mr Loveday, one of the things we heard about is people's concern about how they find out about their condition. There is differing evidence about the Lookback program and people being found that way and finding out themselves. Among the people who contact your service, particularly the helpline, is there a great deal of concern about how people find out they have got hepatitis C?

Mr Loveday—There was, in the past, a great deal of concern. In the early to mid-1990s, when the first helplines were being set up, people were being diagnosed and told of their diagnosis in the most inappropriate way, without any support, without any information. People were being told they were going to die by doctors who knew nothing about hepatitis C. That would have had a devastating impact on the outlook and the quality of life of those people who were informed in that way, without appropriate support. Over the years, the Australian Red Cross Blood Service came in for criticism by us, and we worked with them. They soon changed their ways once we started kicking up a fuss. They were advising people during the Lookback program by letter that they had hepatitis C. That was totally inappropriate because in some instances the letter would arrive on a Friday, a person would get back from work, they would open their post and they would have absolutely nowhere to go on the weekend. They would be getting this diagnosis through the post. So the ARCBS very soon changed that to telling the person's doctor, and then the doctor gave the diagnosis.The knowledge and abilities of the medical profession have improved—I would not say dramatically, but they have improved. They have a long way to go yet. So when people receive a diagnosis it is better now than it was. It still has a long way to go, because pre-and post test counselling is not compulsory. People are not aware of information resources that are available, and the impact of a positive diagnosis that is given in a negative light is huge.

CHAIR—Thank you very much, Mr Loveday. We appreciate your submission and the evidence that you have given us this morning.

(C)

31 May 2004

Mr Elton Humphrey
Secretary
Inquiry into Hepatitis C and Blood Supply in Australia
Parliament House
Canberra ACT 2600

Dear Mr Humphrey

Inquiry into hepatitis C and the blood supply in Australia – subsequent submission

Further to our submission of the 30 January 2004 and our evidence at the public hearing on 6 April 2004, we wish to provide a summary of our perception of the overall matters pertaining to the Inquiry to date. Additionally, we wish to correct incorrect statements that were made about the Hepatitis C Council of NSW during the hearings on 6 April.

Thank you again for the opportunity to make a contribution to this important issue.

Correction of information

1. In verbal evidence on 6 April, Mr Charles Mackenzie, Administrator of the Tainted Blood Products Action Group (TBPAG) implied, when describing the role of the Hepatitis C Councils across Australia, that the Hepatitis C Councils are "[community] groups where people got it [hepatitis C] through sharing needles." The implication that Hepatitis C Councils are in existence solely for and on behalf of people who acquired hepatitis C through illicit drug using means is incorrect. All Hepatitis Councils in Australia, including the Hepatitis C Council of NSW, have *always* provided information, support, referral and advocacy services for *all* people with hepatitis C, whatever the route of transmission. This can be evidenced from all our published reports, media, resources, websites and other information sources that describe our work since 1991, and confirmed in our submissions to this Inquiry.

2. We reject the assertion made by Mr Mackenzie that the reason the Hepatitis C Council of NSW differs from the position taken by the TBPAG with regard to recompense for people with blood transfusion acquired hepatitis C is because we are funded primarily by the NSW government. The Council is a fully independent, community based, non-government organisation with a membership, at 31 May 2004, of 942 individuals and organisations, and with a Management Committee responsible for overall policy and direction, elected from that membership. Many of our members are people who acquired hepatitis C through blood transfusion or blood products receipt, and many members are people who acquired hepatitis C through other means, including injecting drug use. We are funded by the NSW Health Department to perform a range of services, but this in no way impinges on our independence as an organisation or on the views of the organisation.

Summary of key considerations and events

3. Our observation from all the evidence is that the situation regarding hepatitis C acquired through the blood supply in Australia is very different from the circumstances where this happened in Canada and the USA, and as such is not directly comparable in terms of actions and outcomes arising.
4. We note that the risk of HCV acquisition in 1989-90 through the Australian blood supply would have been a little over 1%, or 1.1% in the period 1987 to 1990 as stated by Professors Chris Burrell's and Bruce Barraclough's inquiry evidence based on Professor Yvonne Cossart's and others' work. We understand that Canada and the United States had a much higher risk of hepatitis C acquisition, possibly 6 to 10 % in 1989-90. As early as 1982 Prof Cossart established that the risk of HCV acquisition through the Australian blood supply post-transfusion was 2%, compared with that of around 10% in the USA.
5. The early and consistent introduction in Australian blood banks in 1984-85 of screening questionnaires and tests to exclude, as far as then possible, the potential for HIV transmission further reduced the risk of post transfusion non A-non B (NANB) hepatitis from 2% to 1.1%. This was because the rejection of donors with risk factors for HIV would also eliminate many donors with hepatitis B and C, as they shared risk factors for infection such as injecting drug use, and in the case of hepatitis B, sexual exposure.
6. The need to further reduce this already low risk had to be seen, both then and now, in light of the impact that excluding all blood with elevated LFT levels would have had on the overall availability of bloodstocks. This acknowledges that viral infections are just one cause of elevated LFTs, and notes Prof Cossart's evidence that surrogate testing was just one of four major strategies used during the 1980s to reduce the risk of NANB hepatitis after blood transfusion.

7. The Department of Health and Ageing noted, citing Prof Cossart's evidence, that hypothetical modelling suggests that had surrogate testing been introduced in the 1980s consistently in Australia that the numbers of NANB / hepatitis C infections prevented would have been very small indeed, and even lower numbers of cases of hepatitis C *disease* would have been prevented.
8. We note Professor Barraclough found in the May 2003 inquiry into the 1990 situation they did not have information that showed that Queensland's decision to use surrogate testing in the 1980s had led to a lower rate of hepatitis C infection. One reason for that was Australia's very low level of background risk compared to other countries – and that finding would have required a very large scientific study to confirm.
9. We know that the situation in the USA regarding payment for blood donations has never existed in Australia. The situation in the USA had a major influence on moves taken to reduce the risk of NANB hepatitis in the USA.
10. It is clear to us that the decision taken during the 1980s by the Australian national committee who had examined all available evidence made a difficult but considered choice, and this resulted in a relatively small number of hepatitis C infections which might have been avoided had a different decision been taken at the time. And we note and accept that this decision was taken after extensive debate, amid controversy, and using all the available evidence, knowledge and beliefs existing at the time.
11. It is inconceivable to suggest, in the absence of further evidence, (alluded to by the Tainted Blood Products Action Group in the hearings on 6 April but not seen by us) that there was any malicious wrongdoing at the time. We would have great concern if this were shown to be the case.
12. Likewise we would have great concern if allegations of cover-ups and medical record destruction alleged by the Medical Error Action Group were shown to be true. We are not aware if any further evidence supporting these allegations has been presented to the Inquiry.
13. In hindsight, it is simple to say that the decision taken then should have been to introduce surrogate testing. However we note that an award-winning research review by Harvey J Alter (Nature Medicine 6(10): 1082-6,2000) of surrogate screening over three decades, concluded that despite its conceptual appeal, ALT screening had never been substantiated as a routine measure to prevent post-transfusion NANB hepatitis, and its introduction was driven by concern about the emerging problems in recipients rather than evidence of its efficacy.

Impact of and response to hepatitis C infection

14. We agree with Professor Barraclough in his evidence of the 6 April that where people are harmed by their health care, or where they believe they have been harmed by their healthcare, or where people whose trust in the health care system has been destroyed, that they are often hurt and angry.

15.

We agree with the TBPAG when they say that this disease has devastated some people's lives. Hepatitis C can be a devastating health condition to have no matter the cause of infection, both when inappropriate information or support is given on diagnosis, or where symptomatic illness impacts negatively in a range of ways in the lives of those with hepatitis C and on those around them.

16. It is precisely for these sorts of reasons community-based organisations such as the Hepatitis C Council of NSW came into existence in the early 1990s, to help provide appropriate information, support and referral services for the affected communities.

17. We note the majority view of clinicians and epidemiologists in the 1980s was that non-A non-B hepatitis was frequently asymptomatic or mild and that there had been insufficient natural history studies at that point to provide the now well-known finding that hepatitis C causes a much more serious disease state over a long period of time, with significant impairment of quality of life.

18. We repeat our assertion, made in our verbal evidence on 6 April, that in the case of people with haemophilia, were the current inquiry to find that people involved in the decision not to surrogate test in the 1980s were at fault, then we would support the view that that group of people should have their situation viewed differently and that financial recompense be provided.

19. We note the comments of Dr Robert Baird of the Australian Association of Pathology Practices who stated that people affected as a consequence of the proceedings of this inquiry are those who received transfusions of Red Cross donated blood between the years 1986 to 1990, as prior to 1986 surrogate testing methods were not robust enough to be introduced into general blood bank practice, and after 1990 more specific antibody testing for hepatitis C became available. These 1986-1990 dates are the ones we referred to in our submission when calculating potential numbers of people who contracted hepatitis C through the blood supply.

20. We note the comments of Professor Geoff McCaughan, who had concerns that if financial recompense were to be paid to a particular group of people with hepatitis C who acquired hepatitis through blood transfusion, that this might endanger the overall funding available, within current limited health budgets, which would enable the health care response for the broader group of all people with hepatitis C to be improved. We share his concerns that were recompense to be paid that consideration should be given to ensuring it does not affect ongoing (or future) funding for the current overall hepatitis C response.

21. We repeat our assertion that all people with and affected by hepatitis C, whatever their route of transmission acquisition, should benefit from increased funding on hepatitis C related health care.

Conclusion

22. ***It is our summary view that this inquiry has considered all available and relevant evidence that led to the decision not to introduce surrogate***

testing. On balance while we regret, in the strongest possible terms, that hepatitis C infections arose as a result of this decision, we do not believe that negligence or at fault activities occurred.

23. All Hepatitis Councils continue to offer ongoing services to all people who acquired hepatitis C through medical and blood transfusion means, and are committed to working with them to help reduce the impact that hepatitis C has on their lives and those of their loved ones.

24. We repeat our call for federal and state / territory funding to address hepatitis C to be increased so that all education, health and welfare services and support systems for all people with and affected by hepatitis C can be improved, rather than for a small group of people with hepatitis C to be recompensed for their particular situation.

25. Finally, we strongly welcome the position taken and apology given by the Australian Red Cross Blood Service (ARCBS) at the forum at the NSW Parliament on 27 May 2004, facilitated by Sir Laurence Street. We believe this is a genuine attempt by the ARCBS to convey its sympathy to representatives of people who acquired hepatitis C from blood transfusions, and to address some of their concerns.

26. We consider that this is an honest and heartfelt gesture that will help us all move forward in the current debate. At that forum we suggested to the ARCBS that they publish an open letter in the national media and hepatitis council magazines and newsletters in order to convey to the wider community their apology, thoughts and feelings that were articulated at the forum.

27. We hope this further submission has been of help, and thank you once again for providing the hepatitis C affected communities with a forum to explain their views and needs, and for providing such an in-depth examination of all the issues and circumstances regarding blood transfusion acquired hepatitis C in Australia.

Yours sincerely

Stuart Loveday
Executive Officer