
COMMONWEALTH OF AUSTRALIA

# Official Committee Hansard

# SENATE

## COMMUNITY AFFAIRS REFERENCES COMMITTEE

**Reference: Hepatitis C and blood supply in Australia**

TUESDAY, 6 APRIL 2004

SYDNEY

BY AUTHORITY OF THE SENATE

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**SENATE**

**COMMUNITY AFFAIRS REFERENCES COMMITTEE**

**Tuesday, 6 April 2004**

**Members:** Senator McLucas *(Chair)*, Senator Knowles *(Deputy Chair)*, Senators Humphries, Hutchins, Lees and Moore

**Participating members:** Senators Abetz, Bishop, Carr, Chapman, Coonan, Crossin, Denman, Eggleston, Chris Evans, Faulkner, Ferguson, Ferris, Forshaw, Harradine, Harris, Lightfoot, Ludwig, Mackay, Mason, McGauran, Murphy, Nettle, O'Brien, Payne, Tierney, Watson and Webber

**Senators in attendance:** Senators Humphries, Hutchins, Knowles, Lees, McLucas and Moore

**Terms of reference for the inquiry:**

To inquire into and report on:

(a) the history of post-transfusion Hepatitis in Australia, including the Non-A, Non-B Hepatitis (Hepatitis C) was first identified as a risk to the safety of blood supplies in Australia and internationally;

(b) the understanding of Hepatitis C by blood bankers, virologists, and liver specialists during the past 3 decades, including when Hepatitis C was first identified as a virus transmissible through blood;

(c) when the first cases of post-transfusion Hepatitis C were recorded in Australia;

(d) when the Australian Red Cross and the plasma fractionator Commonwealth Serum Laboratories first became aware of infections from blood contaminated by Hepatitis C, and the actions taken by those organisations in response to those infections;

(e) the process leading to the decision by the Australian Red cross not to implement testing (such as surrogate testing) for Hepatitis C once it became available;

(f) the likelihood that Hepatitis C infections could have been prevented by the earlier implementation of surrogate testing and donor deferral;

(g) the implications for Australia of the world's most extensive blood inquiry, Canada's Royal Commission (the Krever Report);

(h) the implications for Australia of the recent criminal charges against the Canadian Red Cross for not implementing surrogate testing for Hepatitis C in the 1980s;

(i) the Commonwealth's involvement in the provision of compensation to victims of transfused Hepatitis C, including the use of confidentiality clauses in those compensation payments;

(j) the high infection rate of Hepatitis C for people suffering from haemophilia;

(k) the extent to which Australia has been self-sufficient in blood stocks in the past 3 decades;

(l) the importation of foreign-sourced blood plasma for use in the manufacture of blood products, and its potential role in the proliferation of Hepatitis C infected blood;

(m) the number of Australians who have been infected with Hepatitis C through blood transfusion;

(n) the impact that blood-transfused Hepatitis C has had on its victims and their families; and

(o) what services can be provided or remedies made available to improve outcomes for people adversely affected by transfused Hepatitis C.

**WITNESSES**

**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 per cent 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 February 1990 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 surrogate testing 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 long-term 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 upper house, 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 also federally, 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.

[9.50 a.m.]

**ROMANIW, Miss Maria, Coordinator, TRAIDS**

**VELLSCEK, Ms Miriam, Client, TRAIDS**

**CHAIR**—Welcome. 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 be taken in camera if you consider such evidence to be of a confidential nature. We have before us your submission, and we thank you for that. I now invite you to make an opening presentation which will be followed by questions from the committee.

**Miss Romaniw**—Today I will be addressing term of reference (o):

(o) what services can be provided or remedies made available to improve outcomes for people adversely affected by transfused Hepatitis C.

TRAIDS is a state-wide service for people who have medically acquired HIV and/or hepatitis C. We have been established since 1986 for medically acquired HIV, and in 1994 that was extended to provide service for people with medically acquired hepatitis C. The aim of our service is to provide support to people with these blood-borne viruses and to reduce the negative impact these viruses have on people's lives. To achieve this aim we provide counselling, support groups, information nights and workshops for family members, because we feel it is important to strengthen people's community and social supports. We also work in conjunction with other health care providers to raise awareness of hep C in the community and to do training and education for health care workers.

What we are most concerned about is the lack of utilisation of our service, which is tailor made for people who have medically acquired blood-borne viruses. If we find through this inquiry that there are barriers to people accessing our service, it would be helpful for us to look at how we could remedy or at best address these issues.

**CHAIR**—Ms Vellscek, do you wish to add anything?

**Ms Vellscek**—I was going to read out a bit of the submission, which you have probably all read, and add my experiences to it.

**CHAIR**—You do not need to read the submission because we have all been given a copy of it, but if you would like to add some comments we would like to hear them.

**Ms Vellscek**—I have been a member of the TRAIDS support group for three years. It has been running for five years. I have had medically acquired hepatitis C, which was successfully treated with interferon, but I still go to the support groups. Stuart was talking before about people getting a letter from the blood bank. I was one of those people. At the end of 1990 I got a letter from the blood bank saying, 'Guess what? You've got hepatitis C.' I went in for a couple of consultations, and they started talking about liver biopsies. It was all above my head.

The virus was only identified then and there was not very much knowledge. I had the virus for 10 years and, with the virus, I saw the same doctor for 10 years. He gave me virtually no information. To be fair to my doctor, he is a very knowledgeable doctor but in the hep C field he did not know very much at all. So, for 10 years, I carried this alone and isolated. I did not tell anyone in my family about it—I did not know much to tell other people about it. Whenever I went to my doctor for information, I would have a liver function test—once a year—which was close to normal. He would say, 'If it gets any worse, we'll look at treatment; if not, you're right.' I had symptoms during those 10 years, and often I would say to my doctor, 'Could it be the hep C virus?' and he would just dismiss it and invalidate it.

The support group is very important to me, because since mixing with other people with the virus I have found that all these symptoms that I had for a long time before I was treated for it were very real. Lack of information, invalidation, dismissal, carrying it alone and not telling my family—it would have been very nice to have had the information. I particularly thank TRAIDS because out in the western suburbs, in the Parramatta area, that is really the only support place for hep C in our area to which a person from the public can go. Otherwise, there is the hep C council in town. At least it exists and that is good, and I am grateful for that. I wish it was a bit bigger. As well as isolation and depression, I also had a lot of stress during that time. That is my perspective. If there is anything else you would like to know, feel free to ask.

**CHAIR**—Thank you very much.

**Senator LEES**—How did you find out about TRAIDS? At what stage did you become aware that there was a group?

**Ms Vellscek**—When I went onto the interferon treatment, the Storr liver unit at Westmead Hospital and my specialist doctor referred me to TRAIDS because during interferon you do need a lot of counselling, and I used their psychologist on a weekly basis.

**Senator LEES**—So your doctor, the GP, didn't have any knowledge—

**Ms Vellscek**—No.

**Senator LEES**—So is this one of the barriers? I am just looking at what the barriers are for people in accessing the service. What is the biggest problem?

**Ms Vellscek**—My perception is that people in the health system are aware of services; people outside the health system do not hear about them unless they come in contact with the health system.

**Senator LEES**—So there is no automatic system for notification, say, though the Red Cross? If people are notified that they have hepatitis C, is there then an automatic process of giving them the information they need?

**Ms Vellscek**—There is now. The blood bank does refer people on to TRAIDS, but not all people come through the blood bank. Some people are picked up by their GPs.

**Senator LEES**—So what would be the best method of ensuring that people who are diagnosed as having hepatitis C are able to know about and access the service?

**Ms Vellscek**—We are trying to advertise as widely as possible. Also, having contact with health care workers when we do training or education builds up that informal awareness. We also send mail-outs to the division of GPs, but GPs get a lot of information, so it is hard to remember something that you might only deal with once in a blue moon. We are looking at sending another mail-out to coordinators of area health services to see if that raises awareness in rural and regional areas as well.

**Senator LEES**—So, of those people who were infected back in the 1980s through the blood supply, would you have any idea how many of them are accessing the service now, or even know about TRAIDS?

**Ms Vellscek**—It is very hard to get definite figures, because when you look at the surveillance on hepatitis C, only a small percentage have contracted it through blood transfusion. As I say, if people are picked up by their GP, it might not be until they require treatment that they will come into contact with a support service. That may be many years.

**Senator HUTCHINS**—Ms Vellscek, you received a letter from the Red Cross and the Lookback program. You obviously had received infected blood.

**Ms Vellscek**—Yes, but not in Australia. It was overseas. I was born overseas.

**Senator HUTCHINS**—So were they able to trace you at some point to here?

**Ms Vellscek**—I do not even think that little hospital 45 years ago now exists. It happened to me when I was six months old. So I really do not have any recourse. I have been cured now, and I would not sue someone.

**Senator HUTCHINS**—But when you got the letter from the Red Cross about the Lookback, did they advise you to go to your local GP?

**Ms Vellscek**—No.

**Senator HUTCHINS**—Or did they say, 'Please ring this number and come in'?

**Ms Vellscek**—Yes. They said, 'Please ring this number and come in.' I think I went in twice, and had two liver tests or two blood tests with different readings. They told me I couldn't donate blood any more and they told me that I might have to have a liver biopsy. I found that quite frightening—to be a normal blood donor one day and then the next day someone is talking 'liver biopsy' and saying 'You have a virus in your blood'. It is a bit of a shock to the system.

**Senator HUTCHINS**—You had been donating blood, had you?

**Ms Vellscek**—Yes, for nearly three years, or just over three years.

**Senator HUTCHINS**—Prior to 1990?

**Ms Vellscek**—Yes, from 1987 to the end of 1990 I was a blood donor.

**Senator HUTCHINS**—And it was only in 1990 that they found out you had hepatitis C?

**Ms Vellscek**—Yes.

**Senator HUTCHINS**—Do you know how much blood you gave in that period?

**Ms Vellscek**—I did it monthly. I think they take 400 mls each month, times three years—a substantial amount of blood. I feel a bit better because I have been told that a lot of blood gets thrown out.

**Senator HUTCHINS**—When you were advised that you probably had hepatitis C in 1990, did you go into the city Red Cross, or Parramatta?

**Ms Vellscek**—The city one, yes.

**Senator HUTCHINS**—What sort of treatment did they advise you that you might need to take? Did they say you should see a particular doctor or your own GP?

**Ms Vellscek**—No advice was given. The only thing I remember him saying was, 'You might need to have a liver biopsy,' which I found very frightening.

**Senator HUTCHINS**—You talked about the discrimination of people with hepatitis C. When did you tell your family you had it?

**Ms Vellscek**—I told my sister. I did not tell my mother. I told my partner. They were not discriminatory about it.

**Senator HUTCHINS**—We have had a number of submissions about health workers not being all that knowledgeable about hep C. Would you like to comment on that? Miss Romaniw, you might like to comment on that as well.

**Miss Romaniw**—I think that is quite true.

**Senator HUTCHINS**—Would it be too strong to say that there is some discrimination against people?

**Ms Vellscek**—There is a lot.

**Miss Romaniw**—I think that was fairly well documented in *C-change: the report of the enquiry into hepatitis C related discrimination*, which looked at discriminatory practices. Health care workers—GPs and nurses—certainly rated very high. That is because they do not deal with it all the time and because they are not very knowledgeable. We have tried various methods to provide training and education for health care workers, but if you are not dealing with a particular disease you do not retain the knowledge about it. There are lessons to be learned from HIV that should have been known to workers because the same standard procedures are used for all blood-borne infections.

**Senator HUTCHINS**—Would you say that is still the case for hep C?

**Miss Romaniw**—Very much so.

**Senator HUTCHINS**—So not only does the public need more awareness but so do health professionals?

**Miss Romaniw**—Yes, health professionals. And the workplace is an issue because people need to have days off if they are unwell or if they have medical appointments and they take a risk if they tell their employer they have hep C because they are looking for support in having time off. At the same time there have been some very negative reactions when disclosure has happened.

**Senator HUTCHINS**—In relation to the time off I wanted to ask about the financial burden. You referred in your submission to the financial burden experienced by hep C sufferers. Obviously employment is an issue.

**Miss Romaniw**—Yes.

**Senator HUTCHINS**—Would you like to elaborate for us on what other burdens there are for people who have this infection?

**Miss Romaniw**—I think employment is important because once you have used up your sick leave you start using leave without pay. If you are the sole provider for the family, that starts to affect your ability to support your family. Having odd days off here and there, you accumulate a large financial burden. You cannot get sickness benefits for that short term. A lot of people who are not successful in treatment—and some of those who are on treatment—use alternative medicines to try and deal with some of the symptoms they experience. These are not cheap; they are very expensive. If you are a mother, your partner is working and you have to attend appointments or you are unwell you may have to use child-care services. There are a whole range of other things that you would normally not have to expend money on. This adds to the costs of people surviving with hepatitis C, or living with it.

**Senator HUTCHINS**—In your opinion are alternative medicines successful or helpful?

**Miss Romaniw**—I think they are helpful for some people. Some of the herbs have been found to ease some of the symptoms. Increasingly when people find that the treatment is not going to work for them they seek alternatives to orthodox medicines.

**Senator HUTCHINS**—What sort of funding do you receive? Do you receive any funding from Commonwealth, state or local governments?

**Miss Romaniw**—We get ours from the New South Wales health department.

**Senator HUTCHINS**—You receive none from the Commonwealth that you are aware of?

**Miss Romaniw**—I do not manage the money but I think there was some enhanced funding for hep C. But that does not help people who have personal financial burdens.

**Senator HUTCHINS**—Has your service encountered any clients who were asked to sign confidentiality agreements in return for financial settlements in relation to claims against Red Cross or others because of infection?

**Miss Romaniw**—I am not aware of that with any of our clients in relation to transfusion blood.

**Senator KNOWLES**—There seems to be a great degree of universal sensitivity to telling other people whether one has hep C or not, particularly when it is medically acquired. One might ponder the reason for that. If, for example, someone got golden staph or some other infection in hospital, would they have the same reluctance to tell their family that they had got an infection? In your opinion, what is the sensitivity, particularly about hepatitis C, vis-a-vis any other form of infection that one may get?

**Miss Romaniw**—I think there are a number of diseases or conditions where you will get a sympathetic response. If you have cancer you will get a sympathetic response. If you have something like hepatitis C, which is very misunderstood by the community at large, you do not always get a sympathetic response. It is associated very much with illegal drug use, and that is mainly what comes to people's minds. This is a group that is already marginalised because of their illegal activity. People with blood transfusion related hep C find it very difficult that they may also be judged to be an illegal drug user. Many face things like, 'I suppose you're going to tell us you got it through blood transfusion,' as if—

**Senator KNOWLES**—That is the excuse.

**Miss Romaniw**—As an excuse. It is not a condition that gets a sympathetic response in the wider community or within the health system.

**Senator KNOWLES**—I suppose I am really directing that question to why people do not tell their families. One would suspect that their families would know their lifestyle pretty well. Therefore, if a person went to their family and said, 'I have medically acquired hepatitis C,' the immediate family would not be reacting with shock and horror and saying, 'Don't tell me you're a drug user or have been undertaking other unsafe practices.' So that reluctance to tell the immediate family, even if there is that broader misunderstanding, tends to escape me a little.

**Miss Romaniw**—It still gets a knee-jerk reaction from family members. As I said, it is very misunderstood. One of the things that can cause a lot of problems in the family is fear about contamination—how it is going to be spread. I have heard of people keeping their children away from the person affected because they are fearful that somehow the children will get it through ordinary contact.

**Ms Vellscek**—A member of our support group is in her 70s and has recently had a knee operation. She has not told her daughters that she has hepatitis C. She feels dirty. She will never tell her daughter, because she said her daughter would keep her grandchildren away from her. You said that people are aware of people's lifestyles, Senator Knowles—

**Senator KNOWLES**—Surely she does not think that granny is out there shooting up every second day!

**Ms Vellscek**—I am wondering what she does think. Maybe there is a general perception that hepatitis is a dirty disease—not just a drug addict's disease but also a dirty disease; that you are dirty person if you have it. That is lack of education. I know that one of the hepatitises can be spread easily, but the other two cannot. Maybe the common mind does not distinguish.

**Senator KNOWLES**—You have talked in answer to other questions about creating greater awareness among the public and health professionals. Clearly, to expand on that idea, we need to find out what specifically you think should be done to overcome those barriers, particularly when we are talking about next of kin. How would you suggest we overcome those barriers?

**Miss Romaniw**—I think there definitely have to be many more awareness campaigns. In the early days of HIV there were a lot of media awareness campaigns to educate people. We do it on the level of going out and talking to different communities. We talk to the department of housing and Centrelink because those are organisations that people will come into contact with. We talk with other communities and we try to educate health care workers. But they are small steps—

**Senator KNOWLES**—That is sort of in-house, isn't it?

**Miss Romaniw**—in a bigger community that needs to be aware.

**Senator KNOWLES**—How do you suggest we go out to the broader community? If we deal with that in-house, then how do we get out to the broader community?

**Miss Romaniw**—I think there has to be a wider media campaign and more awareness on a broader level. That role could be done in conjunction with someone like the Hepatitis C Council, who are very knowledgeable about awareness and how to raise it on a broader level. It needs to get out of the health system and into the general population so that people are much more aware. People who work in the area and share the knowledge know where to refer on, but when you are not in the health system—and clients are not—you do not know where to get support and information that would help you understand. Your family members also do not know where to get information. I always say that if you tell your family that you have hepatitis C you must also give them information and allow them to talk to people who can answer their questions. Yes, there has to be a much broader campaign that is not just in the health system but outside the health system.

**Senator KNOWLES**—It sounds as though, from the material that you have provided, you run a particularly comprehensive support program. I think that that is fantastic. But when someone comes to you do you provide them with all the information to take home to the family and almost force-feed them and say, 'Sit down and read that'?

**Miss Romaniw**—Before giving information I might get the nurse consultant to do one-to-one education, because with no education beforehand reading material can be quite frightening and people can misread things and think: 'I have cirrhosis; I am going to die.' It is very important that they get some education before reading the material so that there are no misunderstandings and it is clear. The reading material then helps them further clarify information. We try to also arrange some one-to-one education for them as well.

**Senator KNOWLES**—Thank you.

**CHAIR**—It is very evident from your submission that you are of the view that a campaign of information is required. How do you target that? How do you suggest the government undertake an information campaign of that nature?

**Miss Romaniw**—Using the media is always good. Personal stories in magazines are helpful. We have an AIDS Awareness Day but we do not have something of that nature for hepatitis C.

**CHAIR**—Is the AIDS model an appropriate model?

**Miss Romaniw**—Some aspects of it. Hepatitis C strategies have built on what was previously successful in HIV. Some of those models are certainly useful.

**CHAIR**—The level of discrimination troubles me, to be frank—not only the discrimination that your group has given us information about but discrimination across the whole community. How best should governments deal with the fact that people seem to be discriminated against in a whole range of ways?

**Miss Romaniw**—As a result of the sea change inquiry into discrimination, an antidiscrimination project went out to various health services in New South Wales. Again this is targeted towards health care workers—how to make their practice less discriminatory and what would be the ideal. That probably helps with the health care component, but again in the community the lack of information—about what hepatitis C is and how it is spread—causes the negative reaction people receive in public. I think that means having to target the public.

Workplaces need to be very aware of how they should behave with hepatitis C. I have in the past gone to a hearing with a lady who was discriminated against at a public school. It was a very long drawn process to get her hearing. I felt that she did not get a lot of satisfaction through these processes. In fact in the end she gave in to what they wanted rather than what she wanted just to get through this process. When people like the Anti-Discrimination Board deal with people who have been exposed to discrimination they need to ensure that those people get a good hearing, that it is speedy and that these actions by large institutions—such as the department of education—are thoroughly dealt with so it does not happen again.

**CHAIR**—You seem to be saying that it is based on a greater community understanding and once that understanding is made more clear the potential for discrimination will diminish.

**Miss Romaniw**—That is right.

**CHAIR**—Thank you very much for your evidence and your submission. It is much appreciated. Thank you very much, particularly Miss Romaniw, for your openness. Your evidence has been very valuable.

**Proceedings suspended from 10.15 a.m. to 10.45 a.m.**

**BOLLMEYER, Mrs Suzanne Margarette, Member, Tainted Blood Product Action Group**

**CREWS, Reverend William David, Member, Tainted Blood Product Action Group**

**JACOBSON, Ms Jacinta Mary, Member, Tainted Blood Product Action Group**

**MACKENZIE, Mr Charles, Administrator, Tainted Blood Product Action Group**

**POLLACK, Mr Michael James, Member, Tainted Blood Product Action Group**

**CHAIR**—I call the committee to order and advise all present that, due to the fog in Sydney this morning, our scheduled next witness, Dr John Rowell, from the Australian Haemophilia Centre Directors Organisation, is delayed. I thank the Tainted Blood Product Action Group for agreeing to change the order in which we take evidence this morning. When Dr Rowell arrives we will have to have a discussion with him about his commitments later this afternoon, so we will have to play it a bit by ear between now and lunch. I thank everyone for their accommodation of that.

I would also like to thank all of those present here today for your interest in this inquiry. We know the level of interest that you have and we recognise the importance of this inquiry to your future. Thank you also for your submissions. A very large number of submissions, both on the public record and confidentially, have been provided to the inquiry. All of them are valuable and we thank you very much for them. The other issue is that this room is somewhat hard to hear in. We have turned up the speaker system. If you have difficulty hearing, please raise your hand and we will try and do the best we can so that everyone can hear the evidence being presented.

I now welcome the representatives from the Tainted Blood Product Action Group. Do any of you have any comments to make on the capacity in which you appear?

**Rev. Crews**—I am a member of the Tainted Blood Product Action Group and I am also minister at Ashfield Uniting Church and Chairman of the Exodus Foundation.

**Mr Pollack**—I am a member of the Tainted Blood Product Action Group and a transfused hepatitis C victim.

**Ms Jacobson**—I am much the same as Michael and a member of the group.

**Mrs Bollmeyer**—I am a member of the group from Adelaide.

**CHAIR**—Thank you. Information on parliamentary privilege and the protection of witnesses and evidence has been provided to you all. 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 which will be followed by questions from the committee.

**Mr Mackenzie**—I am going to make the opening presentation. It will probably last about 10 minutes. Forgive me for being a little bit nervous today—

**CHAIR**—Don't be.

**Mr Mackenzie**—because this is quite a monumental occasion for tainted blood victims. I will get started and do my best. I would like to take this opportunity to thank you for providing the Tainted Blood Product Action Group and the victims that we represent with a forum in which the tainted blood tragedy can be addressed in an open and fair manner. We are a little group made up of little people. Groups like ours tend to end up fighting injustices often brought upon them by large organisations. It is a tough fight for groups like ours. We have no money to fly in paid American doctors like the Australian Red Cross have done for this inquiry. We do not have the capacity to commission lobbyists like the medical company CSL have done. CSL have commissioned lobbyists who are actively lobbying against the interests of victims of tainted blood as we speak. We can only defend ourselves by trying to call on the support of fair-minded and compassionate Australians.

I would like to commend the courage of three tainted blood victims who are going to give evidence today. As you have heard, their names are Sue Bollmeyer, Jacinta Jacobson and Michael Pollack. I commend them because they have sacrificed their right to privacy in order to help other victims of the tainted blood tragedy. They have received no money; they are not lobbyists; they are just ordinary Australians who want to discuss the full circumstances that surround their infections. They will be followed by the Reverend Bill Crews of the Ashfield Uniting Church. He is a supporter of tainted blood victims and will be giving a brief address.

I would like to start the main points of my address by firstly outlining the Tainted Blood Product Action Group's position on blood donation. The Tainted Blood Product Action Group believes that blood donation is extremely important. Blood donors are true lifesavers—heroes in every sense of the word. Victims wanting to discuss the full nature of the tainted blood tragedy in no way suggest that they wish to see fewer people making blood donations in Australia. Tainted blood victims have suffered enough. They do not want other Australians to suffer in the same way ever again, whether that be due to a shortage in the blood supply or from contaminated blood. It should be said that Australian blood donors are modern-day heroes who deserve Australia's applause and encouragement.

I would like to start now on the issues and the dangers of tainted blood by addressing what I consider to be a medical emergency and a danger to mothers. Evidence given to this inquiry highlights the failure of the Australian Red Cross and the health departments to warn Australians about the dangers of blood contaminated by hepatitis C. Please refer to the report submitted to this inquiry called the *Lookback* report, which highlights this failure. You can find it at the back of the Tainted Blood Product Action Group submission. Also, the committee will note that many of the submissions from victims of tainted blood show that they were unaware of their exposure to hepatitis C. In most cases, many victims found out only through failing health sometimes decades after exposure and not from notification from the relevant health bodies. Sadly, for some their terrible discoveries came too late to save them.

Through my research into tainted blood and via my role as Administrator of the Tainted Blood Product Action Group, I have been horrified by the number of mothers who have acquired

hepatitis C from contaminated blood. The Australian Red Cross and relevant health departments have neglected to adequately warn the public. Letters have not been sent to all those who received blood transfusions in the high-risk blood transfusion years prior to the 1990s. It is imperative that this situation be rectified. Those letters must be sent. The federal government must step in and end the silence on this matter. They must inform the public. Hundreds, perhaps thousands, of Australians have still not been traced. This is a medical emergency. Mothers given blood for pregnancy and childbirth complications prior to 1990 must be warned.

No screening was used by the Red Cross for hepatitis C in the decades before the 1990s even though it knew the dangers were there and that people were being infected. This means that it is a statistical reality that there are mothers out there who still do not know that they are infected. With each day that passes their condition will deteriorate, their lives are at risk and they need to be warned. Those infected need to seek medical treatment and advice before it is too late. The Australian Red Cross distributed hundreds of thousands of blood transfusions in the years preceding 1990. If that organisation believes that the risk of hepatitis C being transmitted to recipients was one or two per cent per unit of blood back then, we have a real crisis on our hands. Given the huge number of transfusions distributed in these earlier decades, it is alarmingly certain that there are thousands of patients, such as women who needed blood during childbirth, who have been exposed to the deadly virus hepatitis C but still do not know it.

The Australian Red Cross Blood Service and the health departments must act on this danger. They have a legal and moral duty to do so. Their first priority must be to warn people like this. To date they have failed in this duty, as can be ascertained from reading the submissions made to this inquiry from victims of tainted blood. I urge all mothers who received blood transfusions for pregnancy and childbirth complications prior to 1990 to go to their GPs and request that they be tested for hepatitis C. Mothers who have received blood prior to 1990 are not the only people who need to be warned. All Australians who have been given blood transfusions prior to 1990 need to be warned. They need to be warned in a responsible fashion. They need to be told the full facts. This is necessary as it will potentially save lives. This is an urgent necessity as the Red Cross cannot, by their own admission, guarantee that all those infected with the deadly virus hepatitis C have been traced.

I would like to quickly move on to the blood system and its unsafe sources. The Australian Red Cross collected blood from prisoners. This is a frighteningly dark chapter in Australia's history. The Australian Red Cross Blood Service harvested blood from prisons, where a high percentage of IV drug users exist, where a high rate of those infected with HIV and viral hepatitis exist, where the practice of unprotected homosexual intercourse exists and where substandard health care also exists. The Australian Red Cross collected blood from jails a full 12 years after other countries ceased this dangerous practice. In fact, the Australian Red Cross maintained this dangerous practice until well into the 1980s. The Canadian Red Cross stopped collecting blood from prisons in 1971 as it was deemed too dangerous. In the 1990s, the Canadian Red Cross were forced out from managing the Canadian blood supply because of negligence relating to hepatitis C. What does this tell us about our own Red Cross in Australia? Prison environments are bug incubators; they are places where, in order to survive, some inmates find it beneficial to lie. What could be worse than collecting blood from prisons? It is little wonder that over 80 per cent of Australians with the blood disorder haemophilia are contaminated with hepatitis C as a result of having received blood sourced from places such as

this—80 per cent of Australia's haemophilia population. Can Australia really claim to have one of the safest blood supplies in the world?

Australians have been lied to; we have been misled. We were lied to when the Red Cross and CSL said that only blood from safe sources was used in its products. Evidence has been submitted to this inquiry which shows that the Australian Red Cross deliberately collected blood from individuals with hepatitis C, they deliberately collected blood from individuals who they knew to be liars and criminals and they deliberately collected blood from people who they knew to be IV drug users. We were lied to when we were told that Australia's blood system was self-sufficient. Now we know that was not the case. The medical company CSL has in recent times brought in blood plasma from foreign countries which they mixed into our blood supply. Australians have been betrayed by this company.

Australia has also purchased blood and blood products from US companies that are known to have harvested blood from the US inmate population on a massive scale and to have shipped it around the world. Senators, please refer to section 7.3 of the submission of the Tainted Blood Product Action Group for more information about our stance on this. The worst such operation where this took place in the United States was at the Cummins prison farm in Arkansas. We know that blood collected from Cummins prison was used throughout North America, Europe and Asia, and we believe possibly in Australia. Right now questions are being asked in Canada, England, Ireland, Scotland and Japan about the Cummins blood program and the international use of US prison blood. Australia should be asking questions too. I urge the committee to send a letter to the American Food and Drug Administration and to the US Department of Justice requesting final clarification on whether any plasma sourced from US prison facilities ever arrived in Australia. The lives of haemophiliacs and other hospital patients deserve this clarification.

I would like to now address the Australian Red Cross Blood Service and their inconsistencies on surrogate testing. I have heard in the last couple of days many suggestions that, really, surrogate testing would have been of no use. I do not think that this fully explains the stance of the Red Cross in Australia on surrogate testing, and I will explain why. When responding to issues regarding hepatitis C, the Australian Red Cross Blood Service will often state that they began testing for hepatitis C in the blood supply in Australia in 1990. They will make proud declarations that they were one of the first blood banks in the world to do so. But there was another test known to blood bankers around the world before 1990 that could reduce the prevalence of hepatitis C in a blood supply. It was known as the ALT test, said by many experts around the world to reduce the incidence of hepatitis C in a blood supply by as much as 50 per cent. Blood banks in the United States and in Europe utilised this test to great effect.

The Australian Red Cross Blood Service have defended their decision not to use ALT testing prior to 1990. Criticisms that they should have done as much as possible to reduce the incidence of hepatitis C prior to 1990 are usually described by the blood service as nothing more than hindsight. The Australian Red Cross Blood Service have stated that they acted appropriately when electing not to introduce ALT testing in a bid to reduce the prevalence of hepatitis C in the blood supply when that testing was available decades before the advent of specific testing in 1990. Does this mean that the Queensland Red Cross blood service acted outside the best interests of Queenslanders when they decided to implement ALT testing to reduce hepatitis C in their state's blood supply in 1988? The Queensland Red Cross were the only blood authority in

Australia to do something about hepatitis C prior to 1990 in terms of donor screening. They introduced a form of blood donor screening but, according to the Australian Red Cross, nothing could be done about hepatitis C before 1990. Either the Queensland Red Cross are lying about their introduction of ALT testing in 1988 or the Australian Red Cross are misleading the public when they say nothing could be done.

The Australian Red Cross Blood Service are supposedly a humanitarian organisation. They claim to have done no wrong when it comes to the management of Australia's blood supply. Yet they do in fact compensate certain victims of transfused hepatitis C. What is not clear to the general public is why they do it. Do they compensate because of legal liability or do they compensate on humanitarian grounds? Why have they secretly compensated some people who have acquired hepatitis C from blood transfusions? Why have certain tainted blood victims been compensated and others not? Why have people who were transfused with contaminated blood in particular years in the 1980s been compensated and people similarly adversely affected but transfused in the 1970s not been? If the Red Cross have done nothing wrong, why do they demand that victims they choose to compensate sign secrecy agreements in exchange for cash? Why would a humanitarian organisation do something like this if they felt they have done no wrong? Have the Australian Red Cross been compensating certain tainted blood victims on humanitarian grounds? If they have, why do they not offer compensation to all victims of tainted blood? Surely this would be a humanitarian response.

There are many victims in this audience today who have not been offered compensation by the Red Cross. They have asked, but the Red Cross have shut the door in their faces. If it is the case that the Red Cross compensate on legal grounds then this Senate inquiry needs to shine light on this. We must know the full terms. It would be unreasonable and irresponsible to expect thousands of uncompensated tainted blood victims to all get lawyers and inadvertently clog up the court system. So let us have this Senate inquiry make recommendations to compensate all victims. If it is the case that the Australian Red Cross Blood Service compensate on humanitarian grounds then let us have them open this up to all victims without discrimination about what years people were transfused. The Australian Red Cross Blood Service should compensate all victims of transfused hepatitis C.

I turn to the way forward. This Senate inquiry into hepatitis C and the Australian blood supply has an opportunity to assist victims. Much of the secrecy that has surrounded and frustrated victims of tainted blood will be lifted post this inquiry. In the last three decades, thousands of Australians hospital patients have been infected with the deadly virus hepatitis C from contaminated blood transfusions and blood products. Victims of this tragedy include adults, children, accident victims, the sick, the anaemic, pregnant women and those who have had elective surgery. They are not isolated to the acutely ill who would have died without an urgent transfusion. While this is a medical disaster it is, in essence, first and foremost a human tragedy that has destroyed the lives of many men, women and children. These are people who went into hospital, received transfusions and ended up with this life-changing disease. Many of them now face a lifetime of disability. The disease increases the pressure on them of everyday responsibilities like being a parent, paying a mortgage and putting food on the table for their families. It is time to provide victims like these with answers. It is time to provide victims with long overdue humanitarian assistance. That concludes my address. I would like to hand over to Suzanne Bollmeyer, who will briefly outline her experiences with her hepatitis C infection from blood.

**Mrs Bollmeyer**—I am one of the people that Charles was referring to. I am 45 and I married Patrick in 1978. At 10.30 p.m. on 11 February 1983 I gave birth to our son, Benjamin, by emergency caesarean section at Flinders Medical Centre in South Australia. My labour was induced and after 13 hours they attempted an unsuccessful high forceps rotation and then did an emergency caesarean section as the baby was in foetal distress and I had lost a lot of blood. I was given several packs of plasma. I was quite ill for many months after the birth. But it had been a difficult time for us and we had a demanding baby and we just assumed that my ill health was due to the trauma and stress of the birth. In 1988 I gave birth to Kathryn by caesarean section, with no blood or blood products given. By the mid-nineties I was starting to be quite ill and there were times when I could hardly get out of bed. I had blood tests and cardiograms and was being treated by a skin specialist.

I changed my GP as my life was becoming more frustrating. In 1997-98 these symptoms were more acute and were joined by night sweats, joint pain and skin problems. In December 1998 my GP, Dr Ian Tattersall, decided to test for HIV, hepatitis B and C and chronic fatigue syndrome. My doctor's partner, Dr Karl Shapel, called our home on 14 December 1998 and asked my husband and me to see him immediately. I was told that I had tested positive for hepatitis C. I was asked if I had had any blood transfusions or products, had used IV drugs or knew anyone with the disease. All I could tell him was that I had been given plasma in 1983.

My husband and children—Ben, 16, and Kathryn, 10—had to be tested as there was a possibility I may have infected them. I cannot put into words how it felt waiting for the results. All were negative. We now had the task of informing family members. My mother is a trained nurse who had also worked at the Red Cross Blood Service and had attended many lectures on blood safety concerns. My sisters took the news differently. One was very supportive but we now have no contact with the other sister and her family. I also had to explain to my children not to mention at school or to their friends or classmates that I had hepatitis C. The stigma of this disease stays with you always.

Dr Shapel contacted the Red Cross Blood Service in January 1999 to report a case of post-transfusion hepatitis C. We received a letter from the Red Cross dated 11 February 1999 stating that a look-back on my behalf had been started. My husband and I went to the Red Cross Blood Service on 23 June 2000 to inquire why we had not received any communication from them since February 1999. We were interviewed by Dr Margaret Frewin, and I was informed by her that I had not been transfused with any blood or blood products. She stated, 'You were only given plasma light.' She also said that I must have done something in my past and that I had no right to question them. The Red Cross Blood Service then sent a letter to Dr Shapel dated 23 July 2000. It said:

There is no evidence in her case notes to support the fact that Mrs Bollmeyer received any blood or blood products during her admission to Flinders Medical Centre.

On 23 August 2003 my mother and I went to the blood service again and saw Dr Helen Ingram. She had copies of my medical notes from Flinders Medical Centre stating that I was given plasma on 11 February 1983. I said that I knew that plasma definitely is a blood product and that I was given two packs. Why have they lied to me and my doctor? Why hadn't they contacted me? I cannot put into words how I now feel about the Red Cross. I was a blood donor before then, before 1983.

Our family suffers greatly, both emotionally and financially. I also have difficulty in doing many tasks around the house, and our social life is affected. I now have severe arthritis and joint pain as well as very high blood pressure and other symptoms of HCV infection. I can now no longer work. My monthly prescriptions are over $120. We have had private health insurance continually since 1981, but this still does not cover costs. I have no superannuation. I cannot get a life insurance policy. Nor would I pass an employment medical. My husband works 70 to 90 hours a week to provide for us. He also bears the enormous strain of this disease. Our personal life is also affected as I am afraid of infecting him.

Our son's 21st birthday was on 11 February 2004. He did not want a party. I asked him why, and he said: 'It is not only my birthday but also the anniversary of you being sick. I do not feel like celebrating that.'

**CHAIR**—Thank you very much, Mrs Bollmeyer.

**Mr Mackenzie**—I would like to now ask Michael Pollack to give a brief address about his circumstances to the Senate committee.

**Mr Pollack**—My story appeared in the *Sydney Morning Herald* on 1 July 2002, the *Sunday* program on 10 November 2002 and the *Today Tonight* program on 12 June 2003. I am a transfused hepatitis C victim. My story in the *Sydney Morning Herald* on 1 July 2002 resulted in the then Minister for Health and Ageing, Kay Patterson, ordering a federal inquiry on 2 July 2002. This inquiry was the federal report into plasma in 1990 by the expert advisory group. This inquiry was chaired by Professor Bruce Barraclough, the head of the Australian Council for Safety and Quality in Health Care.

Although my letter caused this inquiry, I was not called to convey any information about that letter, my meeting with staff from the blood service or my blood donations. It is the perception of many that had I spoken about these events at that inquiry it would have had a detrimental effect on the way the inquiry was being deliberately steered. The terms of reference for that inquiry were too narrow, only relating to 1990, even though Australians were infected by their own blood service for a decade before 1990. In short, this inquiry was a snow job or a whitewash. I urge the committee to take the time to read my submission in its entirety.

I refer to terms of reference (n) and (o) of this inquiry relating to the impact of the disease and what services could be provided for victims and their families. I would like to point out to the committee the huge impact this disease has had on my life and the lives of my family. I was disabled already and had no use for a potentially fatal liver disease to go with my disability. I was coldly informed of my infected status by mail in a very unethical letter. This letter was to compound the problem by asking for repeat blood donations. At this point in my life, 1990, I had just put my life back together. I had met my future wife, Bernadette, and we wanted to start a family. My wife was five months pregnant with our first child and this revelation by the blood service caused immeasurable stress and worry.

The blood service have stated that no contaminated blood went back into the supply after 1990 but 85 per cent—Charles said 80 per cent; I will go out on a limb and say 85 per cent—of haemophiliacs now have hepatitis C as a result of contaminated blood products. That is disgusting. My family know I was asked to repeat contaminated donations for fractionation into

these products. My family know that, in addition to this fact, compensation payments totalling $10.8 million have been paid in return for secrecy agreements. It is obviously stressful for my family to watch as crimes against innocent Australians are still deliberately and continually covered up.

My family watch me get sicker through illness or through trying treatments. My family suffer daily because of this virus. There are times when I cannot have a meal with my family because I am too ill. Sometimes it is impossible to play with my children or attend school related functions. My wife works because I am disabled, and I look after the children. Sometimes I am too sick to mind my children or I become ill trying to prepare food for them.

I do not sleep well, and when I do, I sweat profusely, to the point where I sleep on a towel. I also have to deal with chronic pain, sciatic nerve palsy and a prosthetic limb. I was transfused as a minor and have spent my whole adult life infected with hepatitis C. I doorknocked for the Red Cross for five consecutive years whilst I was at school. When I donated my blood back, it was to pay back what I borrowed. Now I cannot do that.

The blood service has poisoned me and used my blood to infect others. I chose to stop donating my infected blood whilst the Red Cross Blood Service encouraged repeat donations from me—they encouraged them. My family have to listen to the Blood Service executive's repeated rhetoric about patient and donor care always being their top priority. The blood service have never apologised for Australia's biggest medical disaster. Blood service executives maintain that victims are referred to specialists and counsellors, but I have not been referred, nor has my family been offered any assistance. I was not even given any information in the form of a pamphlet, and I was transfused in 1983. The stigma my family have suffered by being grouped in with IV drug users is immeasurable, and that will continue. The blood service could have commenced helping transfused victims and their families years ago, but preferred to cover up what they had done.

My young family are continually made to feel dirty or inferior through no fault of their own. On 13 September 2003 there was herpes in Australia's blood supply. When the TGA investigated, they found five breaches in three months. This was in September last year. This disgusts my family, and considering that my children are the next generation of Australians they will know that the blood system is still broken. My family realise that blood is big business and that the Australian Red Cross Blood Service is just a shopfront for CSL. We know that blood was sought continually from high-risk donors. The blood service wants us as a family to believe the defence of the blood service executives when they tell us that the blood service was fragmented. This sends a clear message that it was mismanaged. My family and other victims know for a fact that if surrogate testing for hepatitis C had been introduced in a timely fashion the incidence of post-transfusion infection would have been greatly reduced—not eliminated, but greatly reduced. If the smallest percentage of infected material was kept from the blood supply it would have helped reduce the rate of infection.

Australians have a right to the best possible product available. Australians are not a second-rate people deserving of a second-rate treatment. We are a proud people, whose very nature consists of carrying on regardless of adversity. The blood service and CSL took advantage of this fact and failed to notify recipients of infected blood and blood products, hoping that the victims would pass without fuss. This practice was about as bloody un-Australian as possible.

It is the opinion of my family that mammoth fines should be imposed on CSL and blood service executives for their negligence. There is easily enough evidence for a royal commission and/or criminal investigation. These companies should be liable for modest amounts of compensation and health care for victims. This should be made available sooner rather than later. This disaster and the treatment of victims are shameful and in no way reflect the moral fabric of this great country. Please read my submission. It is No. 12. I urge you to read it. Thanks for listening.

**CHAIR**—Thank you, Mr Pollack. You can be assured we have your submission in front of us.

**Mr Mackenzie**—I would like to ask Jacinta to briefly outline her experiences.

**Ms Jacobson**—I had a motorcycle accident in November 1987. I got taken to hospital. I had extensive injuries. I had no idea what they did to me, because I was under anaesthetic. It was not until February 2002 that I started getting very sick—I had two young children then; I am a single mother with two kids—and I went to the doctor. She gave me a blood test and it came back with hepatitis C antibodies, which means that my body was making antibodies to fight this infection. I thought it was a death sentence and I was asking how I could have got that. I do not have tattoos. I have never been an IV drug user, which is automatically the first thing that you think of when you get this thing—that you have AIDS, or something like that; that you have done something awful to your body. One of the questions was: 'Have you ever had a blood transfusion?' I said, 'Well, I think I might have because of the accident that I had.'

I did not know what to do. It was just around that time, coincidentally, that I read an article in the paper saying that Charles was starting this Tainted Blood Product Action Group. So I contacted him and I went along to the forum out at Ashfield, and that was the first I had heard about the Lookback program. The doctor did not say anything; nobody had told me anything about it. It was only through this that I had heard about it. This was a good three or four months after I had found out.

So I contacted the Hobart Lookback program—I had the accident in Hobart—and asked them whether they could check it out for me, and they said that they would. Six weeks later I still had not heard anything so I called them again to try to hurry them along a bit. Then I got a letter to say that I had never been transfused with blood during my operation. I thought that that was wrong, because I had a friend who was working in the blood section of the hospital and I remember her saying something about it. So I looked into it further. I went through my doctor and got the records from the hospital myself. The fluid charts clearly state that I was transfused with a pack of blood as well as a pack cell, which is like a plasma and is also a blood product.

I got back to the Lookback program and said: 'What's all this about? You're saying that I haven't been transfused when I have evidence here that I have.' They said, 'We'll have another look into it.' About six weeks after that I called them again and said, 'What's going on?' They said, 'We'll get in contact with you again.' I was just about to go in for a liver biopsy, which is one of the most horrendous things that can happen to you, when a bloke called and questioned whether I had hep C. He said: 'Do you really have hep C? Are you sure?' I thought, 'I'm going in for a liver biopsy, mate; why would I be doing that if I didn't have hep C?' He was very offhand and blase about it and he said: 'We've checked out a couple of the donors and they've come back negative. There's one that we can't track down; he hasn't donated for a few years and

we have no way of contacting him. I couldn't stand up in a court of law and say that he was free of hep C. There's nothing really that I can do about this.' So, what can you do?

I went and had the biopsy. I have just come out of a year of hell. I have been on the drug pegulated Interferon and my hair has fallen out and I am so tired. I am on antidepressants and on constant painkillers. I have no idea whether or not I have been cleared. I have another six months to wait before they give me an all clear, if at all. I have a life sentence here. I have two children and I do not know what is going to happen to them—if anything happens to me, who is going to look after my children? But I have not heard from these people since. The only way I heard from them was by my calling them and writing to them. They lied to me about this—and it was a blatant lie. If they cannot find this evidence and I can, what kind of a program are they running? What is it all about? It is just total deception and lies that they are handing out to us. I am just a normal everyday Australian and it is just not fair that this should happen to me. I am normally healthy and I do not do terrible things, but my life has just totally turned around now.

**Rev. Crews**—I have spent almost all my life fighting for social justice for people. One of the things that drive me nuts about this thing is that people will argue and say: 'There should be no discrimination. People who get hepatitis C in any way should be treated in exactly the same way; whether they get it through self-injecting, using illegal drugs or whatever, it should not matter at all.' In a way I believe that that is really true; I agree with the concept of no discrimination. But there are thousands of these people. One day we advertised with one little note that we were going to have a meeting at the church. It was a cold, wet, windy day and we thought we had better have it about lunchtime because most people with hep C do not get up really early. We had 100 people. Then we had another meeting, and we had another 100 people. There are thousands of people, and the stories are always the same. I think it is really sad that the organisations, like the Red Cross, can put in confidential submissions and these people have to bare their souls—they have to bare their souls yet the perpetrators can say, 'Let's keep it all hidden.'

One of the things I found out—and when you go a bit deeper you find out these things—was that in the 1980s and the 1970s, or particularly after the HIV scare, lots of drug addicts would go to the Red Cross to donate blood because it was a quick and cheap way to find out if they had HIV. The Red Cross knew this and they knew that there would be more chance of getting hep C than AIDS, yet they did not have the tests, they did not do anything. Typically, a woman would go in and have a blood transfusion, come out and feel a bit sick or whatever and then have children. Maybe they would have one child after another, get sicker and sicker, be unable to cope and their relationship would break down. I have found that most women who went into hospital to get blood transfusions or to have children do not have a relationship at all now. Sue is lucky to have hers, because most relationships just break down. You can end up having a woman with children who is sick, unable to care for the children and on her own as well. So the pressures just build up. There are herbal remedies and things that people can have.

One of the questions I began to think about when it became obvious that there were so many people with hep C in the community was: why did the Red Cross set up a Lookback service which is kind of secretive, careful and all of that when in the height of the HIV epidemic they asked people who had had blood transfusions in the 1980s to go forward and have a simple test? As soon as a test was available in 1990, why didn't they ask all those people who had had blood transfusions in the years beforehand to go to their doctor and find out whether they had hep C? These people have lived debilitating lives for an extra 14 years, they have had children and their

relationships have broken down—all of that. How many lives and how many relationships have been affected? How many people would be living a better life now if years ago they had said, 'Let's do a test for hep C like we did with AIDS?' The only thing I can come up with is that there were probably so many people out there that it would have been really scary.

The other thing is that I really and truly believe there should be people in jail over this. I think in the early days the Red Cross took a gamble that hep C was relatively benign and so they were not terribly worried about it. Every now and then some story would come up to question it, but there were ways that could have been looked at from the late 1970s onwards that would have at least lowered the rate of infection amongst people. The typical story is of a person getting sicker and sicker and not knowing why, of a person being told for years and years that they were mad, that it was a psychological disorder—or this, that or the other—until a doctor said, 'I'm not letting you out of this room until I find out what is wrong,' and then coming back later on after myriads of tests saying, 'You've got hep C.' But, by then, 14 years had passed since that person could have found that out.

From what I have seen, the onus has been on the victim to discover that they have hepatitis C and then contact the Red Cross. There has been very little the other way. I see it as an incredible injustice on some people. They deserve to live the rest of their lives in a much better way than they have lived them up to now. I get so angry. I have people coming to me crying. They do not know why they are like this or like that. Why is it that some people have been given compensation and other people in exactly the same circumstances have not? Why is that? How much money has been given out? We know that it is a lot of money because we have heard it on the grapevine. Why is it that some people have been denied and other people have not? I think the reason is that it will shut them up.

This has the same aura as the sex scandal in the Catholic Church. It has the same thing: the lawyers take over and say, 'We've got to protect the organisation.' So what they do is delay and delay and delay, because they know that these people are going to die off. So the longer they can delay it the less money they will have to pay out, and the more they put in legal complications the more difficult it becomes, because by this time most of these people are sick and on welfare so they do not have the resources. The Red Cross employs all these spin doctors who tell lies, and you begin to wonder about the integrity of the organisation itself. I think that is enough. I am sorry; I can go on and on about this.

**CHAIR**—Please do not apologise, Reverend. On behalf of the committee, I thank all of you, particularly those people who have shared their personal stories today. This issue affects lives in a very personal way, and we do appreciate the fact that you have shared your personal experience with us. I will go first to some questions about the Lookback program. It is of concern that we have had two pieces of evidence this morning that say that Lookback had to be instigated by the person who had been infected, and you had to do it in a repeated way. Is that a consistent thing? Is that something that you are hearing from other people?

**Rev. Crews**—All the time.

**CHAIR**—Do you have an understanding of why? Is it that they are not funding the program effectively? What is the reason for the delay?

**Mr Mackenzie**—I will answer that from the viewpoint of this group. I mentioned in my brief address that we have written a report on this called the *Lookback* report. I have literally spoken to so many people who have rung up and said, 'I've just found out I've got hepatitis C.' The classic scenario that springs to mind—I know that Bill has been there with me through all of this—is that a mother will ring up and say, 'I was diagnosed with postnatal depression because I got really depressed after childbirth,' which can be a symptom of something like hepatitis C. Then they have been diagnosed with chronic fatigue syndrome. Then their partners or husbands have said, 'You're not the same person that I married.' Their children have said, 'You're not as active as other mums.'

That has led them to say to GPs and other doctors: 'If I had chronic fatigue syndrome, I'd fight for my family more. I could do something. But it's not working. I love my children, so if I had postnatal depression I could work on something. But there is something else. I'm feeling sick as well.' Very often, sadly—I am willing to testify to this at any point; I will bring more people up if you want—their husbands or partners walk out. So they are left to fend for themselves alone. A member of this group needed community housing right after a split and could not get it. So they move back to their parents, and then the crescendo happens: they basically do not function. The doctors are left, sometimes 20 years after the transfusion, with a situation where they say: 'Okay, I have carte blanche. Let's test you for everything. Forget the costs. This is warranted. Let's test you for everything.'

The big thing here is what happens when some of these women go along to a GP's surgery. One of the issues with hepatitis C is a lack of education, which I am sure the Hepatitis C Council has illustrated. That has really affected tainted blood victims because a GP will look at these mothers, for example, and ask if they have used needles—if the GP suspects that something like hep C could be involved—and the mothers will say, 'No.' They are thinking that the key risks for hepatitis C, to their minds, are things like sharing needles, so it takes a hell of a long time, and it usually involves the person having a breakdown, before the GP will say, 'Okay, let's test for hepatitis C.' Bang! The result comes back positive. The doctor will say, 'Have you ever had a blood transfusion?' Suspecting a blood transfusion does not spring to the minds of a lot of victims, because they were not warned about the dangers.

What happens then is that people are lost. They go to the hep C councils, and the hep C councils have community groups, which are great. But they are not the same: they are people who have got it through childbirth and the blood required for that, and they are going along to groups where people have got it through sharing needles. So there are different issues involved. Both have aspects to them that are warranted. Empathy should be afforded to people who have got hep C from sharing needles. But for the others there is a confusion about how this happened to them and why the blood service did not warn them. That is when they come to me or to Bill and we tell them they need to call up the Red Cross. I have heard that GPs are supposed to notify the Red Cross once they become aware or they suspect that a blood transfusion is involved. But there seems to be little interaction with the victims.

**Rev. Crews**—Often there is a lot of confusion. People are told two or three stories because there is a lot of confusion about which blood was given to which person and how many donors there were. Some of the records are kept by the hospitals, but there are chunks of information everywhere which have to be put together. One person went to the Red Cross and said, 'I've been told that I have hepatitis C.' The Red Cross first looked at the names of the donors on the

sheet who gave blood to that woman. But when they looked back the other way, from that woman up, they found a different list of names, one of them with hep C. So I gather that you get conflicting reports given to people. The Red Cross will say, 'No, you haven't got hep C through blood transfusions,' but then they ring you back later on and say, 'Yes, you have.' I cannot see why we cannot just say to people, 'If you had a blood transfusion between this year and this year, go and have a test.' That would get rid of the need to have a Lookback program at all. I cannot see why they do not do that.

**Mr Mackenzie**—I would like to add that there is another disturbing element to the tracing of victims. Once again, as I said in my brief outline, I honestly believe—and there is absolutely nothing but belief and concern here for other Australians—that if the Red Cross want to come back with: 'We don't want to alarm the public, because there may be a reduction in blood transfusions,' I say that it can be done more responsibly. Australians are not stupid. If Australians are told that hundreds of thousands of blood transfusions were distributed before 1990 and that there is a one to two per cent chance that each unit of blood—some people might have had five units of blood—may have contained a virus, that virus being hepatitis C, they can also be told that there is no cause for undue alarm but they should go to their general practitioner and request the test.

What is the concern here? Is it the cost for tests? This Lookback program has cost the taxpayer millions of dollars. I am really concerned by the integrity of those groups involved in this program. When the Red Cross are asked to trace people who would probably be really upset with them and would probably want to sue them unless the Red Cross offered help—which they have not done—I can see that there would be a reluctance to tell them. I will give you an example, and this is in the *Lookback* report that we have submitted. On the *Sunday* program on the Nine Network there was evidence that the Red Cross were aware that women who had acquired hepatitis C through childbirth had been exposed to hepatitis C. Yet in one woman's case they elected to take 18 months to tell her. I have evidence that in some cases they have never told them. In fact, in the *Lookback* report that we have submitted—and I can actually give you the data that this report was written from—81 per cent of a cohort that we involved in this study had never been officially contacted or offered any medical or support services by the ARCBS.

In one instance, which is incredibly disturbing and needs to be investigated, the Victorian Department of Human Services sent out a letter to a mother who had been given blood for childbirth complications. This was in 1992, by the way, so not in that 1980s period. I am trying to be extremely responsible here about the nature of risk. I have said that the high-risk periods were before 1990, but there are scores of pieces of information that have been given to the Senate as answers to questions on notice about a significant number of Australians who were infected in the late nineties and the mid-nineties as well. So that is a problem, but the main problem appears to be before 1990. The Victorian Department of Human Services sent a letter to this woman saying: 'You will recall that you received a transfusion at this hospital in Victoria. The donor who donated the blood for that transfusion has come back hepatitis C positive.' The letter was sent in 2001 or something like that. It said to the person: 'It is important to understand that no screening was available in 1992 for hepatitis C.' I believe that that is factually wrong. I would have the Victorian Department of Human Services explain that answer.

If this was a template error and they just sent this woman a mistaken letter, then that is extremely serious. But I actually reckon there is something more to it. This is what I mean. The

department explained, when the Melbourne *Age* ran that story—which was a front page story—that they had been involved in a program to send letters to people who were transfused between 1986 and 1990 and that the line that said there was no test available was meant for those people transfused between 1986 and 1990. Why were they so interested in sending letters to people transfused between 1986 and 1990? Why not send letters to people transfused in 1980 with that line 'there was no test available'?

I will tell you why: because they wanted to put those people off from suing and run out their time. When someone has been notified of a danger to their health or an infection the clock starts ticking on legal action. In this woman's case—the one who had been sent a letter saying there was no test available in 1992—she did sit back. Nothing could be done. She believed the Victorian Department of Human Services. Who wouldn't? They are paid by us to help us. As a result, any legal claim from her is going to be problematic. So I think the Lookback program has another agenda. I really believe it is time for an independent body—free of the department of health, free of the Red Cross and free of CSL—to be set up by this committee and to say once and for all that their only objective is to responsibly warn the public and people like these women who have acquired hepatitis C from childbirth.

**CHAIR**—We cannot establish committees. We can only make recommendations to government. I think you are aware of that.

**Rev. Crews**—Can I make a comment?

**CHAIR**—I am a little aware of the time and that others want to ask questions. We come back to that at the end, Reverend.

**Senator LEES**—Who exactly is getting compensation, as far as you know? Does it depend on the year, or on the state or territory government? Who exactly is now getting compensated, on your information?

**Mr Mackenzie**—I have spoken to people who have been compensated. They are reluctant to give their names. They tend to have been transfused in the main between the years 1986 and 1990. I draw your attention once again to the submission of the Tainted Blood Product Action Group, which contains a speech made in the Legislative Assembly in the ACT that talks about the program to compensate people with transfused hepatitis C. It says that the Red Cross are aware that they may be liable between the years 1986 and 1990 for not using ALT testing or surrogate testing. The people to whom I have spoken have gone to lawyers, say—and the most renown ones in this action are Slater and Gordon, the Melbourne based class action law firm. If they meet this criterion—transfused between 1986 and 1990—and if they get the right law firm which has enough research there will be a deal done. I heard recently from one woman that they called it 'the scheme'. It involves the federal health department and the Red Cross.

The scheme has all these categories which go something like: if you just have the infection you are offered this amount of money; if you are suffering from fibrosis or the first stages of scarring of the liver you get another amount; if you have terminal cancer you get the largest amount. I do not think that amount is more than $120,000. We have to console a lot of the members who have been compensated—and we are talking about only a few—because they also have to sign secrecy or confidentiality agreements in exchange for the cash. It is made clear that

if they talk about the terms of the settlement or the scheme then they will be pursued by the Red Cross and other parties for that money.

The bulk of people who were transfused between the years 1986 and 1990 may be offered compensation if they get the right lawyers and if they pursue the Red Cross. But there have also been people compensated who were transfused in the 1990s. On Channel 9's *Sunday* program that played in November 2002—and a transcript of that is supplied in our submission—there was the case of a young lad who got it in the early 1990s who was compensated. There was also, I believe, the case of a girl who acquired HIV and she was compensated in 1999. There tends not to be any general rule of thumb, but I would say that the main criterion seems to be anyone transfused between 1986 and 1990.

**Senator LEES**—Would you have a rough idea of what percentage of people are actually able to access the scheme or some sort of compensation?

**Mr Mackenzie**—I do not know because I do not know how many people were transfused between 1986 and 1990. Most victims get such a rebuff from the Red Cross it is not helpful. The first response is to go to them, not an action group. The Red Cross come back with: 'You're on your own. Go to your GP and they will look after you. If you come back to us we will put lawyers on you.' That is what happens. I think about 400 people—definitely under 1,000 people—have been compensated for hepatitis C. We also believe that there are many thousands more people. As I said before, given this Lookback program, I believe there are thousands out there who still do not know. So I cannot say. There were so many people transfused in so many years.

**Rev. Crews**—We also do know that some of that compensation money has come from the Commonwealth government.

**Senator LEES**—I was just going to ask about that. You mentioned the ACT, and there is some evidence about the Commonwealth. What about Western Australia or New South Wales?

**Mr Mackenzie**—They are involved in the program as well it seems. As I said, it is called 'the scheme' and it looks like they are all involved and are all involved in the demand for secrecy clauses. I know that in legal cases confidentiality is seen as quite standard in a commercial argument but to silence somebody who has just found out they have hepatitis C, a life-changing situation, really scares the hell out of people. It scared a lot of people here. It is really frightening because the government is involved. Why?

We had to put people on TV to get this issue addressed. We had people who wanted to tell other Australians but said they could not because they would be sued. It is like going to an accident scene and saying, 'You have to shut up because the government are involved and they will sue you if you talk about it or discuss it with other Australians.' That is really scary. I think as a bare minimum the government need to withdraw the need to silence victims. I really believe that.

**Mr Pollack**—Minister Kay Patterson was asked by Senator Harradine how many people there were. We had worked out that about $5.47 million had been paid by the Commonwealth and that this had been matched by the blood service—so that is about $11 million—so they did not want

to give us the number of people because then we would be able to work out who got how much. Basically they were not going to give that information when Senator Harradine asked Minister Kay Patterson for that information. She was not prepared to make it available to him—or to put it on the public record, anyway.

**Senator HUTCHINS**—I think Mr Pollack that might have been my question, not Senator Harradine's.

**Mr Pollack**—Sorry.

**Senator HUTCHINS**—In the terms of reference it specifically mentions the royal commission in Canada by Mr Justice Krever. I wonder if you are in a position to comment on any comparisons that you see between an inquiry commenced as a result of decisions by the Canadian national and provincial governments and a Senate inquiry.

**Mr Mackenzie**—The first comparison that can be made with Canada—and I am aware that the Red Cross say that there can be no comparison—is we both have Red Crosses. This Krever inquiry is to be respected. It is actually the world's most extensive blood inquiry ever conducted. It cost over $Can15 million and went for, I believe, five years. It found—and I ask senators if they have time to look at the Krever inquiry findings rather than just go from me—that the blood services in Canada and internationally, although there was some confusion because of commercial interests, knew about hepatitis C in the 1970s and 1980s and knew that it could occasion death. It found that the Red Cross in Canada were aware that there was a problem with the blood supply but, instead of joining America in the mid-1980s in introducing this ALT testing, elected to do further study. The comparison that can be made with Australia is that in 1986 our blood services in the main decided to conduct further study. So instead of introducing the testing—and there were numerous studies by 1980 that suggested ALT was a valuable way of saving lives—they decided to do further study like they did in Canada from 1986 to 1990. Justice Krever was scathing about that decision of the Red Cross because they only released the findings of the study when forced and by that time specific screening had been introduced.

The other issue is that Krever identified that the blood service, when aware of the dangers in Canada, elected to make the decision to contaminate people, rather than introduce screening, because of the cost, a few million dollars, and because of a small reduction in the stock of blood. The comparison that can be made with Australia is that that same decision was made here; that is from the Red Cross's own evidence. So there are numerous comparisons as the Red Cross is involved in both countries, and that is really what I can see.

**Senator HUTCHINS**—So when the royal commission in Canada investigated the blood supply it was not of course just investigating hepatitis C, was it?

**Mr Mackenzie**—It actually investigated the transmission of HIV in blood products as well.

**Senator HUTCHINS**—You have mentioned ALT testing in North America in the 1980s. Do you want to elaborate on that? In your opinion, did that have implications for the decisions that Mr Justice Krever made? I ask that, Mr Mackenzie, because we have had evidence over the last few days that has disputed significantly the role that surrogate testing could have had in eliminating the number of people that may have been infected with hepatitis C.

**Mr Mackenzie**—I am not surprised. The Royal Canadian Mounted Police criminally charged the Red Cross for not using surrogate testing; that was one part of their charges in November 2002. These guys are running scared. We have here a situation—and I know this is the best way to sum up the Canadian situation, particularly Krever's stamp on it—where Krever was looking from a legal standpoint; it was a legal inquiry. What do you do when you become aware of a danger to the public? What is the legal thing to do? What they decided to do was this: 'We know that we're going to contaminate so many thousands but we don't want to reduce the blood stocks by three per cent and we don't want to pay the millions that the testing would cost.' So they then make that decision, and all the while from 1986 in Canada they were aware that the American blood banks were using this ALT testing.

So the argument from the Canadian Red Cross was: 'Oh, but the Americans had a paid donation program; they had a higher incidence of hepatitis C.' The American situation was this: 'Even if we had a lower incidence, if we could prevent a few thousand people from getting this killer virus it is a better thing to do.' So all the while America is doing something but Canada is deciding to send the blood out. Similarly, in Australia we decided to conduct further study. Do not think for a moment that the Australian Red Cross in the mid-1980s were not aware of what was going on in America: they had people come out here; they are closely connected to the Red Cross in Canada. So the Canadians made the decision to send the blood out and contaminate—'We don't think it's serious'—and Krever's summary was that through the range of tests that were available—and I think this is the case—it was felt that the Canadian contamination could have been reduced by over 50 per cent.

That was a serious thing to do. You could have saved thousands of lives, and we did the same thing here. Those thousands of lives 'weren't worth it'. My quick analogy would if the fire brigade were to turn up to this parliament house right now and the place were ablaze and one of the fire chiefs said, 'There are 1,000 people in the building but we can only save 500, so let's not save anybody.' What would the response be? They would be finished, and that is what will happen to the Australian Red Cross if they continue this stance that this virus was mild and there was nothing that they could do.

**Senator HUTCHINS**—I turn to the recommendations of Mr Justice Krever. I assume that he would have had significant medical and scientific assistance in his inquiry. Is that correct?

**Mr Mackenzie**—Yes, he did. That is disputed by no-one. It is a fact that the Canadian Red Cross apologised, post the inquiry, for their conduct in trying to stifle victims. Blood bankers around the world agree that this was one of the most extensive inquiries into blood of all time. They used doctors for the inquiry and they called witnesses. I understand that there has been some confusion over ALT testing at this inquiry. Some people believe it was not much use. You senators have not heard from victims and their defence. We do not have the resources to bring over the kinds of experts that Krever did. So you are hearing from the blood service and government funded bodies, but Krever heard from both sides of the fence. That whole report had so many doctors. I know that the key people mentioned are people like Dr Harvey Alter, who is considered one of the fathers of surrogate testing. I do not know for sure if this is the case, but I have heard that he has been verballed in the last few days for some of his opinions. I have not been at all hearings of the inquiry, but I think that could be a concern. Before we start thinking about what international experts do or do not think about surrogate testing, we need to bring them over and hear from them.

**Senator HUTCHINS**—Or hold a teleconference with them, I would imagine.

**Mr Mackenzie**—Yes. This is a great opportunity, by the way. I am sure that the Red Cross will join me in this. They fervently believe that they have done no wrong, so I say: 'Why don't we bring an end to it? Let's have teleconferences.' Take the Canadian situation. If the Red Cross believed that hepatitis C was mild and that nothing could be done, have them produce medical literature—their own and that of others—that existed in the 1980s that says, 'Hepatitis C is nothing to worry about.' Remember that I am not a doctor, which makes this worse. It is easy for me. In turn, I will—if this committee will allow me time to do so—produce material that says it was a killer virus. These are credible people. Once again, I have to say that the findings of Krever bear out our action group's testimony. This was a serious virus. They elected not to do anything about it and they have been removed from the blood supply as a result.

**Senator HUTCHINS**—You said that criminal charges have been laid against the Canadian Red Cross. On what basis were they laid?

**Mr Mackenzie**—The Royal Canadian Mounted Police laid a number of charges. I believe one was of common nuisance to the public. There were also charges of failing to adequately warn the public and failing to introduce ALT testing in a timely fashion. That is one of charges. That is the way they described it: failing to introduce ALT testing in a timely fashion. The Royal Canadian Mounted Police are really to be respected. This was a five-year investigation. They were not quick about this. They started investigating after Krever handed down his report from the royal commission. They only charged in 2002. So the charges pertain to ALT. The similarities with Australia are, once again, that we both had a Red Cross, we are both Commonwealth countries, we both had the information and we both elected to do nothing about it.

**Senator HUTCHINS**—Would you like to elaborate on the recommendations of the inquiry in terms of compensation?

**Mr Mackenzie**—I know that Krever talked about the tragic circumstances for anyone and about the need to have a no-fault compensation scheme that recognised that all people affected, no matter what year they were transfused, had terrible outcomes. This was attested to today by some of the brave people who gave evidence. Post the inquiry the Canadian provincial governments set up a compensation fund of $1.2 billion, which was only for people who were transfused between 1986 and 1990, because at that time the information they had was that that was when the blood service or the governments were most liable. Interestingly, since that time, new evidence has come to light. In fact, it came to light in an article in the *Kansas City Star* after a massive investigation in America. Internal documents of the Red Cross—that possibly involved us in Australia, but definitely involved the Canadians and the Americans—showed that they knew that ALT was the right thing to do in 1981. In fact, they were going to introduce it but then delayed for commercial considerations. So now many Canadian provinces are compensating, on humanitarian and legal grounds, people who were transfused in years before 1986.

**Senator HUTCHINS**—We have been advised that the United Kingdom government has made decisions to compensate in various parts of England, Scotland and Wales. Would you like to comment on that?

**Mr Mackenzie**—The United Kingdom have decided that on humanitarian grounds rather than legal grounds—they have not addressed those as yet—the right thing to do is to give former unsuspecting hospital patients who acquired a deadly virus like hepatitis C the chance to receive compensation. They have initiated that. The health departments in Great Britain have started that. I am not sure of the figure but I know that that has happened.

There are many other countries in the world that have done the same thing. The most extensive and responsible compensation programs set up exist in Ireland, which supports our action group through their groups that caused their judicial inquiries, and in Canada. I believe that in Ireland they have things like home help for mothers. They have thousands of mothers who acquired hepatitis C through blood products. They have things like home help and compensation that goes, I believe, into the several hundreds of thousands of euros.

**Senator HUTCHINS**—Mr Pollack, you said that you were still being sought by the Red Cross in—

**Mr Pollack**—That is right.

**Senator HUTCHINS**—Would you like to expand on that? What period are we talking about?

**Mr Pollack**—I was infected in 1983 through a major motorcycle accident. I went back in 1990 after I got my life back together to donate back the blood I borrowed. After I made the initial donation they sent me a letter dated 8 August 1990 which states that I was hepatitis C positive but they still could use my blood for fractionation. I had no idea what fractionation was. What would I know? I am not a blood expert. So I went off to the interview. They said that I must come alone. This troubled me greatly. I had a wife who was five months pregnant. The letter was sent to my parents. So off I go by myself to find out what it is all about. She explains fractionation—that they can break my blood up into products for haemophiliacs so that their blood can clot. I said, 'Okay, whatever you like.' But I said, 'You gave me this virus—hepatitis C. If you now put my blood back into the system is it going to infect other people?' They said, 'No, Michael. Don't worry.' That is what I got told—no need to worry.

They asked me to donate at three and six months after that date of August 1990. They have claimed that no infected material went back into the system after, I think, July 1990. They asked me to donate my blood in February-March of 1991, knowing that I was hepatitis C positive and telling me, to my face as well as in writing, that my blood would be used for fractionation into other products. That told me that something was drastically wrong. I did not want to donate my contaminated blood back once I found out. I did not want to give it back. I told them that. They said, 'No, Michael, you keep coming. There is no problem.' After that 1991 donation there was no, 'Don't donate any more, you are positive.' It was, 'Yes, come again,' to the point where they gave me a donor card and said, 'Come again.'

**Senator HUTCHINS**—How often did you go again?

**Mr Pollack**—I did not. Out of conscience I chose not to donate. I could not believe them. However, I did trust them a little bit because they were the scientists and I am just a normal guy. I am not a scientist. I suspected that they were contaminating other people. Years later my mother saw Mr Mackenzie on TV and alerted me to this fact. As it turns out, they were

contaminating other people. Basically, inadvertently my blood has been used to kill people or infect people.

**Senator HUTCHINS**—Ms Jacobson, you said you had extensive surgery in 1987 and when you did your own search you found out that was when you were infected. In February 2002 you felt very sick and that was when you started going to the doctor; is that right?

**Ms Jacobson**—I had been unwell for a long time before that.

**Senator HUTCHINS**—When were you advised you had hepatitis C?

**Ms Jacobson**—In February 2002.

**Senator HUTCHINS**—When was it confirmed that you got that infection in 1987?

**Ms Jacobson**—It has never been confirmed that I got it in 1987. They have always maintained that I was never transfused. I just put it that I had a blood transfusion and ended up with hepatitis C. That must have been where I got it from. I got a letter from the Red Cross dated July 2002.

**Senator HUTCHINS**—Mr Mackenzie, you have mentioned Dr Alter. Dr Alter and Professor Cossartthe are relied upon in a number of submissions to refute the value of surrogate testing. As I understand it, in January 1981 the American Association of Blood Banks met and decided to introduce ALT testing on the basis that they believed it statistically correct that they might eliminate a number of people who might be carriers.

**Mr Mackenzie**—I need to emphasise that these memos could be made available to the committee. I believe they are also published by the *Kansas City Star*. The idea that Dr Harvey Alter believed that ALT testing was of no use and also of no use to Australia will be seen as complete rubbish. He needs to answer this himself. I believe he needs to be asked: could ALT testing have prevented any infections in Australia? Another issue of major concern is integrity. Those memos talk of the seriousness of hepatitis C, and they are dated 1981. This was a meeting of the Red Cross in America with Canadian officials and blood banking officials. A memorandum from 1981 suggested that hepatitis C is a threat to the blood supply and that it is a serious health threat—not mild. So they themselves are saying it. I remind the Australian Red Cross that those memos exist.

I am not a medical doctor and would never profess to be one, but they are. My concern is for the future of the blood supply. If their American counterparts, their Canadian counterparts and Dr Harvey Alter met in 1981 and said that hepatitis C is serious, how can the medical company CSL and the Red Cross come to this inquiry and think that we can take them seriously when they say that they believed it was mild in the 1980s?

**Senator HUTCHINS**—We have been advised in questions on notice to Senator Patterson when the Red Cross stopped receiving blood from prisoners—as late as 1983 I think in Victoria and Tasmania. I think you mentioned earlier in your submission the date they ceased collecting blood from prisoners in America. Do you know roughly when that was?

**Mr Mackenzie**—In the submission that the Tainted Blood Product Action Group made we do not give a specific year. We talk of Canada and America. I believe that blood stopped being taken from American jails for use by Americans at some point in the 1980s, but until 1994 American prisoners continued giving blood which was distributed overseas. The Canadians stopped taking blood from their prisoners for use by their hospital patients in 1971 because of the risk of hepatitis. It was deemed too dangerous. We know from these answers that you speak of, Senator Hutchins, that Australia collected blood until 1983. That is really the comparison. That is extremely serious.

**Senator KNOWLES**—Mr Mackenzie, in your submission you make some very serious allegations. You say, for example, that the ARCBS chose to allow people to become infected. Do you honestly believe that individuals deliberately made a decision to say that human life and wellbeing were expendable?

**Mr Mackenzie**—Could you show me where I have said that they chose to allow people to become infected? I said that the Australian Red Cross Blood Service knew that the blood supply had a percentage of contamination. They will say that themselves. We are talking about a blood bank that has bags of blood that is going out to thousands of people and we know that, according to them, one to two per cent of that blood carries hepatitis C virus. That is what I am saying.

**Senator KNOWLES**—Hold on. I am just trying to narrow this down. Do you believe that individuals willingly made decisions to infect people? Yes or no? Or do you believe that individuals made decisions based on good faith and what they thought was the best scientific evidence available at that time?

**Mr Mackenzie**—If you are asking for a yes or no answer on whether I believe that individuals made decisions in good faith, my answer is no. I believe that some individuals did not make decisions in good faith.

**Senator KNOWLES**—Have you had legal advice that those individuals could be sued?

**Mr Mackenzie**—Yes, I have. They have been, and they have paid out compensation themselves.

**Senator KNOWLES**—Are you prepared to provide that legal advice to the committee?

**Mr Mackenzie**—I think you should ask Slater and Gordon for that. They are the lawyers, not me. They have sued them. They settled out of court. They are the people to go to.

**Senator KNOWLES**—What individuals?

**Mr Mackenzie**—What individuals in the Red Cross?

**Senator KNOWLES**—Yes.

**Mr Mackenzie**—If you will give me time, I need to seek legal advice myself, again, because you have put more specific questions to me on this. But I will say this to you: I believe there is enough material—perhaps not for this inquiry, with its limited investigative powers and limited

time—to warrant a criminal line of investigation, particularly through the courts, on the basis of that decision to send out tainted material and not warn the public.

**Senator KNOWLES**—But you are telling the committee that individuals—individuals; not the Red Cross—have been sued successfully.

**Mr Mackenzie**—No, I am saying that the organisation has been sued. Do not get me wrong there. The organisation has been sued, not the individuals.

**Senator KNOWLES**—I am asking about what you believe to be the role of individuals who make these decisions.

**Mr Mackenzie**—If you are asking me whether I believe that they engaged in criminal conduct, my answer is yes—guaranteed.

**Senator KNOWLES**—Why do you direct your attack to the Red Cross when in fact the National Blood Transfusion Committee, made up of a whole range of people, actually made the recommendations on which the Red Cross acted?

**Mr Mackenzie**—Because they were spoon-fed by the Red Cross. Were people on the committee associated with the Red Cross? They were all funded by the one thing. Let us not put down the Red Cross and their responsibility here. They are the managers of the blood supply. They are the people who collect. That committee can say that they made decisions. I am sure that the committee did not agree with some of the things the Red Cross did day to day. There is evidence in this submission of things that they have done.

**Senator KNOWLES**—Do you have scientific evidence that the National Blood Transfusion Committee made contrary recommendations to the ultimate decision the Red Cross made?

**Mr Mackenzie**—This is basically a battle of countries. I believe they are too closely linked. I believe that that committee you refer to are linked to the Red Cross. They were going to do what the Red Cross wanted them to do. I believe there was an undue and unhealthy influence. If you are asking me whether I have scientific evidence to go against that committee, my answer is yes, I do. I believe that there were people in France and in blood systems of other countries around the world who disagreed with that committee's decision. An example could be the decision to take blood from hepatitis C donors in 1990. It was not world's best practice. Many countries disagreed with it.

**Senator KNOWLES**—What we need, as a committee, is your specific scientific evidence to back up your claims.

**Mr Mackenzie**—Will you allow me resources? I need more time.

**Senator KNOWLES**—I presume when you make a claim that you have the scientific evidence to support your claim.

**Mr Mackenzie**—Yes, I do.

**Senator KNOWLES**—That is all I am asking. I want you to inform the committee of the basis on which you made certain claims. You must have the scientific evidence on hand on which you made those claims. It would be very helpful for the committee in its considerations if it could refer to the evidence that you believe was overlooked.

**Mr Mackenzie**—Can I do it by this afternoon?

**CHAIR**—Mr Mackenzie, you can have a couple of days.

**Mr Mackenzie**—I will just submit the Krever report because that is where the evidence is.

**CHAIR**—We have that report.

**Mr Mackenzie**—Well look at that because that is good enough.

**Senator KNOWLES**—We are talking about the National Blood Transfusion Committee making certain recommendations. I am trying to get from you, for the committee's deliberations, the precise areas you believe the National Blood Transfusion Committee, and subsequently the Red Cross, overlooked in their decision making processes. The Krever report will not answer that question. You have made the claim and I am looking for assistance so that the committee can consider your claim in a specific fashion instead of a general, Krever fashion.

**Mr Mackenzie**—I have done that in the submission. You are saying to me, 'I want you to come back to me, Senator Sue Knowles, with specifics.' You are talking about the committee and their policies. I am saying that that committee is in bed with the Red Cross and always was. I want you to give me your specific questions and ask me to back those up with science. For example, the Tainted Blood Product Action Group submission talks of an IV drug user that was known to the blood service yet they continued to collect blood from that donor. Are you asking me to give the committee a scientific view on that? Are you asking me to get scientific opinion on why they did that? The National Blood Transfusion Committee did not approve that. They did not have a policy to do that. The Red Cross broke the law by doing that. What can I do without more resources? Can I have the police come and help me? What can I do? I have given you this in my submission. We are a small group. I can only say that I have given specifics in the submission. Did they break the committee's policies? I do not care. I just care about the result it had for victims and the fact that they may well have broken the law. Not alerting the victims to the danger to their health is one example.

**Senator KNOWLES**—Why do you have a view different from that of the Hepatitis C Council—

**Mr Mackenzie**—Because I am not paid by the government.

**Senator KNOWLES**—Can you just allow me to finish the question.

**CHAIR**—Let us just finish the process of questions and answers. Applause is not usually allowed.

**Senator KNOWLES**—The Hepatitis C Council have made a submission that is well considered. I do not think it serves the committee's purpose to start denigrating others' evidence, because we have to consider all the evidence. The Hepatitis C Council have said in their evidence that the decision might have been wrong in hindsight but on the evidence that was available at the time it was a justifiable decision. Is the reason for your differing viewpoint simply, 'We're not paid by the government and they are so they are going to be subservient'? Surely there is something more substantial that you have to offer that would counteract the Hepatitis C Council viewpoint.

**Ms Jacobson**—Can I ask what their justification was in making these decisions? On what basis did they do this?

**Senator KNOWLES**—I am asking what justification you have?

**Mr Mackenzie**—It is broader than that; I agree with you. It is not just that they are paid by the government and that they are too close to the government and to the blood service. Let me emphasise: I am not a medical doctor. The Hepatitis C Council say that, given the evidence they had at the time—what doctors did they use? What doctors did they cite in their submission? I am saying that, if you give me more time, if you will allow me some kind of access—because this can be very difficult for me in terms of resources; I spend everything I have on this—I can pull in the scientists. You are asking for that scientific evidence; ask the Hepatitis C Council to call in theirs. I am giving you the best that I can do. I believe that the Hepatitis C Council submission is wrong because Krever believes that something could have been done. The Australian Red Cross believe that something could have been done. They started ALT testing for hepatitis C in 1988 in Queensland. They paid compensation to people who acquired hepatitis C in the 1980s. That is all I can do. Give me the resources, give me the time and give me the chance to get these scientists. I believe the Hepatitis C Council submission is wrong.

**Senator KNOWLES**—There are number of different views, as you know. You cite Krever as your authority, but there are number of other authorities that hold a different view. Therefore, I ask your organisation why—if you like, I am playing the devil's advocate here—the committee should take Krever's line instead of the evidence of all the other people who are, quite frankly, saying that the ALT testing would have thrown up a lot of false positives and false negatives and, therefore, would not have benefited those people?

**Mr Mackenzie**—Out of respect for another Commonwealth country, the Krever royal commission was not conducted lightly. The Canadians have a sophisticated and advanced legal system. They are a Commonwealth country. When they decided to conduct a royal commission, they did not take that decision lightly. I maintain that it is one of the most extensive legal inquiries into blood in the history of mankind. I understand that you are saying there are witnesses, perhaps expert witnesses, who hold a different view. The benefit of the Krever royal commission into blood in Canada is that it was a legal inquiry. Will those doctors say the same things in such a setting? I believe not. I believe that the difference between Krever, and I cite that because it was a legal inquiry and it was a well-funded legal inquiry—Justice Horace Krever is a High Court judge in Canada; he is well respected. The Royal Canadian Mounted Police decided to launch a criminal investigation after that inquiry, and you are asking me why we should take the evidence of Krever, the Canadian government and the Canadian legal system over the other expert witnesses who have given what I consider to be sometimes offhand opinions on ALT. I

say to you that until we have an Australian royal commission, if that is what you are asking, where there are experts who will say those things in that forum, I will be using the Krever inquiry above offhand advice from certain doctors. You can get a doctor to say almost anything when they are paid. Will they do the same in a legal inquiry?

**Senator KNOWLES**—Do you honestly believe there would be that many professional scientists who would collaborate to create a false impression, bearing in mind their own professional integrity and reputations?

**Mr Mackenzie**—I honestly believe that some of the advice given to a legal inquiry in Canada which suggested that ALT testing was of value was given as good advice. I do not believe there are loads of doctors who are experts in their fields—gastroenterologists and liver specialists—who believe that ALT testing is of no value. I draw your attention once again to the *Sunday* program. If you will allow I will go to the words of a well-respected Australian doctor in the *Sunday* program transcript. I will have to look for this person's name but he was involved with Professor Barraclough in the expert inquiry into hepatitis C.

**Senator KNOWLES**—We have read the transcript of the *Sunday* program.

**Mr Mackenzie**—So you know who I am referring to. When asked whether he thought ALT testing should have been introduced in the 1980s—and he is an Australian expert—he said, 'At the time, I wish they had.'

**Senator KNOWLES**—Hindsight?

**Mr Mackenzie**—Call it hindsight, call it what you will.

**Senator KNOWLES**—I am asking a question. That was not a statement.

**Mr Mackenzie**—Are you asking me whether that was hindsight?

**Senator KNOWLES**—Yes.

**Mr Mackenzie**—He said, 'At the time,' which was in the 1980s. He is saying that that was his view at the time. That is not hindsight; that was at the time.

**Senator KNOWLES**—But, once again, there is a diversity of views, and I do not think we are going to come to that—

**Mr Mackenzie**—I agree with that.

**Senator KNOWLES**—Something that really does concern me is the welfare of the many people whose lives rely on blood and blood products. Are you concerned at all about such a public pursuit of the Australian Red Cross blood service for what happened some time ago and the impact that very public pursuit will have on the donations in the future?

**Mr Mackenzie**—I am concerned that the managers of the blood supply have done the wrong thing in the past, and I am concerned that they will not do the right thing in the future. I believe

that Australians who donate blood are heroes. Australians are smart enough to know that blood transfusions when safely managed are a great asset. I am not concerned that Australians will donate less because victims of a terrible tragedy would like to see some answers. If you believe that I am concerned that there is a threat to speculative Australians' lives in the future because of less blood, I believe that will not happen.

**Senator KNOWLES**—Why?

**Mr Mackenzie**—Is this an argument that the Red Cross feels? I think it is.

**Senator KNOWLES**—No, it is quite a legitimate question based on those who have approached me and said, 'Please don't risk at any cost the future blood supply of this country, because my family members rely on it.'

**Mr Mackenzie**—I agree with you in the sense that people who rely on blood products deserve to be given a supply of clean blood products. Do I believe that this media attention or this attack on the Red Cross could endanger their lives? The answer is no. I may need more time, but I will give an example now. The biggest media coverage on tainted blood ever in Australia occurred in 2002 and for part of 2003. The Red Cross, by their own admission, have experienced more donations over that period—in fact, record levels. I need to make it clear on the *Hansard* that they, the Red Cross, issued a press release saying that there have been record levels of donations. This year, in 2004, there has been very little media but in 2002 and 2003 it was heightened and there were record donations. I believe it is because of responsible organisations like ours which say that Australian donors are real heroes and that Australian blood products need to be of plentiful supply and of the safest possible quality.

**Mr Pollack**—Let us put it into perspective. There are people who are affected by the AIDS crisis, along with their families and their distant relatives. Now we have people affected by the hepatitis C crisis, along with their families and their distant relatives. If there is no proper judicial investigation, there will not be any faith in the blood supply. There has to be that judicial investigation to give the Australian people the faith in the blood supply. My kids know that the Red Cross poisoned their father, and they are the next generation of Australians. They are waiting for me to come home with news that the senators are going to help us make it right, so they will know that their future blood supply is safe. It is that simple. It has to be done to restore faith in the blood supply. The view at the time was volume, volume, volume for the blood services. I would have thought that a safe, strained blood supply would have to be better than a free-flowing contaminated one. Wouldn't Australians be much happier if the blood supply was strained but it was safe? If we have plenty of blood, that is okay, but if there is a risk you can catch something. People do not want that.

**Mrs Bollmeyer**—In reply to Senator Sue Knowles's question: I know personally that my mother, who worked for the blood bank, still donates blood despite all that has happened, and so does my sister. The Red Cross are trying to keep the blood safe so that this does not happen again. In other words, it has gone full circle: they are trying to keep the blood clean so that this does not happen again.

**Senator MOORE**—I have a question to do with the relationship between your group and the Red Cross, which seems interesting from previous discussion that we have had. In terms of the

process, I do not think that in any of the evidence that we have had is there any denial that there are people who have contracted hepatitis C from blood. Your group is working really hard for the people who have identified to you that that is the case. The Red Cross are also working hard. We have a significant submission from them about what they are doing to work with the people affected. What communication is there between your group and the Red Cross on a regular basis?

**Mr Mackenzie**—None; I would like it to be more. In fact, I will say for the record, for *Hansard*—and this will be borne out by witnesses—that no matter how damning I am or this organisation is of the Red Cross, if people come to us saying they have been infected and ask, 'What should I do?' I tell them to go to the Red Cross. We have done that. There are people here today who have done that, and they have got no joy. They have been told, 'Look, there's nothing we're going to do for you; you're on your own,' or words to that effect.

I would love there to be more communication; I have tried. We have had meetings and we have asked the Red Cross to come. We will hold another meeting—I think it will be in a month—and I would like the leadership of the Red Cross to come. It does not have to be adversarial—that is the thing. We would love more communication with them and to work with them. They are a humanitarian organisation that, in my view and in this organisation's view, have lost their way, but it does not have to be that way forever. Certainly those in Canada apologised to the victims, after the judicial inquiry, about not using ALT testing. Regardless of what some experts chosen by them failed to win over in the Canadian inquiry, they apologised. I believe that it could be a really good feature here if they were to give an apology and join us at the next meeting and communicate and work with us because we have so many people who do not know what to do or where to go. So the communication is zero but, honestly, that is not because of us. I have led a protest outside the Red Cross in Clarence Street because of this issue. No-one came out to talk to us then. We would like that talk.

**Senator MOORE**—What have you specifically asked the Red Cross for?

**Mr Mackenzie**—I remember sending an invitation—and Bill might remember me showing him this—to them. I would still have that, I believe. I know that they probably would. I sent them an invitation in early 2002 to join us at a meeting. I asked them, 'Will you sit down with victims and discuss ways to help them?' They responded with, 'No, we will not,' and the communication from that point on was really limited because they refused to meet with us. It was like beating your head against a brick wall in the end; that has been the extent of it. It has not been through a lack of attempts by us. In fact, I will give you an example. We have asked them to meet with us; they have not asked us to meet with them.

**Senator MOORE**—Have you got a copy of that exchange? Was that a written exchange between you and them?

**Mr Mackenzie**—I do not have it here but I can provide that to you.

**Senator MOORE**—Do you have a copy of the Red Cross response? Was that in writing as well?

**Mr Mackenzie**—Yes, I believe I do.

**CHAIR**—Reverend Crews, do you have something to say?

**Rev. Crews**—Yes. I would just like to say my overall impression of all of this is that in lots of ways up until the time of the awareness of AIDS and for a bit of the momentum afterwards the blood supply was not really managed by the brightest sparks in the firmament in a sense because these sorts of things were not envisaged. So in lots of ways, from what I can gather, it was looked upon as being like managing water.

**Senator MOORE**—We have had the same assessment of that management too.

**Rev. Crews**—They were not the brightest sparks in the firmament. They took a collective view that hepatitis C was relatively benign. As time went on it was proved that that was not so, and the Red Cross and these blood organisations have been faced with a dilemma of how to get over a monstrous stuff-up. So what they have done is delay and whatever and, in a way, they have magnified the whole problem and have brought this huge calamity on themselves. So many people have said to me: 'If, when I had rung, they had just said, "Sorry, we made a mistake," I would feel so much better.' Instead they did not do that. They put up a brick wall and created this huge problem of their own making. So somewhere, some time somebody has to say: 'Yes, we stuffed up. We will fix that up as best we can and then we will move on.' It seems to me the Red Cross is nowhere at that point. They get spin doctor after spin doctor to try and cover up stuff-up after stuff-up—and that is where I honestly think they are at.

**Senator HUTCHINS**—Queensland have been mentioned on and off in relation to their introduction of the ALT testing in 1987-88. Do you have any information that you would like to comment on about the Queensland blood service breaking ranks with the rest of the country with the introduction of that testing?

**Mr Mackenzie**—Yes, I believe that a paper was written and submitted to the *Medical Journal of Australia*. This might be of interest to Senator Knowles. She asked me before about specific scientific evidence, and I will use this opportunity to mention it. I refer to Australian Red Cross or Queensland Red Cross staff. Catherine Hyland and the late Dr Ian Young of the Queensland Red Cross wrote a paper—I am not sure whether the committee has a copy of it—that talked about the benefits of ALT testing and that they believed they had a legal responsibility to do it. I am not exactly sure from memory, but I think the paper mentions the severity of hepatitis C being part of their decision to introduce ALT at that time in the late eighties. When I am asked by someone like Senator Knowles about evidence, it is hard for me to come forward with all this information on the spot. But I would like to draw Senator Knowles's attention to that *Medical Journal of Australia*. I believe that that document from the Queensland Red Cross stated that in their scientific opinion, as workers of the Queensland Red Cross, ALT was of value.

**Senator HUTCHINS**—So it was the Queensland Red Cross?

**Mr Mackenzie**—Yes, the Queensland Red Cross Blood Transfusion Service. I think it needs to be mentioned, in case there is any confusion, that prior to 1996, although the Red Cross had a federal umbrella situation, each state had their own leadership in the blood services. That changed in 1996 when it became a federally managed body. But at that time Queensland and the late Dr Ian Young decided to break ranks; they could hold off no longer. I guess that was because

they were well aware of the infections and their severity. This is what they said in that journal letter.

**Senator HUTCHINS**—This may not be a fair question to ask you, but do you know of any studies that have been conducted subsequently to see whether or not that reduced the amount of hepatitis C in Queensland? There have been other studies conducted retrospectively to prove that, if they had introduced ALT testing, it would have been almost next to useless in reducing the amount of infection.

**Mr Mackenzie**—In relation to those studies that say it is next to useless, I would question the sample survey of people that they used. Queensland has a marvellous opportunity, but what I am concerned about is a fear in the former workers of the Queensland Red Cross Blood Transfusion Service who are now with the Australian Red Cross Blood Service. I do not know of any study about whether it reduced the hepatitis C prevalence in the Queensland blood supply. I am sure it did. I do not know of any study; I would love to see such a study. I would like to see records from the time. But I am very concerned about any workers from that period who were involved in that study, because it is my understanding—and I will say that this tainted blood thing is the sort of stuff that goes around—that there are people in Queensland, and Dr Ian Young was one of them, who were dealt with unjustly by the Red Cross because of their decision to introduce surrogate testing.

**Senator HUTCHINS**—We might have to call Dr Hyland. If he is still about, he might make himself available. Undoubtedly we would know how many tests were conducted in the period between 1988 and 1990.

**CHAIR**—There being no further questions, I thank your group for your presentation today, and for the openness with which we have had the discussion. We look forward to a report that progresses this matter.

[12.49 p.m.]

**ROWELL, Dr John, Chairman, Australian Haemophilia Centre Directors Organisation**

**CHAIR**—Welcome, Dr Rowell. I understand that 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, for which we thank you. I now invite you to make an opening presentation which will be followed by questions from the committee.

**Dr Rowell**—Thank you for allowing me to present to the Senate inquiry into hepatitis C and the blood supply in Australia. I am the Chairman of the Australian Haemophilia Centre Directors Organisation, which is an independent body—it is incorporated in Victoria—representing the 16 medical directors of haemophilia treatment centres in Australia. These haemophilia treatment centres primarily deal with inherited bleeding disorders, including haemophilia A, haemophilia B, von Willebrand disease and other more uncommon bleeding disorders.

There are several objectives of our organisation: to advance the care and treatment of people with haemophilia in Australia; to advance the education of the medical profession and the broad range of health professionals associated with haemophilia in haemophilia and its treatment; to promote haemophilia research and to disseminate the results of such research; and to liaise with and provide advice to the Haemophilia Foundation of Australia, federal, state and territory governments and other such bodies involved in the welfare of people with haemophilia in Australia. We aim to maintain liaisons with similar organisations in New Zealand and other countries—the UK and Canada—and aim to develop clinical guidelines for the management of bleeding disorders and other associated problems.

A major initiative of our organisation is the Australian Bleeding Disorders Registry, which data in the submission that we presented came from. At present the New South Wales treatment centres do not contribute to this database, and the total impact for Australia of hepatitis C and haemophilia needs to be extrapolated from the existing data that we provided. Requests have been made by AHCDO to the New South Wales department of health via the Commonwealth Department of Health and Ageing for further submissions from New South Wales. We are still awaiting progress on that.

There are four specific things I want to add to and highlight in the submission. I also want to talk about the high hepatitis C infection rate for people suffering with haemophilia. The numbers have not changed greatly since our submission, but through the Bleeding Disorders Registry they have been updated since that time. The numbers for haemophilia A and hepatitis C have increased slightly to 447—that is an extra person—and for haemophilia B up to 86 people—that is an extra three people. It is still possible that there are others with bleeding disorders either haemophilia or von Willebrand disease who are hepatitis C antibody positive and are not on our register as the treatment for these conditions can be quite infrequent and they may not present to doctors for many years. A very pertinent case came up in Brisbane where someone with mild

haemophilia had not presented to us for some years and then presented to another hospital. They are now part of the register.

The incidence of von Willebrand disease and hepatitis C from our original submission has not changed, but I emphasise that, similar to mild haemophilia where treatment can be infrequent and while the number affected with hepatitis C may be a minimum, there may be more. Of note 85 people with haemophilia A and haemophilia B on our register are HIV antibody positive. Although data is not available, probably all these individuals are co-infected with hepatitis C. Co-infection with hepatitis C increases the incidence of complications and reduces the time to develop complications of hepatitis C. For our organisation and for the patients this is a major issue.

To AHCDO's knowledge there has been no hepatitis C seroconversion since 80 degree heat treatment of products and the introduction of hepatitis C antibody testing. Of note, more severe heat treatment—that is up to 80 degrees for prothrombinex, which is the treatment used for haemophilia B—was not available for some time after hepatitis C antibody testing and screening was introduced.

What about the extent to which Australia has been self-sufficient in blood stocks for the past three decades? I have not made this a point of the submission but I would like to comment that production of coagulation factor concentrates in Australia has never been able to meet demand. From a clinical view, self-sufficiency has not been achieved. A special meeting was convened in Hobart in 1992 to address this issue and discuss strategies to improve factor VIII availability. This led to the introduction of recombinant factor VIII for children undergoing prophylaxis and in other situations.

I do not want to be quoted on the numbers because they come out of what I can remember, but factor VIII production at the time was roughly 1.2 international units per head of population and certainly was not sufficient for those being treated for haemophilia. By comparison, the production and usage of factor VIII is now approximately 3.4 international units per head of population. So in 12 years there has been a massive increase in the amount of factor VIII available. This is an indication that we were not self-sufficient. The amount of factor VIII available at the moment is made up of plasma derived and recombinant factor VIII. Conversely, for treatment of haemophilia B there has never really been a shortage of factor IX concentrates—that is, products like prothrombinex and, later, monofix. But virally inactivated concentrates for more uncommon disorders, such as factor XI deficiency, are difficult to obtain worldwide. So, again, self-sufficiency for those uncommon disorders is very difficult to achieve.

I turn to the impact blood transfused hepatitis C has had on victims and their families. Hepatitis C has had a devastating effect on the haemophilia community, both psychologically and physically. Most of those infected with hepatitis C have been infected for up to 25 years. The incidence of serious complications of hepatitis C—that is, liver scarring or cirrhosis—is greater after 20 years of infection. Co-infection with HIV increases the incidence of cirrhosis. It also increases the severity of complications and affects the time taken to develop them. Deaths from hepatoma have occurred. Liver transplants for cirrhosis secondary to hepatitis C have been successfully performed.

Symptoms of hepatitis C can affect the employment prospects of individuals who may already have significant and serious disabilities. Many of these people, in spite of their disability, try very hard to maintain their employment for their sake of their family and their own psychological wellbeing. The addition of hepatitis C and, in some cases, HIV makes this more difficult. This affects their family income and their emotional wellbeing. Many strive to provide for their families in spite of these disabilities. Psychologically, the haemophilia community suffer greatly with hepatitis C. Many were relieved not to be infected with HIV in the early eighties, but were then devastated by their hepatitis C infection. One can only admire those people who dealt with HIV initially and now also deal with hepatitis C. It has had a serious psychological and physical effect on those infected. It has also affected those in the haemophilia community who were not infected, because they are now concerned about the blood supply.

I turn to the services and remedies that can be made available to improve outcomes for people adversely affected by blood transfused hepatitis C. People with haemophilia and related bleeding disorders have their condition managed at one of 16 haemophilia treatment centres around Australia. These centres have a wide range of professional staff, including medical, counselling, nursing and physiotherapy staff. The complications of haemophilia treatment—that is, viral infections such as HIV and hepatitis C—are managed within those centres or in close liaison with infectious disease units, liver clinics or immunology units. The haemophilia treatment centres have been modelled on centres in the UK and the United States. We believe that their holistic approach is greatly beneficial to those patients with haemophilia and with haemophilia and viral infections. We want to ensure that adequate funding is made available for these centres to continue that work.

As the use of plasma derived factor concentrates has a risk of further unknown virus or infectious particle transmission, our organisation strongly supports the greater use of recombinant factor VIII concentrates for those with inherited bleeding disorders. We are working with the federal government in several arenas to try to progress that. Recently, antiviral treatment for hepatitis C has been made available for those who are HIV antibody positive. Until November it was not available. It is very important for this group of people that any new agents for hepatitis C are also made available to those with HIV. It has been more difficult to assess the degree of disease associated with hepatitis C in haemophiliacs because the disorder makes liver biopsy, which is the trademark investigation technique, very difficult. That is very important. A very large group of people have been infected with both HIV and hepatitis C. They have not had the same opportunity for treatment as people who are infected with hepatitis C alone. I thank you for the opportunity to make those comments. I am happy to answer any questions.

**CHAIR**—We heard evidence from the Haemophilia Foundation of Australia, which supported your position on the increased use of recombinant factor. I want to talk about that a little more. Do you have any idea of the cost differential between plasma derived factor VIII as opposed to recombinant factor VIII? Do you have a notion of the cost differential in Australia?

**Dr Rowell**—No.

**CHAIR**—Can I ask why you do not know? You are a very senior person.

**Dr Rowell**—I know the price of recombinant factor VIII but I do not know the price of plasma derived factor VIII. That has been kept fairly close to those people. We do not know the

price, but we have asked. The cost and the price are two different things. I do not know the cost of making it or the price that people are charging the federal government for it. Previously the price for recombinant factor VIII was $A1.14 per unit. My understanding is that the federal government has organised another contract to provide recombinant factor VIII. I do not know the price.

**CHAIR**—Where is recombinant factor VIII purchased from?

**Dr Rowell**—At the present time the contract that Australia has is with Baxter. They now have two factories, one in Switzerland and one in the United States.

**CHAIR**—Over what period of time are the contracts let? I am sorry, you are the wrong person to be asking this.

**Dr Rowell**—I think it is three years, with a chance for extension after that.

**CHAIR**—The position is that children are being given recombinant factor VIII and others are not. What is the rationale for decision making along that line?

**Dr Rowell**—At the present time, the criteria for treatment with recombinant factor VIII are probably a little woolly. When recombinant factor VIII was introduced into Australia, or was funded to come into Australia, it was initially for prophylaxis of those with severe haemophilia who were under the age of 18. They were people who had not been exposed to plasma or they had not had any evidence of viral infections. Those criteria have been extended in different ways to include people with mild haemophilia who may require surgery, who may never have been exposed to plasma and products and who were virus free. Recently those criteria have been extended a little as there was a shortage of plasma derived factor VIII in Australia in about November.

**CHAIR**—So, once you have that baseline, if you are not succeeding in producing enough you fill it up with—

**Dr Rowell**—We have been fortunate that recombinant factor VIII has been available to top up what has been required. Prior to April last year, CSL produced a product called AHF—antihaemophilic factor. This was discontinued and a new product called biostate was produced, which has two viral inactivation steps. Unfortunately with that process and the conversion, the efficiency with which factor VIII is extracted from the plasma into the biostate was reduced compared with the previous concentrate and it was possible that we could predict that there was going to be a shortage. This gradually loomed over November. So we were actually able to obtain funding to get more recombinant factor VIII to top up those needs.

**CHAIR**—When I asked the question about cost at the very beginning, you asked whether it was in Australia or internationally. Do you know of any difference in the production cost? Do you know the difference of that cost internationally?

**Dr Rowell**—No. I can only guess. You are probably looking at the cost of plasma derived as it was probably 30 per cent of recombinant factor VIII. I believe that the cost of recombinant factor

VIII overseas is much more than we pay, so we are doing pretty well. I cannot quote any costs or prices.

**Senator MOORE**—I just have one question, Dr Rowell. Yesterday I asked about whether a patient could receive a combination of the plasma based and the synthetic treatment, and the person I was asking was not sure. From your point of view as a professional, can they?

**Dr Rowell**—At the present we in the organisation, in trying to promote the use of recombinant factor VIII over plasma derivatives, have argued—and I think that has been agreed—that if someone changes over to recombinant factor VIII they should stay on recombinant factor VIII.

**Senator MOORE**—Subject to availability.

**Dr Rowell**—Usually recombinant factor VIII is available. There was a shortage of one product two or three years ago. The aim is to maintain recombinant products as soon as they have started. It is possible, in some situations when a complication occurs with haemophilia, to develop an antibody. In the past we have actually given them plasma derived factor VIII. There may be a scientific reason for that. It may be a better treatment to actually get rid of the antibody. It is very difficult to prove that. That is a situation where someone might go back to a plasma derived factor VIII: when they have developed a complication of haemophilia that is developing an antibody. But that is relatively uncommon.

**Senator MOORE**—Thanks.

**Senator LEES**—Thank you for your submission. I am just looking at the data collected by the Australian Bleeding Disorders Registry. Is that not including New South Wales data?

**Dr Rowell**—Yes; it is not including New South Wales.

**Senator LEES**—Why? What is the problem with New South Wales data? Who collects that?

**Dr Rowell**—At the present we are in negotiations with the New South Wales department of health to try to obtain that data and put it into this bleeding disorders register, but that has been a difficulty.

**Senator LEES**—Have all haemophiliacs in Australia been checked for hep C?

**Dr Rowell**—I cannot actually say that. It depends whether they have presented to a haemophilia centre or not. Some of them may well have not come along for 10 or 15 years. As an example, I met someone who came along and told me: 'I've got to get some teeth done. I'd better do something about this.' I said: 'You've got haemophilia. How long? Have you had any problems with it?' He said, 'Yes, I nearly bled to death.' I asked, 'How long ago was that?' and he said, '25 years ago.' I am just saying that occasionally there may be someone whom we regard as having very mild haemophilia who may not have presented. I would have thought they would have all been done. We should really be very close to 100 per cent.

**Senator LEES**—Thank you.

**Senator HUMPHRIES**—Liver transplants can be a solution for some sorts of infections or diseases of the liver caused by hep C. I presume liver transplants may be conducted once a liver has been seriously damaged or is on the way to being seriously damaged by hep C. What number of such transplants take place in Australia each year in these circumstances?

**Dr Rowell**—I think there have only been two or three liver transplants. There have certainly been two up in Queensland. I cannot say for other centres. They were for haemophilia but really for cirrhosis or complications of hepatitis C in someone with haemophilia.

**Senator HUMPHRIES**—Is the low number due to the lack of availability of suitable livers?

**Dr Rowell**—I could not really answer that, as to whether that is the reason or whether it is the severity of the disease.

**Senator HUMPHRIES**—I would have thought, given that hep C is a blood-borne disease, that a transplanted liver might also eventually suffer the same risk of succumbing to cirrhosis or whatever.

**Dr Rowell**—I think that is the same case. If you have active hepatitis C, the liver will actually get a hepatitis C infection. One of the complications of hepatitis C is scarring, which is called cirrhosis. One of the difficulties with that is that you develop varices in your oesophagus and stomach, which are basically haemorrhoids. They can bleed. If someone without haemophilia develops those normally, their mortality is quite significant. You can imagine what would happen if you had haemophilia and a bleeding disorder: if they bled, that would be a major problem. In those situations it is important to treat them.

**Senator HUMPHRIES**—Can you clear up for me a question in my mind about how it is that despite non-A, non-B hepatitis being known about for quite some time—several decades—until even the eighties people were talking about it as a benign condition and saying that it was not a serious concern if it was contracted. How did that view come about?

**Dr Rowell**—I cannot speak for my organisation but I can speak personally. Many probably did not perceive that as a serious chronic disorder. From my personal experience, in 1984 HIV came along and that consumed people completely. Certainly, people were aware of complications affecting the liver, enlarged spleens and chronic liver function test abnormalities. You had come from a phase where there was no treatment of haemophilia. You then went to a phase where there was fresh blood and then plasma. Then you were developed into a phase where you had concentrates, which were a much more concentrated form of factor replacement. People possibly thought—and I was not there at the time—that it was far better to have that and to accept that possibly there was a complication from the concentrates. This certainly varied across countries. Germany was involved in pasteurising factor concentrates in, I believe, the early 1980s. They were very aware of that and what they were doing. There was quite a variation of approaches between different countries as regards their knowledge and what they thought the situations were.

**Senator HUMPHRIES**—The availability of these sorts of treatments was considered to be able to keep the effect of the disease at bay.

**Dr Rowell**—Prior to the onset of HIV the major cause of mortality for someone with haemophilia was a cerebral haemorrhage. One could use that as a gauge: is it important to have treatment to try to prevent that and to prevent the complications? They were possibly not aware of what the other complications of non-A, non-B hepatitis were.

**CHAIR**—Dr Rowell, you said that Germany was pasteurising concentrates. In what years did that occur?

**Dr Rowell**—Do not quote me on that. I think it was in the early 1980s. I am not sure. They had become aware of those sorts of things and they were trying to pasteurise concentrates. One of the difficulties with pasteurising or heat treatment is that you actually lose a lot of factor VIII.

**CHAIR**—Can you point us in the right direction to go and get some more information about that? This issue of pasteurising is coming up more and more. When did we know that we had to move up to 80 degrees?

**Dr Rowell**—There was a paper published some time in the mid-1980s which was looking at different concentrates and their effect on HIV. They noted that the 60-degree heat treatment did not prevent non-A, non-B hepatitis. At the time they did have an 80-degree heat treatment that might have been from the UK. That was probably about the mid-1980s—I am not sure exactly.

**Senator HUTCHINS**—Dr Rowell, you said that there are 16 haemophiliac treatment centres in Australia that are incorporated. Has that always been the case?

**Dr Rowell**—The Australian Haemophilia Centre Directors Organisation is incorporated in Victoria. Those centres are part of hospitals. There are several centres in New South Wales, two in Victoria, two in South Australia, three in Western Australia and two in Brisbane. They are all part of hospitals.

**Senator HUTCHINS**—I do not know whether you heard Mr Pollack's evidence earlier or whether you have heard his statements before about the Red Cross. Even though they were aware he had hepatitis C they still asked him to donate blood to fractionate. Were you here for that?

**Dr Rowell**—I was here, yes.

**Senator HUTCHINS**—Do you have any response to that?

**Dr Rowell**—I cannot comment. I do not know what the situation was.

**Senator HUTCHINS**—You may not be able to answer this, but was your organisation part of the National Blood Transfusion Committee?

**Dr Rowell**—No. The organisation was set up about two years ago. Many of the directors were members of a medical advisory panel for haemophilia prior to that—for maybe eight or nine years before. As an organisation or as individual members, I do not think they were on the National Blood Transfusion Committee.

**Senator HUTCHINS**—So no-one from your organisation was on the committee—not even the state committees—that you are aware of?

**Dr Rowell**—I was on a blood product user group for Queensland.

**Senator HUTCHINS**—When the product has to become available to the centres now, you would assume that that plasma is 100 per cent safe; is that correct?

**Dr Rowell**—At the present time we do not say that it is 100 per cent safe. If I was discussing it with someone or counselling someone about whether they needed to have plasma for a condition I would advise them of what I thought the risks were and what the alternatives were. Unfortunately we never say it is 100 per cent safe. It is obviously very close.

**Senator HUTCHINS**—It is 97 per cent safe?

**Dr Rowell**—It is much better than that.

**Senator MOORE**—Is that so for any plasma derived or synthetic treatment?

**Dr Rowell**—The synthetic treatment is theoretically safer on the basis that it has fewer plasma components. And there are newer-generation recombinant products coming out that have been manufactured without plasma contaminants, without plasma, and not resuspended in albumin, which is a plasma component.

**Senator MOORE**—So do you give the same advice to people who are—

**Dr Rowell**—No, we change it slightly. I would say that there is a risk of viral infections with plasma derived concentrates and that there is very little risk with the other products.

**Senator HUTCHINS**—There was an incident about 12 years ago that is referred to as the Gosford incident. You are obviously aware of it.

**Dr Rowell**—I had to read something about it to find out what was going on.

**Senator HUTCHINS**—That is why I asked earlier about these treatment centres that were previously set up in hospitals. I asked a series of questions of Senator Patterson, when she was health minister—and I got answers from Senator Ian Campbell—on people who were advised of this plasma product. I have here documents showing how many people were advised. Do you recall whether your organisation—

**Dr Rowell**—I cannot recall being advised. When this came up in discussion certainly one centre remembers being advised by the Red Cross but others do not remember.

**Senator HUTCHINS**—There was a problem with blood or blood plasma in a period from 1990. I forget where I read it but there was a major incident at IMIG—or something like that—with imported US blood. Would you be advised by CSL or the Red Cross that this product was questionable?

**Dr Rowell**—At the present time?

**Senator HUTCHINS**—Has there been any period in your experience when that has occurred?

**Dr Rowell**—We certainly get notified about different product problems—it could be problems with red cells, platelets, or donor issues. They would usually notify where they felt the blood had gone, to follow up with the patient who may have received it—or, if the patient had not received it, to return the product. They are usually fresh products. I cannot recall other issues with other pooled products that we have been notified about but there is certainly a process in place for fresh products.

**Senator HUTCHINS**—When you are advised that there might be a difficulty are you expected to report that back to—

**Dr Rowell**—We are expected to report back the outcome.

**Senator HUTCHINS**—Are you required to do that now?

**Dr Rowell**—Yes. We are supposed to report back whether there is an issue and whether we have notified the patient and the doctor.

**Senator HUTCHINS**—The answer from Senator Campbell to my question was that it was in the hands of the hospitals and the territories to do that. The answer was that no-one was reporting back to make sure. If you had the opportunity earlier you would have heard a number of people being critical of this Lookback program for people who have received hepatitis C.

**Dr Rowell**—The Lookback program is an issue for us. There is certainly information we get sent regularly by the Red Cross: numbers of donations that we need to try to find the fate of, where they have been and what has happened et cetera. That is quite regularly—every month.

**Senator HUTCHINS**—So every month?

**Dr Rowell**—Yes, on a range of products and a range of dates. The dates go back maybe to the early eighties; I cannot remember. Sometimes we are unsuccessful in finding the fate of those products and where they have been, so we need to feed back to the Red Cross about that and follow up the Lookback program as best we can.

**CHAIR**—We have had very different evidence about how effective the Lookback program is and how it works. What is your general view? Is it an efficient and effective program of providing people with information about how their infection may have occurred?

**Dr Rowell**—I am only involved in the Lookback program as a director of haematology of a large hospital. My role in the Lookback program is to organise the follow-up of donation units notified to us and then to notify the Red Cross. I really could not comment on whether it is successful or not.

**CHAIR**—In your view, is it well run? Is it predictable? Is it administratively efficient?

**Dr Rowell**—It is efficient. If we do not reply in a period of time, we get reminders to try to do that. From the point of view of efficiency in trying to follow up the fate of donations, yes, they try to follow them up until we say we have found the fate of that donation or else we say we do not know what has actually happened to it because the medical records have been destroyed.

**CHAIR**—You said it was 'an issue for us' because it is onerous?

**Dr Rowell**—It is a technical problem because you get a list of 30 units and you have to look back 15 or 20 years. We have tried to garner all the records that we have had on paper et cetera. We go through them and we have to continue to go through them. It is a practical issue; that is all.

**Senator LEES**—When I was looking for your submission I saw that you mentioned that, of the people who have von Willebrand disorder, more than half of those registered on the database have not had their hepatitis C status documented. Does that mean that we may still have people with this disorder who do not know if they are hepatitis C positive?

**Dr Rowell**—The database is not in its infancy as it has been going for four or five years. It really is dependent on each centre putting in data. At the moment resources are not high in that, so what may have happened is that for these people they have not put that data in. I know there are some people whom we have noted but who have not received the new products and who may not have had a test as yet. I would think there would be practical reasons why the data was not complete within the data set.

**Senator LEES**—Should we be looking at retesting anyone who has had product for whatever reason throughout that time when, as we know, there were contamination problems?

**Dr Rowell**—Certainly it would be useful to do that after they have been counselled as to what the benefit of it is.

**Senator MOORE**—I have a general question about your specialty in terms of people training and choosing to go into your sphere of medicine. Do you have any difficulty in filling those places? Is it an attractive decision for people who are studying to say, 'Yes, I will go into that specialty'?

**Dr Rowell**—From the point of view of a haematologist, I work in a laboratory and I also work in my clinical sphere of haemophilia. Not everyone wants to go into that, so there is a difficulty in attracting staff to do it. There are difficulties in training people. I believe there are still shortages of medical posts for clinical haematology across the board—and certainly it is difficult to attract people who are interested in dealing with haemophilia and other bleeding disorders.

**Senator MOORE**—Is the training available in every state? You can actually do training in every state?

**Dr Rowell**—Yes. The issue is that it is a small component of a clinical haematology job. It is a very useful one. It is very beneficial for a team to have nursing staff, counselling staff and physiotherapy staff. Most of the centres are very proud of what they have achieved so far. Trying to maintain the skills necessary for looking after people with haemophilia when they have viral

complications or orthopaedic complications—and there are developmental issues that occur for children growing up who need to acquire three doses or treatments a week et cetera—or family issues is still very important. The product is quite expensive. It is important that the haemophilia centres and the patients they are treating have a good handle on how it is best managed. From that point of view the haemophilia centres are very important in ensuring the best management of factor concentrate usage.

**CHAIR**—Thank you very much, Dr Rowell. We appreciate your being able to come and speak with us today.

**Proceedings suspended from 1.25 p.m. to 2.35 p.m.**

**BARRACLOUGH, Professor Bruce Henry, Chair, Australian Council for Safety and Quality in Health Care**

**CHAIR**—Welcome. Do you have any comments to make on the capacity in which you appear?

**Prof. Barraclough**—I appear as the chair of an expert advisory group into some aspects of hepatitis C and plasma. My normal occupation is Professor of Cancer Services at Northern Sydney Health.

**CHAIR**—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, for which we thank you. I now invite you to make an opening presentation, to be followed by questions from the committee.

**Prof. Barraclough**—Thank you. I would like to make a short statement to put into context the submission that I made, which is the report that the Commonwealth has published *Report of the Expert Advisory Group on Hepatitis C and Plasma in 1990—May 2003.* That report was produced by the activities of a group that I was asked to lead. The putting together of that group followed articles in the *Sydney Morning Herald* in July 2002 by Mr Gerard Ryle. The other members of the expert group were Professor Peter Angus, Director of Gastroenterology and Hepatology, Medical Director Victorian Liver Transplant, Austin and Repatriation Medical Centre, Melbourne, and Professor Geoffrey Farrell, Professor of Hepatic Medicine at the University of Sydney and director of the liver unit at Westmead Hospital. Our terms of reference were to:

… consider the claims that plasma testing positive to the hepatitis C antibody was used in the manufacture of plasma products for several months in 1990, against the following Terms of Reference:

(i) What were the key decisions and events associated with the Red Cross blood transfusion services forwarding plasma, testing positive to hepatitis C antibody, to the then Commonwealth Serum Laboratories (now CSL Limited) for use in the manufacturing process of plasma products, during 1990?

(ii) What were the scientific and policy reasons for these decisions?

(iii) To what extent were these reasons consistent with credible scientific opinion at the time including international scientific opinion?

(iv) What could have been, based on scientific opinion at the time and now, the impact, if any, of these decisions on the safety of the Australian Health System and the blood supply?

In order to answer those terms of reference we needed to understand the background and context. That background and context is quite well canvassed in our report. There is an extensive chronology of events from 1988 to 1994, starting on page 17 of that report. I would like to read,

if I may, the last two paragraphs from our conclusion, which is on page 82 of that report. Those paragraphs say:

> We are satisfied that the decisions made in 1990 are unlikely to have adversely affected the safety of plasma products produced and that to date, fractionated plasma products from this period, the subject of our inquiry, have not been implicated in the transmission of HCV. However, there have been reported cases of HCV from the use of whole blood or blood components in 1990, in particular, 11 cases in which there was evidence of HCV infection arising from whole blood transfusion following the 'Gosford incident'—

which is described in section 4.2. The conclusion goes on to say:

> In our view, this incident demonstrates that the potential for compromise of blood-product safety exists where there are ineffective governance and management systems involving a fragmentation of responsibility and where new systems are introduced without appropriate education and infrastructure support.

We went on to make a recommendation and we identified some further matters for consideration by the minister.

**Senator HUMPHRIES**—Who set up the expert advisory group?

**Prof. Barraclough**—Senator Kay Patterson, the Commonwealth health minister at that time.

**Senator HUMPHRIES**—Who were the other members of the group?

**Prof. Barraclough**—Professor Geoffrey Farrell and Professor Peter Angus.

**Senator HUMPHRIES**—You made recommendations to do with the proposed national blood authority, which I understand have been carried forward.

**Prof. Barraclough**—Yes.

**Senator HUMPHRIES**—You made other recommendations to the minister, which I assume have been responded to in a formal way so far, indicating what the minister proposes to do with those recommendations.

**Prof. Barraclough**—The minister was in my view supportive of those recommendations, but what has in fact happened I am not privy to, because there has been no appropriate opportunity for feedback on that.

**Senator HUMPHRIES**—I assume that you would be aware of some of the other submissions to the inquiry, including that from the Medical Error Action Group.

**Prof. Barraclough**—I have not seen that.

**Senator HUMPHRIES**—I will just summarise what the group has said. It referred to the expert advisory group report and it described the report as being a missed opportunity. Particularly, it said that the inquiry 'failed to interview key witnesses and failed to address key evidence submitted to it'. We are yet to hear from this group, so I cannot tell you exactly what is

meant by that phrase. But, given that you will have finished your testimony by the time they come forward, can you give any indication of what they might have meant by that comment?

**Prof. Barraclough**—The people that we interviewed and the processes that we followed are in the report and have been published. They are in the public domain and they are clear. I have not seen the Medical Error Action Group's submission.

**Senator HUMPHRIES**—Do you know if there were people who sought to give evidence to your inquiry? Did you take witnesses in your inquiry?

**Prof. Barraclough**—We took those who asked us to, yes.

**Senator HUMPHRIES**—And there were no people that you turned away in that inquiry?

**Prof. Barraclough**—Not that I am aware of.

**Senator HUMPHRIES**—They go on to say that in the course of your inquiry there was legal action taken in the shape of a contempt of court motion instigated by the Red Cross. They then say:

Consequently victims withdrew from making submissions for fear of violation of their submission and privacy.

Do you have any idea what is meant by that?

**Prof. Barraclough**—No, I do not. What was happening in the courts was not part of our review. We were looking at what happened with the blood supply back in 1990.

**Senator HUMPHRIES**—Were you aware of litigation going on around your inquiry?

**Prof. Barraclough**—Quite obviously there was activity going on. I did not particularly know that it was in relation to what we were doing. There was certainly litigation going on.

**Senator HUMPHRIES**—But you are confident that your group had the time and the resources to look comprehensively at the issue that had been placed before you in the terms of reference?

**Prof. Barraclough**—We are happy that the report stands as an appropriate record of what we did. The experts I worked with—who are experts in this field—and I are happy that we assessed all of the literature that we felt was appropriate and accessed information from a significant number of people who may have had information that was useful to this. Everybody we approached and had contact with was very helpful.

**Senator HUMPHRIES**—Nothing since you report has been brought down would change your opinion if you had to look at this issue again?

**Prof. Barraclough**—Not that I am aware of for that period of time that we were asked to investigate.

**CHAIR**—Professor, the terms of reference were very clear about you investigating essentially six months of activity in 1990. The Medical Error Action Group are alleging—and this is not an allegation against you personally or the work of your committee—that the opportunity to fully investigate this issue could have been taken by the minister but was not. I think, to paraphrase Senator Humphries, that is essentially what they are saying. That is for clarification only. In your executive summary you say:

Inevitably, even with the level of cooperation given, it can be difficult to reconstruct events of 12 years ago and to avoid hindsight bias.

I think that is advice that this committee can probably take as well.

**Prof. Barraclough**—Everybody is human and everybody remembers things in a way they feel they should remember them. There may not be a paper trail 12 years later. Quite possibly information existed in 1990 that does not exist now, but I do not know that. It is just a statement that sits by itself. When you are investigating something 12 years on you are investigating something 12 years on with all of the provisos that that has.

**CHAIR**—Certainly. The period of time you were asked to report on was after the time that the first generation test was developed. Did your committee investigate or look to surrogate testing and its usefulness? I am also interested in your view of the ability to compare the use of surrogate testing in Australia with other countries.

**Prof. Barraclough**—While our terms of reference were quite limited in some ways, in order for us to do the job that we were asked to do we reviewed a lot of information that went before. So while the period of time that we needed to report on was the early part of 1990, which was when that first hep C test came into place, we did need to understand what had happened prior to that in order to make sense of what was happening at that time. So, while not wishing to step too much beyond our terms of reference, we did undertake a review of some literature about what was happening before the first tests were available for hepatitis C.

You may well have already had testimony about the scientific debate that was raging around the world at that time. There were quite a lot of views about surrogate testing using a particular liver function test called ALT. That was something we addressed on pages 39, 40 and 41. As far as we could tell, one Australian state decided to implement that from about 1987, we felt largely on the basis of legal questions that had been raised at that time. We were not convinced from our reading and from the information that was available to us that surrogate testing would have been likely to have had a net benefit to the community. Already there had been close to a 50 per cent reduction in risk in the 10 years leading up to 1990, by virtue of the fact that all sorts of changes had happened in medicine, predicated on the HIV-AIDS activity that was going on from 1984, with the donor deferral, the more stringent assessment of donors, the reduced use of blood, the use of autologous blood and blood salvage at surgery. All of those issues had reduced the risk quite considerably, and there were a couple of Australian papers that alluded to that.

The risk in Australia in about 1989-90 would have been a little over one per cent, maybe 1.1 per cent, 1.2 per cent or something like that per patient that was being transfused at surgery. Other countries around the world at that time had decided that there was no value in surrogate testing at that level of risk. In countries where there was a much higher level of risk—such as in

Canada and the United States, where the risk might have been nine or 10 times that—it was decided in some situations that that testing should be performed. It was doubtful to us that there would have been any significant reduction in risk by doing that, and there may have been significant disruption to the blood supply. As you might have noted, at the end of our recommendations, on page 83, we say:

The use of blood and blood products in health care will always remain a balance of risks. The extremely low risk of transmitting a viral infection in Australia—

which has been described in this report—

must always be compared with the possible life threatening consequences of not receiving a transfusion.

So the committees that during 1990 were deliberating on issues and, one assumes, the committees that were deliberating on the issues before then, had that balance in mind. Some of the minutes that we saw certainly indicated that the various committees were considering those sorts of issues.

**CHAIR**—Did you have a look at the minutes of the National Blood Transfusion Committee?

**Prof. Barraclough**—We had a look at many sets of minutes from many meetings of numerous committees. It was not just one organisation at that time. The governance of blood activity in this country before about 1996 was quite a fragmented exercise, which is why I read into your report that where governance is fragmented there is more potential for human error than there might be where good governance exists, which is why we were very strongly pushing for the National Bloody Authority to take really strong governance of the issues around the blood supply and the safety of blood.

**CHAIR**—I will come to the question of Queensland in a moment. Could you explain briefly: is it your understanding that the governance of the use of blood in Australia was based on state based Red Cross committees interacting with their state or territory governments?

**Prof. Barraclough**—That is generally the case. State based organisations dealing with state based health systems were managing the blood supply. Not all blood banks were under the control of the Red Cross committees of that state; some were under state health department control.

**CHAIR**—So the decision not to surrogate test was taken on a state by state basis?

**Prof. Barraclough**—Ultimately, the decisions needed to be taken on a state by state basis although there was a national committee, the name of which I forget for the moment.

**CHAIR**—I think it was called the National Blood Transfusion Committee.

**Prof. Barraclough**—There were two or three different levels of committee but there was certainly a national committee that made recommendations which the members took back to the state based bodies and then decisions were taken.

**CHAIR**—So your understanding was that that national committee was solely advisory?

**Prof. Barraclough**—It was solely advisory.

**CHAIR**—My understanding is that they made a decision not to recommend to introduce surrogate testing.

**Prof. Barraclough**—They may well have done that. It may well be in here but I do not remember that at the moment. You may see that if you go through the chronology in detail but my understanding, having looked at their terms of reference and a lot of the things that they said and did, is that at that stage they were an advisory committee and while they may have collectively come to a view and made recommendations, it had to be actioned at another level.

**CHAIR**—Turning to the Queensland question, you said earlier that you thought that the decision in 1987 in Queensland to introduce surrogate testing was made on the basis of legal questions. Would you like to expand on that?

**Prof. Barraclough**—I took that view from a paper by Hyland and others published in 1988 looking at ALT surrogate testing to identify potential non-A, non-B hepatitis carriers in blood donor populations in Queensland. They did some research work and, depending on the level of the test that they applied, they thought that it might negate about 2.5 per cent of the donations as being unusable. They thought that in the social climate of the time the introduction of another screening test for a viral marker had clear medico-legal implications. These rested on the need for a transfusion service to be seen to maintain a safe blood supply that had been tested according to the highest acceptable professional standard to be able to defend a claim of negligence.

They noted that the need to screen blood donations for ALT was being debated within Australia because of the absence of a specific diagnostic test for post transfusion non-A, non-B hepatitis—that was what hep C was called at that stage—and the paucity of data concerning the disease in the Australian population. A judgment in a recent court case had indicated that provided the transfusion service was implementing screening procedures appropriate to published professional knowledge at the time of a transfusion, there should not be a case for negligence in law. In light of this experience and given the development of a cheap and convenient assay the authors had decided that concern regarding chronic effects of non-A, non-B outweighed the arguments against the implementation of surrogate testing. As I understand it other states decided against that. And in New South Wales in particular there was a study to try and determine what the level of benefit or problem might have been. I think that study was by Ismay and others and I think it was not published until 1995, but it refers to that time.

**CHAIR**—I think you are right that the decision was taken on a legal basis. Do you know if there is any difference in infection levels in Queensland recipients of blood that had been through that other level of surrogate testing compared to other blood services?

**Prof. Barraclough**—At some point in this report we state that there had been no evidence in populations with the level of risk that ours might have that that was likely to be helpful. I think the Ismay paper alludes to that. But that was in retrospect; that could not have been known at the time.

**CHAIR**—You refer to the precautionary principle.

**Prof. Barraclough**—The precautionary principle is something that has been enunciated since that time. We need to be aware of that hindsight bias. The precautionary principle really was not something that was strongly used at that stage. It was just coming to be part of the lexicon.

**CHAIR**—You have also talked about the balance that is brought to the decision making process.

**Prof. Barraclough**—It is a very serious concern. If you read through, as we did, many minutes of many meetings of quite concerned people, there is obviously a concern expressed from time to time about the adequacy of the supply in this country, both for whole blood and for fractionated products. That concern is more acute from time to time. Even today from time to time you hear advertisements on the radio asking people to donate because supplies are getting very short.

**CHAIR**—The question in my mind is: in any of those decision making fora were decisions about balance and the continuity of supply issues given greater weight than information about transmission levels? The point you make about looking back in time has to be added to that.

**Prof. Barraclough**—Looking back in time is very tricky. My supposition is that if the same people had been sitting around a table with a different population of donors, they may have come to different decisions. The balance swings if the donor population has a high probability of having non-A, non-B or hep C. Those decisions become a little easier when the benefit is likely to be a little greater by excluding those. When the risk to the patient is a little over one per cent, it becomes a doubtful proposition. That was reflected in some of the things that we read and it really highlights the difference between the North American countries and countries like Australia and the UK with their much lower levels at that stage of hep C in the donor population.

My view is that the issues were considered effectively by quite serious and concerned people who were trying to balance quite momentous national issues in effect but without adequate scientific knowledge to give them the certainty and security that they would normally have when taking decisions of this nature. Even the decisions they were taking about hep C testing were not strongly based in science until later. The fact that Australia was so early in introducing the first test says that people were taking those issues of public safety very seriously. If you run down the list—it is on one of the pages of the report—of European countries and even countries with quite significantly greater risks than for our population, you will find anything up to 12 or 18 months later for even that first test, which effectively reduced the incidence quite dramatically.

**CHAIR**—It has been put to us that Canada and Australia were very similar in their levels and rates of infection. Is that your experience?

**Prof. Barraclough**—That is not the information that was presented to the Krever inquiry. The Krever inquiry was quite laudatory in some places about what had happened in Australia, and was comparing what had happened in Canada in a rather negative way. There was a paper, the authors of which I forget, that suggested that the incidence of hep C for donors in Toronto was about 9.2 per cent, from memory. We know that in Australia the risk is so much less. The Canadian system was different: the relationship with the government was different, the donor

population was different—lots of issues were quite different. While they had also been successful in reducing risk, by virtue of what they had done with HIV-AIDS, they had done it later than we had. They may have reduced the risk from nine to three; whereas we reduced the risk from 1.7 to 1.1 or thereabouts.

**Senator HUTCHINS**—Your terms of reference were very narrow, weren't they?

**Prof. Barraclough**—We were asked to do a particular job.

**Senator HUTCHINS**—I am not having a go at you. You were asked to investigate the period from February to July or August 1990, weren't you?

**Prof. Barraclough**—Yes.

**Senator HUTCHINS**—I assume that was the basis of the submissions you received or sought for the inquiry.

**Prof. Barraclough**—Yes.

**Senator HUTCHINS**—So when the inquiry started to look at that recent history—I forget the term you used—

**Prof. Barraclough**—The context and background before that time, yes.

**Senator HUTCHINS**—Did people seek to make submissions to your inquiry on the basis of that background?

**Prof. Barraclough**—Yes, there were a number of folk. You must remember that people who are harmed by their health care, or people who believe they have been harmed by their health care, are people whose trust has been destroyed. Their lives have largely been severely affected—they are hurt and they are angry. All that information was brought to us, and it is very understandable. That is something that we took on board. As you can see, we suggested as best we could other things that the minister might consider over and above a particular recommendation relating to the narrow terms that we were required to follow. So the report that we put together provides a little more information than you would expect from the terms of reference, because it does look into context and background in order to make those terms of reference realistic. It represents the concerns that the three of us felt when we were apprised of the concerns and the life changing activities of the people who had contracted hepatitis C through, as they believe, blood transfusions or blood products.

**Senator HUTCHINS**—When you talked about people who have been affected, I did not know where you were leading. Was it that that may have affected their judgment in terms of the submissions?

**Prof. Barraclough**—No, not at all. I think you must understand the depth of concern, the depth of feeling and the depth of frustration. Everybody dealing with blood viruses from time to time has felt significant frustration and concern because the expectation from the community in relation to infection often far outweighs the science that relates particularly to viruses. It was the

same with both the HIV episode and the subsequent hep C activity. If you look at some of the papers that were written back in 1989, even the natural history of hepatitis C was not known—yet, it largely is now. When you look backwards, you use what you know now. One of our own group, Geoff Farrell, wrote quite a significant paper back in 1989. At that stage, the disease was described as frequently asymptomatic or mild; however, there has not yet been any large enough study of the natural history to describe its course. Recovery was difficult to define, and people were sceptical that it had a benign natural history.

So they did know certain things about it but they were not sure of them. When you mix that volatile exercise of scientific knowledge at one point in time as against that at other points in time with people's concerns, fear, social stigma, lack of trust and anger, it is a very emotional exercise. Of course we heard lots of things from those people who had been so affected and we were quite moved by those. Their contributions did not stick to our terms of reference; we heard lots of stories that were way beyond those.

**Senator HUTCHINS**—We heard from one this morning who called your inquiry a snow job and a whitewash.

**Prof. Barraclough**—I indicate to you that when that sort of trust in health care has been lost the anger is intense. Lord Wolfe, in his access to justice report in the United Kingdom in 1995, said that the black anger that comes with medical litigation is so different from all other forms because that trust is broken. I perfectly understand people feeling that way. I would contend that if you read our report you would see that it is not a whitewash or anything else; it actually dissects, in our view quite well, the information that was available at the time.

**Senator HUTCHINS**—You said that in fact Australia was complimented on the rapid introduction of testing after 1990. Do you think that one of the reasons why we acted so swiftly was because of the recommendations of Dr Hyland and the legal situation at the time?

**Prof. Barraclough**—I do not think so. I cannot know this but my impression from reading the minutes and the various papers of the time is what most of the folk thought—and you must remember once again the hindsight exercise and that the legal situation was not anywhere nearly as much in the public eye as it is now. I do not think that was more than a passing thought by the scientific community. I think that the success of what had gone on with HIV and the potential concerns that had been engendered in the community around HIV said that, as soon as there was true knowledge of what could be done and a test that could be effective, people should be breaking their necks to get it out there into the community. As far as I can determine, there was only one other country that beat us, by a month or two.

**Senator HUTCHINS**—I think you mentioned that you did not go into depth about the legal reasons behind the Hyland recommendation or the Queensland one?

**Prof. Barraclough**—No. You have referred to our terms of reference, which did not really allow us to dissect the surrogate question in great detail. What we have done is to put information in this report that allows people to understand what had gone before, in order to understand what goes afterwards. So if we had been asked to investigate surrogate testing, there may be another few more pages there but quite what they would be I do not know. We have

included what we found and we felt that that was appropriate information to allow us to understand the context and background in order for us to answer our terms of reference.

**Senator KNOWLES**—There have been comments, as have been alluded to, about your inquiry in that the terms of reference were deliberately designed to exclude pointing the finger at CSL and the blood service. What is your opinion of that claim?

**Prof. Barraclough**—If we had found evidence that would point the finger, as you say, at any of the players—whether they be government or commercial or volunteer or any of the organisations—we would have been quite at liberty to say what we found. There was no pressure on us to make a particular finding. I do not believe that any inquiry could be set up without somebody determining terms of reference, and those terms of reference were something that were given to us. We were asked to deal with those, and there were questions to be answered and we answered those questions. There was no pressure put on us to make a particular answer and we had good relationships with the various groups that were involved.

You will notice that a particularly troublesome incident, the Gosford incident in New South Wales, was clearly dealt with in our report. We had access to the information from New South Wales health about that. We did not have any sense that we were in the spotlight because of what we might find. We were asked to do something. If you knew the three of us you would know that if anyone had put that pressure on us it would have forced us to go in the opposite direction.

**Senator KNOWLES**—In your reports a series of claims have been made. One of them is that the Red Cross actively encouraged donations from people known to have hepatitis C. There is an article in today's *Age* where Mr Mackenzie from the Tainted Blood Product Action Group is quoted as saying:

They knew that the blood supply was unsafe, they knew that people were going to be infected ... in hundreds and perhaps thousands of cases ...

Is that your finding?

**Prof. Barraclough**—That is dealt with, and it is a complex issue because of the state of scientific knowledge at the time. We go into it quite significantly.

**Senator KNOWLES**—I want you to encapsulate that so it appears in this part of the *Hansard*.

**Prof. Barraclough**—On pages 60 and 61 or thereabouts of our report there is a section headed 'Expert analysis and findings in relation to the terms of reference.' In that section we start to dissect those sorts of issues:

- Donors whose blood repeatedly tested positive to hepatitis C screening tests were told they could continue to donate blood for the manufacture of plasma fractionation products only until July 1990, after which blood banks were advised that this practice was to stop. Donors were not finally deferred from donation until tests that could confirm their hepatitis C status became available. Such tests became available from September 1990.
- From July 1990 until July 1991, some plasma testing hepatitis C positive was sent to the Commonwealth Serum Laboratories for segregated storage with a view to future use in the development of a new hyperimmune anti-hepatitis C immunoglobulin, but with clear instruction for it not to be used in manufacture

of other products. The plasma sat in safe storage. Any remaining stored hepatitis C positive plasma was destroyed by May 1994.

- Decisions to exclude donations of plasma that tested positive for hepatitis C from the manufacturing process for fractionated plasma products were taken in June and July 1990 and rapidly implemented.

The international scientific exchange around that sort of issue was argued in the *Lancet* and other medical journals in those early months, with papers being published in February, April and May. In June the various committees that decide these issues in this country decided that we should no longer use that plasma for fractionation even of products that have been shown to be safe when they did contain hepatitis C. When you are fractionating plasma products you are largely depending on the virucidal process to kill the virus. Prior to May 1990 or thereabouts—it might be April or May—there was a body of evidence, not conclusive, that suggested that it might actually be protective to have antibodies in the serum that you were using. The science was muddied; it was not clear. Anybody taking decisions at that time had to balance the value of the various opinions, and they were opinions rather than absolute evidence. That balance was taken in favour of safety at probably the earliest time that international literature would have supported that.

**Senator KNOWLES**—Professor, you said earlier that you had looked at the minutes of various advisory bodies. Do you recall whether any of those minutes showed any conflicting outcomes from the deliberations about the recommendations that they were to make or were they on balance decisions based on the scientific evidence they had at that time?

**Prof. Barraclough**—You need to understand the sorts of deliberations that these people were making. These are all folk who are senior and are quite steeped in the science of blood. They were not there to grandstand or to put particular views; they were there to assess what was known in a very difficult climate in which they needed to take note of safety so that they could recommend to their states what they could do. I think their decisions were taken in that collegiate way. I did not see evidence that there was a clique doing this or a clique doing that. As is really the nature of the sorts of people who were doing it and the nature of the types of committees that were then in place, the decision making appeared to be on a collegiate basis.

**Senator KNOWLES**—You also made reference earlier to the fact that the state blood services were also collecting blood. Are you aware of any of those state blood services, as opposed to the Red Cross, that seriously contemplated taking a different line from the recommendations of these advisory bodies?

**Prof. Barraclough**—I am not aware of anything. You must remember that the main focus of our investigation was around plasma so we would not have looked at the finer detail of all the decisions of all the committees in different states, and that might have taken a very significant period of time. While we looked at whole blood and whole blood products to the extent that was necessary to understand the context and background for our review of plasma, given that that was not as detailed as our review of the plasma situation we were not aware of anything like that.

**Senator MOORE**—I am coming from the same kind of angle. In your executive summary, referring specifically to the plasma decision you say that the science relating to the decision was still unclear. You go on to say that using 'what is now called "the precautionary principle",' people came up with the decision they made. The precautionary principle—I think I know what that means but, for the record, what does it mean?

**Prof. Barraclough**—My understanding is that if you have a requirement to be safe, even if you do not know that a problem will happen the fact that it might happen means that you would err on the side of safety and make a decision to exclude that risk. On the basis of a public good in relation to safety, you would take such a decision even though it might not be absolutely proven. That is a stronger background to decision making in the public domain now than it would have been 12 or 14 years ago.

**Senator MOORE**—With the benefit of having waded though all those lots of minutes—which I do not think any of us wants to do—can you tell us whether the community of decision makers was dynamic? We have heard about the way the decisions were at different levels. Were people moving through those different positions, or were similar people working in the industry from about 1982 through to about 1992?

**Prof. Barraclough**—Some of the people would have been consistent throughout that time—some of the well-known and highly esteemed names in the science of blood transfusion around the world such as Professor Yvonne Cossart, whose name appears over a significant period of time during those episodes. There were others who were in place in state-level organisations for significant periods of time, like Gordon Archer. So there were people there as a consistent identity and there would have been some corporate knowledge and good science on the back of that. There were others, obviously, as issues changed and people moved. It is interesting that people were seeking out international support for what they were trying to do or thinking of doing. There are references there to European meetings and to the American FDA and various other groups that were working on the same sorts of questions. There was a consistency of people—they were always high-level folk as far as we could tell—and there would have been a core of them who would have been the same throughout all that time.

**Senator MOORE**—One of the things we keep hearing is that the debate was raging and, whilst if you were not in the community that took part in it you might not have known anything was going on—

**Prof. Barraclough**—Exactly.

**Senator MOORE**—the impression I get from reading the various things is that the people who were in this industry were deeply involved in this issue. They were studying it, they were reading about it and they were arguing fiercely all the way through this period.

**Prof. Barraclough**—They were looking at opportunities for further research to clear the science, and they were working with others internationally to do that.

**Senator MOORE**—I am struggling with one thing at the moment. We had had the turmoil of the HIV experience—and I do not think anyone can put into words just how devastating that must have been—and this process was evolving and then along came hepatitis C. I know the precautionary principle has evolved as well, but if the same precautionary principle which coloured the decision in 1990 was around in the 1980s would the decisions about the other elements of blood transfusion have been done in the same way? You cannot determine that without hindsight.

**Prof. Barraclough**—It is impossible to go back and take those exact same steps backwards. It is just not possible. My supposition is that there would have been a continued difference of opinion, as there was even once there was the first test for hepatitis C and even once hepatitis C had been identified, because until the science is absolutely clear you are not going to get absolute agreement. Then it depends on what value people put on whether there might be a protective value in having antibodies or there might not be, and what on earth you do with the vast number of people who do not actually have hepatitis C but who you suggest might when there is nothing you can do to ameliorate their worry and concern. All of those questions are unanswerable. Heaven forbid that I should be part of one of those committees at any stage because you would have to have the wisdom of Solomon to make those decisions.

**Senator MOORE**—And they are life impacting.

**Prof. Barraclough**—And they are life impacting for the people who make the decisions as for everybody else.

**Senator MOORE**—But in terms of the recommendations you made from your study with your terms of reference, in the 1990 decision about the plasma the precautionary principle overrode maybe other elements—

**Prof. Barraclough**—Once there was some reasonable clarity that the balance was swinging away from there being a protective value of having antibodies in the serum towards there may not be a protective value but we do not know if there is any harm—

**Senator MOORE**—And even if the science was not absolutely clear, that coloured the decision.

**Prof. Barraclough**—I believe so. That is the way I read it in retrospect.

**Senator HUMPHRIES**—Can I get you to repeat the answer you gave to an earlier question by Senator McLucas about whether the use of surrogate testing in Queensland led to a lower rate of infection for hepatitis C.

**Prof. Barraclough**—I do not believe that we had information that that was so. One of the reasons why it is hard to get that information is the very low level of risk compared to other countries—you would need a very large scientific study to understand that. You must bear in mind that other things were impacting on risk at that stage as well—progressively the selection and deferral of donors was tightening, the use of autologous blood was increasing and the reduction in the number of transfusion units given was accelerating. All of those issues were reducing risk at the same time that was happening. I think that it would be very hard, no matter how hard you tried, to actually find hard and fast evidence that it made a difference.

**Senator HUMPHRIES**—Do we have data-collecting mechanisms in place at the moment which would give us the answer to that question if this situation were to arise again today?

**Prof. Barraclough**—I do not know the answer to that. You would have to ask maybe Professor Smallwood, who chairs the National Blood Authority. I do not work in the blood

transfusion system; I work as a cancer surgeon and I was using some leadership and safety and quality background in order to lead this team. I cannot answer that question for you.

**Senator HUMPHRIES**—Do you see the role of the Australian Council for Safety and Quality in Health Care as primarily promoting and lifting the quality and safety of health care or as promoting Australian health care as safe and of a high quality?

**Prof. Barraclough**—Both of those things, but you must bear in mind that the Australian Council for Safety and Quality in Health Care is an organisation set up by all health ministers and answerable to all health ministers. It is not of itself empowered to take vast amounts of action at a state or other level, and so we work with state and other authorities to actually achieve the things that we achieve. We are building the will, skill and capacity for change and putting some standards and other things in place to help achieve improved safety of the health system. Our role was to take a systemic view of health with an aim to reduce adverse events and the effects of error. There are some 90-odd projects and programs under way at the moment, all of which are aiming to do that.

**Senator HUMPHRIES**—I suspect some health ministers would be happy for you to talk up the quality of Australian health care as well as actually lift it. That is a comment rather than a question.

**Prof. Barraclough**—It is not part of my job to talk up the quality of Australian health care. It is one of the better health systems in the world—and people should regard it as such, because it is. The particular mix of activities that we have in this country of ours is to access 21st century health care pretty much across our geography, without significant cost in many circumstances. Yes, we have a health system that is the envy of many other advanced countries, but it is not my job to talk that up. In fact, a couple of weeks ago there was an expression of interest in the *Australian* for people to actually measure again the safety of the Australian system, so before we finish we will be identifying for ministers what the system is.

**Senator LEES**—You mentioned before, I think, that you were not aware whether those four matters you drew to the minister's attention had been acted on—

**Prof. Barraclough**—Not in detail.

**Senator LEES**—relating to reviewing the implementation of the National Hepatitis C Strategy. Looking at that specifically, you are not aware of whether that recommendation was followed.

**Prof. Barraclough**—I am not aware of that. As I said, we had some positive and grateful comments around the recommendations that we had made, both from policy makers and bureaucrats. I have no reason to doubt that there is good motivation to try and follow those recommendations. How quickly it is going to happen, I am not privy to.

**Senator LEES**—I am wondering whether, as a cancer surgeon, you had any evidence that there had been any activity on the one relating to liver cancer research. You were foreshadowing that there would be an increase, if not a doubling, in that.

**Prof. Barraclough**—I do not know that there has been specific funding put aside. The National Health and Medical Research Council has a vast budget that it administers appropriately.

**Senator LEES**—Perhaps we had better ask some other people about your recommendations.

**Prof. Barraclough**—Quite seriously, you will need to ask other folk about that.

**Senator LEES**—We will take that on notice for us to do.

**Senator HUTCHINS**—In 1987 the Blood Transfusion Committee makes a decision not to introduce surrogate testing and Queensland goes and does its own thing. We know who comprises this committee. If we had a similar crisis today, who would make a decision about what path to go down in relation to a test? Would it be the Commonwealth and state health ministers on advice from, say, the National Blood Authority? Would that be the way?

**Prof. Barraclough**—I expect that would be the way. The National Blood Authority is a joint state-federal exercise. The National Blood Authority has a very strong advisory role, and one would expect that that group with advice from appropriate experts would advise AHMAC, health ministers and governments more broadly about what should be done.

**Senator HUTCHINS**—In 1987 there did not appear to be any political decision makers involved.

**Prof. Barraclough**—As we have mentioned, the governance of the system—the governance of many corporations and government instrumentalities—has improved quite dramatically in the last 12 years, and this is not only in relation to blood. People understand governance much better now than they did 12 or 14 years ago. In fact, 1987 is longer ago than that. Nevertheless, there was not a national structure. There is continuing to be press about whether the health system should be more national or state based, and there are kites being flown about that. Nevertheless, we did not have it at the time, and that is why we have referred to the potential for that lack of national governance to lead to human error because of the complex and mixed reporting lines that existed.

**CHAIR**—Thank you for providing us with your submission and for your evidence today.

[3.35 p.m.]

**LONG, Miss Lorraine Irene, Founder, Medical Error Action Group**

**CHAIR**—Welcome. 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. We have before us your submission, for which we thank you. I now invite you to make an opening presentation, to be followed by questions from the committee.

**Miss Long**—I will just give you a short address. This is what I had in my submission:

Blood is life. In transfusions it saves millions of lives every year. Blood also provides plasma—a precious liquid used in the manufacture of various medical products that are indispensable, particularly for haemophiliacs.

But between 1980 and 1988 the lifesaving act became synonymous with death throughout the world: 30,000 haemophiliacs and tens of thousands of transfusion recipients were victims of blood that was infected with the Hepatitis C and HIV viruses.

This is the blood scandal.

A single product requires the blood of thousands of donors yet a single sick donor is enough to contaminate everything.

In the USA, Canada, Japan, Germany and France—

**CHAIR**—Miss Long, we have your submission—you do know that?

**Miss Long**—As I said, I was just reading from the foreword of my submission.

**CHAIR**—We have got your submission, which we have all read. Are there any additional comments that you wanted to add to that?

**Miss Long**—Not as an opening, no.

**CHAIR**—You have been here this afternoon and heard the discussion Senator Humphries raised about your criticism of the reporting process undertaken by Professor Barraclough. Would you like to make some comment about the discussion that Senator Humphries and I had with Professor Barraclough around the criticism from your group of the process that he undertook?

**Miss Long**—When that inquiry was announced we made a submission and we also informed the federal health minister, Senator Kay Patterson, that we had a vast amount of people who wanted to contribute to that inquiry. Each person was denied that inquiry. When we found out the inquiry's time to speak to victims had actually ended, we contacted Senator Patterson's office. There were various letters going back and forth. We told Senator Patterson that victims had been denied the right to give evidence at that inquiry. Some of those people were here today. When Senator Patterson did not announce the findings of that inquiry—it was continually being

delayed—we still thought we had an opportunity for the victims to be heard, but they were not heard. Professor Barraclough knows me quite well and knows the work of my group. I have been part of the safety and quality council consumer reference network for over three years. I was also invited by his council to write a report on medical error and how it affected families generally, Australia wide. So it was up to Professor Barraclough then to come to our group and also the tainted blood group to seek those opinions and views of victims, for them to give evidence.

There is one particular case that I make a point of. It concerns the stages and the dates of the occurrence of a person making a submission, then the Red Cross taking legal action against this person and then Professor Barraclough making his report to the federal health minister. It will stand on its own. I recommend the inquiry get hold of that court case judgment, because that motion failed. That, I think, let a lot of people down, because it meant that straightaway when they were making a submission—and quite a few people did make a submission to his inquiry—it appeared that their submissions ended up in the hands of the Red Cross. We do not know how they got there, but there was complete violation of people's privacy. It distressed a lot of people. They said, 'We're not giving you any more information because you've obviously handed it over to the Red Cross.' Our group came up looking like we had done it, and we most certainly had not.

**CHAIR**—When you say that people were denied access, do you mean they were denied access to speak to the inquiry or denied the ability to—

**Miss Long**—They were denied the chance to be heard. They had contacted our group. We made representations to the inquiry and when we did not get feedback we wrote directly to Senator Patterson's ministerial office and dealt with people there. We were then put on to other people who were looking after the inquiry. There are extensive letters on the record complaining, 'Why aren't you listening to these victims?' They come in the time frame of those terms of reference.

**CHAIR**—What were the reasons given by Senator Patterson's office and then by the committee of inquiry as to why the people in your group could not be heard?

**Miss Long**—There never were any reasons. We just wrote extensively and nagged them. That is all on the record. Everything we send to a minister's office we send by post and by fax, because a lot of mail we send to ministers around the country they do not receive but they all seem to receive the faxes. I can produce documentation pertaining to that. I complained vehemently, 'You've got the people you need to speak directly to and you've denied them their chance to speak.' They have never been heard. I think this inquiry today has given people a chance to be heard.

**Senator KNOWLES**—Professor Barraclough said that the committee of inquiry had actually spoken to a number of people who were sufferers. Are you saying that they did not speak to any, or that they did not speak to the ones you wanted them to speak to?

**Miss Long**—They did not speak to anyone from the Medical Error Action Group. We have over 13,000 families in our group. A substantial number of those are tainted blood victims.

**Senator KNOWLES**—But you are not saying that they did not speak to any sufferers? He said quite the reverse: that they actually spoke to a number of people outside their terms of reference.

**Miss Long**—They did not speak to the people from our group, and I believe they did not speak to anyone from the Tainted Blood Product Action Group except the founder.

**Senator KNOWLES**—That still does not answer my question.

**Miss Long**—Would you like to repeat the question.

**Senator KNOWLES**—My question is: are you saying that they did not speak to anyone who was a sufferer—

**Miss Long**—I do not know.

**Senator KNOWLES**—Can I just finish—that they did not speak to anyone or just people who are members of your group?

**Miss Long**—People are not members of our group. They have come to our group because they are affected families, and we make representations on their behalf. We have provided a forum for them to do that.

**Senator KNOWLES**—That still does not answer my question.

**Miss Long**—They did not speak to any victims in our group. They did not speak to any victims in the Tainted Blood Product Action Group except the founder.

**Senator KNOWLES**—But are you still saying that they did not speak to any sufferers?

**Miss Long**—I do not know if they did. I have not seen that evidence.

**Senator HUMPHRIES**—You say that members of your group attempted to speak to the expert advisory group but were not given a chance. How did you do that?

**Miss Long**—We did that in writing. There was no response.

**Senator HUMPHRIES**—You wrote to Professor Barraclough?

**Miss Long**—Yes, to the expert advisory committee.

**Senator HUMPHRIES**—Was that while the inquiry was still hearing evidence?

**Miss Long**—Yes, and before. As soon as it was announced we started making submissions. We wrote and said we had a vast amount of information we would like to provide. Then when we found out that that information was not going to be sought we wrote straightaway to Senator Patterson, who was the federal health minister.

**Senator HUMPHRIES**—You heard Professor Barraclough say that he did not consciously reject anybody's attempt to appear before his inquiry. I am a bit bemused about this difference.

**Miss Long**—Professor Barraclough, as I said before, knows our group. He knows the work of our group. He is chair of the safety and quality council. That council invited me into its consumer reference network and also asked me to provide a report on the families. I touched on this subject in the extensive report we wrote on that. That report has been with the safety and quality council since December 2000. So it is not as if Professor Barraclough did not know; all he had to do was read the correspondence.

**Senator HUMPHRIES**—You did not get a reply to the correspondence?

**Miss Long**—Not from the expert advisory committee, no. We did from Senator Patterson's office.

**Senator HUMPHRIES**—You are sure this was before the inquiry had completed hearing evidence?

**Miss Long**—I am sure. This goes back to November-December 2002.

**Senator HUMPHRIES**—Do you know when the inquiry finished taking evidence?

**Miss Long**—I think it was in December. When Senator Patterson had not announced the finding of the inquiry we were making continual phone calls to find out what was happening. We do not know why Senator Patterson delayed announcing the finding of that.

**Senator HUMPHRIES**—That is a different question, I think. I am asking about the submission to the inquiry of the expert advisory group. You say that before they had finished their hearings you had written to them. They did not reply. After they finished taking evidence you then, because you had not heard from them, wrote to Senator Patterson.

**Miss Long**—We wrote to Senator Patterson before the submission date cut-off, because we had not heard from them. This is quite normal.

**Senator HUMPHRIES**—Can you recall what the lapse of time was between writing to the expert group and writing to Senator Patterson?

**Miss Long**—Probably about a month.

**Senator HUMPHRIES**—Is it possible for you to table the correspondence that you had?

**Miss Long**—Yes, it most certainly is. We can table, also, the log of all the telephone calls and the people we spoke to in the minister's office. It is quite extensive.

**Senator HUMPHRIES**—It would be handy if you could do that. Can you help us understand why Professor Barraclough's group did not reply to you? Have you spoken to Professor Barraclough about the matter since then? It was some time ago.

**Miss Long**—No, I do not think I have. It is quite normal to be ignored. It is quite normal for action groups to be ignored by departments of the government. All you do is just keep writing.

**Senator HUMPHRIES**—You talk on page 4 of your submission about the cost blow-out in the implementation of the Progesa computerised blood management system. Of course we will speak to the Red Cross tomorrow and I will be interested in putting to them the comments and assertions that you make. Do you have any evidence that we can look at to demonstrate the things that you refer to in that paragraph?

**Miss Long**—Yes. I have got an addendum to our submission. In that I do attach documents about that. The *Australian* newspaper covered it and so did crikey.com. I have got that information for you here today.

**Senator HUMPHRIES**—Thank you very much.

**CHAIR**—You could table those documents now, Miss Long, if you are happy to do that.

**Miss Long**—Yes, and then I have got some other things to talk about.

**CHAIR**—All right. If you would like to table them and continue your contribution, that would be good.

**Miss Long**—There is another worrying aspect of the tainted blood matter. I have made some notes here, and I am going to table those as well, with supporting documentation. In 1994 law firm Slater and Gordon filed statements of claim on behalf of hundreds of victims of hepatitis C contaminated blood. Slater and Gordon came to an out of court settlement with the Australian Red Cross Blood Service in 1999-2000 over blood transfused hep C. Slater and Gordon are believed to have achieved compensation for hundreds of people. However, not all of the people they represented were successfully represented by Slater and Gordon. Oddly, in 1999 Slater and Gordon started getting rid of many of their own clients. They did not fit into their compensation scheme with the Australian Red Cross Blood Service and their insurers.

One such client who was dumped by Slater and Gordon is the plaintiff known as ZN. In 1999 ZN was left to fight for justice alone. By 2002 ZN obtained legal representation through a Sydney based law firm called Marsdens which agreed to act on his behalf in pursuit of a claim against the Australian Red Cross Blood Service. Incredibly, Slater and Gordon withheld ZN's legal file, with all of the research that was collected in order to fight his case. In the end, ZN had to take Slater and Gordon to court in 2002 in order to try and force Slater and Gordon into handing over his property. This case ran in the Supreme Court of New South Wales. The court found in ZN's favour and ordered Slater and Gordon to hand over the complete file along with any of the research relevant to a blood transfused hepatitis C matter. I have tabled that judgment from the Supreme Court. It is our understanding that nearly two years later that file has still not been handed over in its entirety to ZN by Slater and Gordon.

ZN has informed Medical Error Action Group that there is a fear that Slater and Gordon may have acted out of the best interests of their clients in order to achieve a multimillion dollar settlement with the Australian Red Cross Blood Service. ZN has said that it appears that the settlement made with the ARCBS was for anyone transfused between the years 1986 and 1990

who had been given no more than approximately 30 transfusions. ZN believes that Slater and Gordon may have offered up a method by which they could get rid of a significant number of their clients to suit the Red Cross. Principally they used an expert witness, paid for by their own clients, to devise a plan at Slater and Gordon's behest which would rule out many of their own clients, thus satisfying the Australian Red Cross.

This situation, if true, is a peculiar method by which to run a legal action on behalf of plaintiffs. Since 1999, Slater and Gordon, who once acted for plaintiffs, now seem to have an unusual relationship with the defendants—namely, the Australian Red Cross Blood Service. In fact the ARCBS currently in some cases refers certain tainted blood victims to Slater and Gordon. I have several documents to table to support that. One of the things that came to mind when I was putting this together was that Slater and Gordon's handling of tainted blood smacks of hypocrisy. In 2002, whilst representing a cancer patient in a claim against British American Tobacco, Slater and Gordon alleged that Clayton Utz, who were BAT's legal representatives, had been involved in an attempt to subvert the course of justice. Clayton Utz had their reputation tarnished, but it appears that Slater and Gordon may be the ones guilty of subverting the course of justice in the way they have treated some of their tainted blood product cases. I am attaching documents to support that.

This unusual relationship between Slater and Gordon and the Australian Red Cross Blood Service needs to be examined by this inquiry. In fact the whole tainted blood disaster warrants this kind of extensive and perhaps judicial investigation. As stated in our submission earlier, there have been many opportunities to address the full nature of the tainted blood disaster that have been either passed up or covered up—or both—by the relevant authorities. Since founding my group I have been stunned by how hard it has been for tainted blood victims to get a fair hearing into this matter. Tainted blood is not a recent issue; it has been known world wide since the 1980s.

I am concerned by some of the submissions that have been made by various organisations. One in particular, the Hepatitis C Council of New South Wales, has put forward an argument that providing financial compensation to victims of hepatitis C tainted blood would be unfair on individuals who acquired the virus from IV drug use and the sharing of needles. One really cannot compare the two. Tainted blood is a medical issue; it is to do with faulty medical products. IV drug use and its correlation with hepatitis C is a regrettable situation but it is not related to this inquiry. It should be seen as a separate matter and dealt with in a separate arena.

I have some questions here about preventing medical error. Does a blood service have a legal responsibility to warn patients should it become aware that they have been exposed to a virus? What time frames are involved with warning someone about a danger to their life? Do they have to wait to be harmed to find out that there is a potential threat to their health? Can we be sure that something as awful as the hepatitis C tragedy will not happen again when it is very likely that there are still patients out there who have not been told that they have been exposed to hepatitis C through blood? Are we going to protect the rights of hospital patients who expect to be warned about the potential dangers of tainted blood? We know that many people who received blood contaminated by hepatitis C were not warned. So are we going to discipline those responsible for not warning them when it is clear that those responsible knew the dangers? The Australian Red Cross Service has made a complete mess of the handling of the hepatitis C

tragedy. How can Australians be assured that another tainted blood disaster will not occur when the next blood borne pathogens come along?

**CHAIR**—Thank you, Miss Long.

**Miss Long**—I have documents to support that and I am tabling them.

**Senator HUTCHINS**—Miss Long, on page 3 of your submission you state that the taxpayer is paying twice for the Red Cross's public relations bill. Do you have any evidence of how the Commonwealth has funded the Red Cross's public relations efforts?

**Miss Long**—No, only by the Red Cross as a statutory authority. It is funded by the taxpayer so of course they would be funding a spin doctor.

**Senator HUTCHINS**—Why do you say twice?

**Miss Long**—The taxpayer is already supporting the organisation, and anyone that they employ—any person they get in—is being paid for as well.

**Senator HUTCHINS**—On page 4 of your submission you speak of key evidence and witnesses being excluded from the Barraclough report. Do you want to expand on the nature of that evidence? We saw a bit of an exchange about witnesses. Certainly in the Barraclough report a number of individuals and organisations were interviewed, but it does not seem to me as if any actual sufferers were amongst those individuals. They all look like professionals or groups representing people.

**Miss Long**—We are still sitting on information to give to that inquiry. We gave some of it in brief form to the federal minister for health, and that is where it ended.

**Senator HUTCHINS**—Do you want to expand on the nature of the evidence?

**Miss Long**—Pretty well what you heard here this morning—extensive. In 1999 our group had an enormous amount of contact with tainted blood victims. I do not know why particularly at that time. At that time the group had a legal referral service, and no solicitor in Sydney would touch tainted blood victims except Slater and Gordon. Most people who contacted our group have not had any compensation and have not even got a case off the ground. People come to our group because there is nowhere else to turn. No-one will listen to them. It gets down to basics: how do you go about complaining to a government department about what has happened to you? Their first priority is their health and then someone to talk to. They can get that help from our group. Taking it to the next step and complaining, it is very hard to be heard. It is hard for an action group to be heard. Most government departments do not want to be seen dealing with action groups as they have a reputation as troublemakers. We can only go on the number of families who have contacted us and the cries for help.

I will read you a couple of little snippets from a letter from someone in New Zealand. She wrote:

On 6 February 1989 I was admitted to the Royal Melbourne Hospital for a hysterectomy. I haemorrhaged and was given blood. A year later I returned to New Zealand. For the next 10 years, I was unwell. I was burnt out. I had no energy. I went and had a hep C test. It came back positive. Unbeknown to me, the blood tests had been done for hep C in 1996. They were positive then but, due to a medical slip-up, no-one told me. I had tests done again because I did not believe the doctor. Then I was told completely to make me sure that they were positive. I have my final discharge papers from the hospital, so I have the proof that I was given blood and it has cross-references to where the blood came from. My last 12 years has been absolute hell—sickness, unable to hold a job, chronic fatigue, cannot look after my children, the list goes on. I am absolutely desperate for help.

She wrote again a few weeks later:

I really need your help. I have suffered long enough. If I do not get that help, I will just end it.

That is the plight of that person. This person lives in New Zealand. She cannot get any help whatsoever because the lawyers she has been to see said: 'You'll have to get a lawyer in Australia. It's not our responsibility.' So she has had no treatment whatsoever.

**Senator HUTCHINS**—You said that Slater and Gordon had handled a number of cases in Victoria.

**Miss Long**—No, New South Wales and Victoria.

**Senator HUTCHINS**—They were cases that were settled with the Red Cross, were they?

**Miss Long**—Yes.

**Senator HUTCHINS**—You suspect how many people were involved in those settlements?

**Miss Long**—I have no idea of the number of settlements, but I was astounded by the people who came back to me and said, 'I have to sign a confidentiality clause and I am not allowed to discuss this with anyone.' I have tabled the confidentiality clause here today.

**Senator HUTCHINS**—You know a number of people who have signed confidentiality clauses. I know you cannot identify them, but when were they infected with hepatitis C?

**Miss Long**—Around the 1989 to 1990 mark. Most people who contacted me in 1999 had been infected around the period of the late eighties, early nineties.

**Senator HUTCHINS**—Is the confidentiality clause with the Red Cross?

**Miss Long**—Yes, it is. When people have contacted the Red Cross and said they have been found to be hep C positive, the Red Cross has told them to contact Slater and Gordon. I have tabled those letters today.

**Senator HUTCHINS**—Is that because Slater and Gordon is facilitating the settlement of confidential clients?

**Miss Long**—I do not know. I think this was raised this morning. I find it quite peculiar. Charles Mackenzie said that people contact his group and they are told to contact the Red Cross, which is what I do. We tell people to go back to the source. If they have a complaint about a particular hospital, we will help them write a letter of complaint. I tell them they must get back to the hospital and tell them what they have done wrong. It is through the hospital or the Red Cross receiving that information that they will know they have a problem. You would hope that they would look at it and say: 'We've got a problem here, and we had a problem in that year. Why would that be?' But when people do that, 99 times out of 100 they are ignored.

**Senator HUTCHINS**—I do not know if you were here this morning but there was significant criticism of the Red Cross's Lookback program. Is that your experience as well?

**Miss Long**—Yes, absolutely.

**Senator HUTCHINS**—Do you have any particular instances that you would like to highlight to the committee? We heard this morning about people finding out indirectly that they have hepatitis C and it has been left in their hands to try to identify when they received the infection.

**Miss Long**—There are also a couple of instances of people in our group who had the finger pointed back at them as being promiscuous. After women give birth, quite often they are given a blood product and they do not even know it is a blood product—they are never told. It is only years later, when they discover they are ill and that they have hep C that they have to try to pinpoint when and how they got it. When someone is asked whether they have had a blood transfusion, they say no; and then they are asked whether they have had a blood product, which means going back to their medical records. They can get their medical records from the hospital and find out the vital page is missing. But generally when there has been a blood transfusion there is enough data in the medical records to tell you where it has come from.

**Senator HUTCHINS**—To your knowledge, is there a period when the Lookback program say, 'We can identify that you were infected at Royal Melbourne Hospital in 1987'? And do they then say, 'You should speak to Slater and Gordon'?

**Miss Long**—No, in my experience it has been the people who have contacted the Red Cross. We have told people to do that in Perth, Brisbane—everywhere. We have said: 'You must contact the Red Cross. You must tell them this information. They must have that information on the record from you so there can be no disagreement later on.' Most of the time the Red Cross do not what to know and they will say: 'That is not possible. No-one got tainted blood in that time frame.' But then as the years have gone by all these people who have been told that they have got it from some other means have had it pinpointed back to certain dates when the blood supply was tainted. Their medical records confirm it, but it is quite interesting how many vital pages in hospital medical records disappear when the patient asks for the medical record. The first thing we tell families is that they must get hold of their medical records. Usually they have told the Red Cross that they have a problem. By the time they get the records and hand them to us, we tell them that the vital page is missing. We get on to the hospital and ask them to send the vital page to the patient, and there is no vital page.

**Senator HUTCHINS**—What I am trying to find out is this. To your knowledge—and it may be unfair to ask you this and maybe it is something for the Red Cross—when does someone in

the Red Cross advise Steve Hutchins that he should speak to Slater and Gordon if he has been infected with hepatitis C? To your knowledge, do they ask specifically whether you can demonstrate that you got the infection in January 1983 at Westmead, as opposed to January 1987 at Westmead? Do you know if anything is said like that?

**Miss Long**—Take a first phone call to the Red Cross. When the Red Cross person phoned back, they said: 'Go and see Slater and Gordon. We can sort something out.' It was said straightaway like that, and that was said only recently, before Christmas. When the people contacted me about it, I said, 'Get them to put it in writing.' They did, and I have tabled that letter here today.

**Senator HUTCHINS**—So once someone advises the Red Cross that they have been infected the Red Cross advise them to ring up Slater and Gordon.

**Miss Long**—Yes. I just find that peculiar.

**Senator HUTCHINS**—To your knowledge, do they ask for a specific date? When someone rings up, do they have something in front of them that says that such-and-such received the infection at that date. Do you know that at all?

**Miss Long**—No, I do not, only that some people have been told that they could not possibly have received tainted blood because the blood was clear during that period. But then others have called and it has been on a return phone call that they have been told, 'You had better go and contact Slater and Gordon.' So there have been vast differences yet sometimes the time frames have been the same. It depends on whether you have contacted the Victorian Red Cross or the New South Wales one.

**Senator HUTCHINS**—I was going to ask if there is a different approach.

**Miss Long**—Yes, there is completely.

**Senator HUTCHINS**—What is the difference?

**Miss Long**—The New South Wales Red Cross blood service is like a war zone. It treats groups like ours as being the absolute enemy, yet we are coming to them and telling them there is a problem. They should be welcoming our comments. They should be inviting us in and saying to us: 'Tell us what you have got. Where have we have gone wrong?' But it has been far easier to just ignore us or paint us as being radicals who do not know what they are talking about. Groups like mine can be seen as compensation seekers, but with tainted blood, which is a component of our group, the people have already been sick for 10 years. It is not as if they have had an operation and the wrong leg was chopped off so that straightaway they know they have a problem. With tainted blood the issue surfaces years later, especially with women. They are just perpetually tired. They have got young children and they think they are tired because they are looking after a family, running a home and usually working. It is 10 years later and they cannot work out why they are so tired. The key when looking at every victim of hepatitis C is that they are sick to look at; you can just tell straightaway.

**Senator HUTCHINS**—If going into the New South Wales Red Cross is like going into a war zone, I assume that going into the Victorian one—

**Miss Long**—It is worse. It is pretty bad down there.

**Senator HUTCHINS**—So you do not have a good relationship with the Red Cross anywhere in the country?

**Miss Long**—I do not know. I do not know what they think about our group; I do not particularly care. I only care about the families who contact us. But we have always said to everyone who contacts our group what I said before: you must tell the hospital; you must tell the Red Cross. We have always recommended that people make complaints to the health care complaints commission in their respective state—and that usually gets you nowhere as well. The Health Care Complaints Commission would certainly be a source that the inquiry should tap into for some information because I have certainly given it extensive information on tainted-blood victims.

**Senator HUTCHINS**—You say in your submission that victims are fearful of intimidation by the Red Cross, so for people to actually make that phone call to advise the Red Cross that they have been infected must be a fairly brave step. Would that be right?

**Miss Long**—It is very difficult. They have made those phone calls in our office. I have said, 'You make the phone call now, and we'll listen to it'—we are not listening in on the phone call, but we are listening to them.

**Senator HUTCHINS**—Can you tell us what form you believe the intimidation from the Red Cross takes?

**Miss Long**—There are a lot of anonymous phone calls. Once they lodge the information there seems to be a pattern of anonymous phone calls.

**CHAIR**—Have any of those matters been taken up with the police?

**Miss Long**—Yes, I know a couple of them have.

**CHAIR**—Has anything happened as a result of that?

**Miss Long**—Only that the police have interviewed two people who made complaints.

**CHAIR**—Were charges laid?

**Miss Long**—No. There was not enough evidence. Other intimidation was a feeling of being followed. Their mail has been opened. Their mail has been delayed. There are too many similarities among people in different states to think, 'Well, maybe that's just happened there.' There seems to be a pattern. That has been the crucial finding of the group. This is a national group. We are hearing the same thing from people all over Australia—from all parts of Australia, and from New Zealand and New Guinea. So it cannot just be something that is happening in one geographical location. It is Australia-wide.

**Senator HUTCHINS**—Have you ever had any evidence of, say, haemophiliacs feeling particularly intimidated by the Red Cross?

**Miss Long**—When the group was founded it had quite a lot of dealings with haemophiliacs. But, unfortunately, a lot of them died. I have kept in contact with a few families, but because they have died the matter died with them. I think haemophiliacs were a portion of society that was completely ostracised. It was a bit like the stigma of HIV. If anyone ended up with HIV, straightaway they were tainted with the reputation, when in fact people ended up with HIV in a number of ways. It is like a stigma. I think hep C victims are always looked at along the lines of, 'What have you been up to, to have ended up with hep C?' It is very difficult dealing with the Red Cross and trying to get them to understand.

**CHAIR**—Miss Long, you made a quite significant allegation just a moment ago about records from hospitals not being provided to patients in a complete way. That is a very significant allegation. Do you have any evidence that could support it?

**Miss Long**—I have a lot of evidence on it. I would give it to the police this afternoon, but you cannot get anyone interested in it. There are two parts to medical error—I can bring the tainted blood in there, because it is a medical error. First, the medical error happens. That, I would say, is not intentional. The next stage is where the intent sets in, because that is where a deliberate attempt is made to cover up and to destroy records. That is the criminal part of medical error and that is what needs to be investigated. All the time I hear doctors saying, 'You families, all you want to do is blame us.' If they think that, why do they go to such lengths to cover it up? If they have not done anything wrong and they do not believe they have been negligent, why do they go to such extreme lengths to cover it up? Sixty-five per cent of death certificates are false. Can you get the police to investigate that? Once a doctor signs off on a death certificate he is opening himself up to perjury. You cannot get police interested in it. I have extensive death certificates that are false. They have one recording, and then the coroner's finding is that it is something else. I have medical records with vital pages missing. This is a routine, normal procedure.

**CHAIR**—The allegation you are making is that the Red Cross is somehow—

**Miss Long**—Getting the vital page pulled.

**CHAIR**—in cahoots with a hospital so that pages are missing from documents that are someone's health record.

**Miss Long**—Yes.

**CHAIR**—That is a very significant allegation. But if you have—

**Miss Long**—The Health Care Complaints Commission, the Health Services Commissioner of Victoria and the Health Rights Commission of Queensland have all that evidence.

**CHAIR**—If those allegations have been made to those appropriate authorities and they have not been on-referred to legal authorities, directors of public prosecution or whomever, then to my mind your allegation has not been fully substantiated. If you have something else that can assist me to come to a view that this did occur then if you want to provide it to the committee I

would be pleased to receive it. If you want to provide it on a confidential basis then I am sure that the committee would receive it. I am troubled that that allegation sits there on the record without evidence.

**Miss Long**—I have a lot of evidence, so have the New South Wales police and the Victorian police. I have sent that evidence to them.

**Senator KNOWLES**—Why have the police not acted?

**Miss Long**—The excuses are that it is too old, they do not have the resources, you do not want to bring down someone who is now in the government department, you do not want to ruin a young doctor's life. I have heard all the excuses under the sun. I have written extensively about medical record tampering and false death certificates.

**Senator KNOWLES**—Why have you not taken it further? Why have you not taken it to the commissioner or the ombudsman?

**Miss Long**—I do not deal with the ombudsman's office. I find they are just a post office. I have sent stuff to the Attorney-General's Department in New South Wales. I have sent stuff to the Attorney-General in Victoria.

**Senator KNOWLES**—What is their response?

**Miss Long**—The Attorney-General in Victoria said, 'Thank you for your report but we are not looking into this subject just now.' I sent stuff to SCAGS—the Standing Committee of Attorneys-General—on false death certificates. I have supported it with documentation: here is the death certificate, here is the medical record, here is the coroner's finding—on those three entries causes of death differ. Hepatitis C is a reportable disease. It must be on the death certificate; most of the time it is not.

**Senator KNOWLES**—You are making serious allegations of criminality here. I endorse the line of the chair to seek that information for the committee's consideration.

**Miss Long**—I wrote about that in my report to the safety and quality council and I cited documentation. I quoted people who had made those points in reports. Tampering of records is well documented—apart from by groups like mine it is well documented by government departments. I think the New South Wales Attorney-General's Department has got all my stuff on false death certificates. I sent it in to them.

**CHAIR**—If there is anything that goes to the questions that this inquiry is investigating and that you think would be useful, please forward it to us.

**Senator KNOWLES**—This is very specifically hepatitis C as opposed to other actions.

**Miss Long**—Yes, that is what I am concentrating on. Medical records can be submitted on written consent of the family. I would need to seek that. When people contact our group and want us to help them they have to sign a consent form. We are very specific about the ways we

help them and what they are consenting to. I think you would find they would be quite willing to hand over their records. Nothing could be made public from them.

**CHAIR**—Certainly.

**Miss Long**—I can tie things up with certain entries and letters that our group has written to hospitals and told them, 'One page is missing from the medical records; would you please provide it to the family?' and they do not get it.

**CHAIR**—Thank you, Miss Long, for your submission and for coming to give us evidence today.

**Proceedings suspended from 4.22 p.m. to 4.39 p.m.**

**McCAUGHAN, Professor Geoffrey (Private capacity)**

**CHAIR**—Welcome. For the record, would you explain your area of profession?

**Prof. McCaughan**—I am a liver specialist. I am director of the gastroenterology and liver centre at Royal Prince Alfred Hospital. I am director of the liver transplant program there. I see a lot of patients with hepatitis C. I run a diagnostic laboratory for hepatitis C and I also run a basic research laboratory that investigates hepatitis C disease.

**CHAIR**—Thank you. 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. We have your submission, for which we thank you. I now invite you to make an opening presentation, after which the committee will ask you some questions.

**Prof. McCaughan**—I do not have in front of me the full range of terms of reference for the committee, but I remember that they were quite extensive. Although I could comment on several of the terms of reference, I decided only to comment on one. That was because I thought that most of the other terms of reference would be covered by other people. The point in the terms of reference that I was particularly interested in was the use of surrogate testing and its role in preventing post-transfusion hepatitis in the eighties. I was a bit disturbed by the Canadian finding—not that the Canadian finding was perhaps inappropriate in deciding that surrogate testing might have taken place but by the concept that blood bankers were somehow irresponsible in making that decision.

I was a young liver specialist when I first joined Prince Alfred as a full-time consultant in 1986, and I remember anecdotally that there was discussion at the time and that this was quite controversial—that there were reasons for surrogate testing but also significant arguments being put forward against surrogate testing. I remember that the New South Wales Blood Transfusion Service, as I think it was called then, was actually conducting studies to try to help understand post-transfusion hepatitis. What I decided to do when this Senate inquiry came up was to see if my biases in memory were correct and whether this was as controversial as I seemed to remember some 14 or 15 years later. So I deliberately did a PubMed search on non-A, non-B post-transfusion hepatitis from the early 1980s through to about 1989 and tried to review as many as I could of the papers that addressed this issue.

In the report I have submitted I point out—and I think my 'biases' have been reconfirmed—that in fact there were arguments for surrogate testing. There is no question about that. The first evidence came in 1981. It would seem that it took till about November 1986 for the American blood transfusion service to decide that this was now appropriate in America but that the controversy persisted outside America, particularly because of the nature of American donors and the lack of an HIV questionnaire. I knew that this had taken place in Sydney and other blood banks in Australia and that the controversy still existed. There was a study going on in New South Wales to address the issue. It was more or less overtaken by the discovery and cloning of the hepatitis C virus, which turned out to be the agent for non-A, non-B hepatitis, in 1989 and the rapid introduction of testing for anti-HCVs.

So my impression was that in Australia the controversy never quite got to a punch, because it was overtaken by hepatitis C testing. I think that is what my report says. I would like to think that it takes a balanced view of the controversy at the time. I believe—at least I have not seen evidence otherwise—that the blood bank people who were involved in this were trying to grapple with the issue; it was not as though they were ignoring the issue. In retrospect you might say that they might have got it wrong—I emphasise the word 'might'—but it was not a reckless or negligent decision as far as I know. I do not have any evidence to suggest that they ignored evidence or ignored the issue. That is what I wanted to put to the committee.

**CHAIR**—Thank you. In fact, your paper is an excellent analysis of all the literature that was around at the time. Having it on the public record invites others to make comment on it and provides a nice beginning to the history of the academic literature of the time. I think in your document you say that it may have been the wrong decision not to introduce surrogate testing, and you have just said that 'they might have got it wrong'. Today we heard about the precautionary principle and that it was early days of grappling with that notion and that the decisions were made with a balance: the continuity of the blood supply was balanced with the potential for infection. The other part of the discussion was the notion that non-A, non-B hepatitis was a fairly benign type of disease. There are a whole range of issues in there. Just going to the last one first, when do you think the medical community realised that non-A, non-B or hep C, as we know it now, was in fact a benign type of disease?

**Prof. McCaughan**—It is quite interesting. Non-A, non-B hepatitis is described as a benign disease by many people in the literature, yet people did report a 20 per cent incidence of cirrhosis over a 20-year period, which is one of the estimates we have now—although that is an upper estimate of the problem. I think non-A, non-B was also confounded by not understanding that a lot of it was a single disease. It became apparent when hepatitis C testing came along that the majority of it was a single disease caused by hepatitis C, and that focused the natural history. Up until then we had abnormal liver function tests and, at that stage, we thought obesity and other things were causing that, which mixed up the picture.

It is clearly a severe disease in a minority of patients, and we realise the severity of the disease is affected by many cofactors. They include particularly gender and alcohol consumption. There is a certain view that we think that hepatitis C might be a more benign disease—I do not mean infection—now than perhaps five years ago when studies were suggesting that 20 per cent of patients developed cirrhosis and 30 per cent developed liver cancer in 20 to 30 years. The studies in the literature now seem to show that that is in fact a biased view of hospital clinics which were referred the worst patients. The natural history of the disease is now thought to be perhaps an eight to 10 per cent cirrhosis rate at about 20 to 30 years. Clearly the Irish women have a two per cent incidence of cirrhosis after 17 to 18 years. The application of the words 'severe disease' depends on where you stand in the spectrum. I think your question was: when did we realise that hepatitis C was a severe disease? I think that realisation would have occurred in the first part of the nineties. I saw the first 50 patients referred from the New South Wales Blood Transfusion Service that were detected with chronic hepatitis C, and it was quite a benign disease in those first 50 patients.

**CHAIR**—When was that?

**Prof. McCaughan**—That was in about 1990 to 1991. It was published in 1992 in the *Medical Journal of Australia*.

**CHAIR**—The other issue that the committee is dealing with is that many of the submissions compare the Australian experience with other countries' experiences. It is evident to me that you cannot compare, for example, blood in the United States of America—because of their blood collection policies—with that in Australia. What should we be looking for when considering comparative experiences?

**Prof. McCaughan**—I think there are two big comparisons. I was just trying to remember this before I came and I could not remember. My memory of the first paper—and I will stand corrected because I have not double-checked it—is that the Americans did their studies in the two major factors that were different. They were the use of paid donors—I do not know whether they were all paid donors, but I think some of them were—and the absence of an HIV screening questionnaire. I cannot remember when Australia introduced it. They certainly did not have paid donors, and I cannot remember in what year they introduced the HIV questionnaire. I have no idea whether it was '81, '82 or '83. Those two things would change the epidemiology and the chances of getting non-A, non-B hepatitis quite significantly. So I think they are the two big differences between Australia and America, if they stand reanalysis.

**CHAIR**—Do you have any comment on the Canadian experience—the difference between Australia and Canada?

**Prof. McCaughan**—I do not know the details in Canada.

**Senator LEES**—Have you had any information on the Lookback program and how that is working—tracing the donors and donations?

**Prof. McCaughan**—I have not been involved in that.

**Senator KNOWLES**—Professor, I want to seek your professional opinion as a liver specialist on how difficult it potentially could have been for you to have a system whereby you would have had a lot of false negatives and a lot of false positives.

**Prof. McCaughan**—The literature does discuss this, and I quoted in my report that one of the downsides of screening was the detection of a lot of people with abnormal liver function tests at a stage when we did not have a test for hepatitis C. We had to advise them what this meant. Clinical practice where there are persisting elevations of ALTs and you do not know what it means is usually a liver biopsy, which is a procedure that has morbidity and mortality. The introduction of anti-HCV testing meant that we had a diagnosis, so that the issue with liver biopsy was severity of illness or assessment for treatment for hepatitis C, while in the eighties it was an issue of diagnosis. More and more people would have come forward with abnormal ALTs where we did not know what the diagnosis was. That would have increased the liver biopsy rate, and then we would have had to advise people how that affected their lives. I do not think we really understood it before anti-HCV antibody testing, which has clearly changed how we divide up the patients with abnormal ALTs. It would have been murky territory as it was.

**Senator KNOWLES**—So, in other words, it would have been very difficult to deal with a lot of patients who were unnecessarily alarmed at, say, a false positive test.

**Prof. McCaughan**—Yes. In fact, one of my quotes points that out. I cannot remember which one, off the top of my head.

**Senator KNOWLES**—It is a very good submission. If I have overlooked that particular quote, I apologise.

**Prof. McCaughan**—That is all right. I cannot find it at the moment.

**Senator KNOWLES**—If it is in there, Professor, do not worry, I will certainly find it. The point that I am concerned about is that the surrogate testing, as you pointed out, could have created quite a high false positive and false negative response and therefore—

**Prof. McCaughan**—Yes. The retrospectoscope tells us that only a third of those patients whom we would have excluded on this basis actually would have had chronic hepatitis C infection. The rest would have had fatty liver, alcoholism et cetera.

**Senator KNOWLES**—So 66 per cent of the people would have been unnecessarily alarmed.

**Prof. McCaughan**—Yes.

**Senator KNOWLES**—It might have been an opportunity for them to change their lifestyle.

**Prof. McCaughan**—That is right. You could make that argument now that, with an increasing recognition of the metabolic syndrome and obesity related liver disease, this could have been a good thing. At the time, obesity related liver disease was a bit ho-hum.

**Senator MOORE**—Yesterday we had evidence from the haemophiliac association. One of their concerns—and they said they had no particular evidence to back it up—was having access for their members to the full range of liver transplant services. In your professional role, is there any particular reason why that group would worry about their access to the liver transplant services? From your point of view, are those services available, pending on a whole lot of issues, to anyone in the community?

**Prof. McCaughan**—Yes, as far as I know. We have not transplanted anyone with chronic hepatitis C and haemophilia. I am not too sure why. It is a very appealing concept because it improves or gets rid of the haemophilia. I know that a lot of the hepatitis C infected individuals have also had HIV infection. It generally is an exclusion for liver transplantation, unless the virus is cleared or completely suppressed. We have just done our first HIV positive patient. The other thing is age. That is all I can think of. We have not been referred, as far as I know—I am thinking off the top of my head—anyone with hepatitis C cirrhosis and haemophilia for liver transplant. We have had some people die with hepatitis C cirrhosis and haemophilia, but they had other issues that prevented them having liver transplantation.

**Senator MOORE**—You might have a look at their submission at some stage. It was in their list of issues. I know you would have relationships with those groups. In your specialisation, is

there academic interest in moving into that particular field? We have talked with a lot of doctors at a number of inquiries about people choosing medical specialties. Your area is one where there is great need. I am interested in the attraction of your area to people who are studying medicine. Is it one that people rush into? Do you have a lot of people wanting to come into your field?

**Prof. McCaughan**—It is a very broad question. I have not really thought about it with regard to the inquiry. Australia has very few isolated liver specialists—isolated in terms of that is all they do. Liver disease as a specialty comes out of specialist training in gastroenterology in Australia because we would not generate enough liver specialists by themselves. Liver specialists tend not to do what are called endoscopy procedures, so we tend to earn less money than our gastroenterological colleagues. Some people have said that is an issue. There is no specialist individual training in liver disease in this country. It comes out of gastroenterology, and the specialisation usually comes beyond your specialist training. America, for example—I do not know about Britain—has specialist training in liver disease.

**Senator MOORE**—In the terms of reference, one of the issues is the services needed for people who have hepatitis C. It would be people who have severe liver disease and who might be calling upon those specialist services. I am looking at what is available in this country in terms of the long-term impact. My reading of this particular condition is that it is a long-term condition so that the longer it goes on the worse it gets.

**Prof. McCaughan**—I think the manpower to look after liver failure, liver transplants and liver cancer at that level is okay. I think the manpower to look after chronic hepatitis C that needs assessment for treatment and to manage patients on treatment is a major deficiency. 'Major' may be a bit too heavy handed. There is certainly a major deficiency in the number of qualified nurses. Many of these patients in treatment assessment and management during the treatment with interferon, which has quite a lot of side-effects, require quite intensive nursing hours, and there is certainly a limitation on the number of nurses who are experienced in that area. Many of these patients also require mental health services, drug and alcohol services and access to those services in a multidisciplinary team, which we try to run at our hospital. It certainly puts a lot of pressure on those services. I know that across Australia there are significant deficiencies in access to those areas of care.

**Senator MOORE**—Your area has a kind of one-stop shop where people can come and access those wide-ranging services?

**Prof. McCaughan**—Yes, it does, but the demand is great and puts a lot of pressure on the services.

**Senator MOORE**—How many patients go through your area?

**Prof. McCaughan**—I knew you would ask me that.

**Senator MOORE**—You can get back to us. We are interested in this particular area of expertise and the number of people who need the services.

**Prof. McCaughan**—It is well over 1,000 per year. That is not new patients; that is services to a group of patients with chronic hepatitis C. We look after lots of other liver disease as well, but that is quite significant.

**Senator MOORE**—How many centres of your kind are there across New South Wales and the country?

**Prof. McCaughan**—In the city there are four or five at various levels of activity. New South Wales has had quite a good health care plan for hepatitis C. I think it was one of the first in the world to have a strategic plan for hepatitis C; it was certainly the first in Australia. It was built on the health care areas. There was a plan to try to have a medical specialist and a nurse identified in each health care area related to hepatitis C. That has enabled programs to be spread throughout New South Wales. But they do struggle. As they build their service, the demand increases as the service becomes available. I am involved in doing that in Northern Rivers at the moment. They are going to try to build a public service clinic, and I will go up occasionally. One of the issues is what impact that will have on the health care budget in Northern Rivers. There is quite a good network, but the levels within the network sometimes need more support.

**Senator MOORE**—One of the other issues that has come out in evidence to this inquiry and also to the 'C-change' antidiscrimination inquiry in New South Wales is the concern of some people in the community about the knowledge and awareness across the board in the medical profession of issues to do with hepatitis C and identified areas of discrimination and the need to have within the health supply area at all levels awareness, training and sensitivity to hep C issues.

**Prof. McCaughan**—Yes, and indeed that is what these key people across the state have tried to do—with, I think, some success. In my own health care area, saying to people in drug and alcohol community health, youth affairs and multiethnic affairs, 'Hepatitis C is an issue for you people and you need to put this on your agenda and perhaps prioritise it over some of the other things that you're doing,' you just got horrified looks six years ago; but now I think all those groups, certainly in our health area, are addressing hepatitis C. We have people involved in education in youth affairs, multiethnic affairs and English as a second language trying to get hepatitis C awareness into those communities. Hepatitis C is on all those agendas now.

**Senator HUTCHINS**—Your chronology of the identification of the virus has been very helpful. In your chronology you mention Queensland and how a decision was made by the Queensland Blood Transfusion Service in 1987 or 1988 to introduce surrogate testing. Do you recall from your 'look back' what led the Queensland Blood Transfusion Service to make that decision?

**Prof. McCaughan**—That is a very good question; I have asked myself that question. I could not identify it from the literature apart from reading between the lines. I remember hearing that Queensland had done this at the time. I think people were surprised that Queensland had done this and I think it made us all think that maybe we should not be sitting on our hands. We were not sitting on our hands, so strike that from the record. While reading their paper, it seemed to me that they did introduce a high-throughput test for ALT which made it practically possible for them to screen for ALT in a much more rapid and much more efficient way. I got the impression that influenced what they did. I am not saying that is the only explanation. I think the other

explanation is that they assessed the literature and came to the conclusion that the American data should be transferred to Australia. In fact, I think generally that is what they felt.

**Senator HUTCHINS**—You said their testing had a higher speed. Was their testing better than what was being done in the United States, from your study of the period?

**Prof. McCaughan**—I cannot remember reading about that.

**Senator HUTCHINS**—But they did introduce it from 1987 or 1988?

**Prof. McCaughan**—They introduced surrogate testing. I think it would be very important for the Senate inquiry to ask them specifically why they did that. I think it was that they made a judgment on evidence. Senator McLucas made a comment earlier—and I forget the phrase—about a principle—

**CHAIR**—It was the precautionary principle.

**Prof. McCaughan**—Thank you, I had better write that down. One of the other principles about analysing this is in clinical study. It is the equipoise principle. If on the balance of the evidence you do not know what to do, then either choice is ethically acceptable. I would say that it is a balance between an equipoise principle and a precautionary principle. The equipoise principle in clinical medicine, for example, leads to randomised, controlled trials. That is the basis of interventional therapeutics where we do not know what to do and we feel that we can choose either measure for a patient or randomise them into a patient. Indeed, I quote from one of the reports here that actually suggests that a randomised, controlled trial should be done—I forget whether that is in the United States or somewhere else—to try to work out this issue. This was in the mid-1980s. Indeed, I know that there was at least one research grant submitted to the NHMRC—I had nothing to do with it; I heard this second hand—to do exactly that study, and it was not funded.

**Senator HUTCHINS**—To your knowledge of that sort of research done in that period—and you may not be able to answer this—did the introduction of this surrogate testing lead to a drop-off of donors in Queensland in that period?

**Prof. McCaughan**—I do not know.

**Senator HUTCHINS**—Following on from Senator Knowles's question as to where this testing identifies positives and negatives, if something like 60 per cent are identified as negative then you assume that 30-odd per cent or more are positive, which obviously may have led to that blood not being put into the system.

**Prof. McCaughan**—Yes. If surrogate testing had been introduced, the prediction from most of the papers is that it would have identified that about one-third of the people who had the abnormal markers would have in fact had hepatitis C retrospectively. But you would have excluded the whole 100 per cent.

**Senator HUTCHINS**—I think we are up to speed on it all now. In your presentation you mentioned that you were disturbed by the Canadian study's finding. What did you mean by that?

**Prof. McCaughan**—I was not disturbed by the Canadian study. I had not gone back to check the primary sources of my bias here, so my bias may be incorrect. My understanding is that there was an inquiry in Canada—I don't know at what level—and there was a compensation issue. Compensation was given for people who received blood that perhaps should have undergone surrogate testing and the members of the blood transfusion service who were held responsible for making a decision related to surrogate testing were under some form of legal assessment about whether they had acted negligently or not. I do not know the status of that court case. I believe that was the outcome of the Canadian study. I am also aware that huge amounts of resources were put into compensation. There is a feeling amongst Canadian doctors who look after hepatitis C that a significant amount of the money that was put into compensation in the Canadian system was actually taken away from the investments in resources to look after patients currently infected with hepatitis C.

**Senator HUTCHINS**—Is that what you are disturbed about?

**Prof. McCaughan**—No. I guess I was disturbed that an inquiry here may find, or be presented with opinions, that people acted negligently in this area. My experience of the people involved and of reading the literature tells me that these were balanced decisions. They were equipoise type decisions and perhaps they were wrong. You could make that argument. I am not making the argument that they were wrong, but you could certainly make the argument that they were wrong because if a precautionary principle were established over an equipoise principle then the principle should have been to protect the people getting a blood transfusion at any cost. That is a legitimate view. I would just say that an equipoise principle is also a legitimate view. I wanted to make sure that balance was put to the inquiry. If someone else has put it, that is fine.

**Senator HUTCHINS**—This morning we had evidence given to us that there was a royal commission in Canada that cost a few million dollars, headed by a Supreme Court judge, that had the advice and assistance of a number of medical and scientific experts—something that this committee does not have. We have an ex-health minister. I think that is as close as we have to anybody with any expertise in this field.

**Senator HUMPHRIES**—We plead ignorance.

**Senator HUTCHINS**—I do not have any further questions.

**Senator HUMPHRIES**—I want to clear up what you were saying about the effect of hepatitis C on people. You were not quite playing it down, but you were suggesting that the number of people who get cirrhosis is a relatively small proportion of those who contract hepatitis C. We have heard a lot today, though, about other symptoms of hepatitis C such as chronic fatigue. I assume that affects a much larger proportion of the people with hep C. Is that universal?

**Prof. McCaughan**—Yes, it is almost universal. If you probe hard enough, it is universal. It is hard sometimes to dissect out the causes of chronic fatigue, say, amongst members around the table versus someone with hepatitis C or versus a young mother or a young father of a small family who has a big, heavy workload and who is chronically fatigued. It is hard. I think it is hard for the patients at times to work out. Certainly if you take a group of patients with chronic hepatitis C and a group of patients without chronic hepatitis C who have cleared the virus, there is good evidence that people get better once they clear the virus and that chronic fatigue—at

least anecdotally from the patients that I see—is the most common symptom by far. Personally, I think it is due to the hepatitis C virus. I do not think it is due to the liver disease; it is due to the viral infection.

**Senator HUMPHRIES**—I think you have already answered this question, but I will get you to put it on the record anyway. The Tainted Blood Product Action Group submission cites comments by Dr Gordon Archer, a former Red Cross director in New South Wales. The submission states:

At the time the disease—

that is, hep C—

was agreed by everyone to be extremely mild.

The group goes on to say:

Dr Archer's assertion on the *Sunday* program does not reflect the medical opinion of the time. Hepatitis C had been considered internationally to be a chronic and deadly disease from the mid 1970s.

You would not take that view. What you have already said suggests that there was much more ambivalence about the opinion on hep C in the seventies and right up until the late eighties.

**Prof. McCaughan**—I find myself at both ends of this opinion. I saw the first 50 patients with documented hepatitis C in this city, and my conclusion was that it was a mild disease with very few symptoms. However, by early 1990 we were starting to see hepatitis C patients being referred for liver transplantation, and now hepatitis C is the most common disease in adults requiring liver transplantation in this community and throughout the world, apart from Asia. I see both aspects of this chronic infection. It can be mild in many patients, it can be almost asymptomatic in some patients, and it is commonly symptomatic for most patients. It affects their lifestyle; they have chronic fatigue, plus other symptoms. At the other end is a group of patients who have a deadly disease, which results in liver failure and their premature death somewhere between the ages of 40 and 60. So I think it is a spectrum of disease. I do not think you can say this is a mild disease overall, but I also do not think you can then say this is a deadly disease in every patient.

**Senator HUMPHRIES**—I was not so much asserting that it was or was not a chronic disease. I was talking about the state of knowledge about it. The submission asserts:

It was considered internationally to be a chronic and deadly disease from the mid 1970s.

**Prof. McCaughan**—Hepatitis C was not identified in the 1970s. It was known as non-A, non-B hepatitis. The diagnosis was based on risk factors of mainly a blood transfusion. In the seventies and early eighties, 50 per cent of people with non-A, non-B hepatitis, following a blood transfusion, were dead within three years or five years from their underlying disease. Of course they were receiving blood transfusions. My impression is that it was the same spectrum. The first long-term natural history study of post-transfusion hepatitis C showed that there was a 20 per cent incidence of cirrhosis, liver failure and death. That is high, but it is not 100 per cent.

One of the early pictures of hepatitis C, as some speakers that I remember explained it, was a bit like looking at an elephant—if you were only looking at the trunk you would have a different view of what the elephant looked like than if you were looking at the tail. So your personal concept of the outcome of this infection is very much influenced by what you are looking at. If you only work in a liver transplant unit and a liver failure unit, you would see chronic hepatitis C as the commonest cause of liver failure outside of alcohol and as the commonest cause of requiring a liver transplant. There is no doubt that you would come to the conclusion that this is a deadly disease if you did not then see patients who were referred from the community who were relatively well with some symptomatology and who have had low levels of fibrosis on liver biopsy.

Gordon Archer was a director of a blood transfusion service. The patients he was seeing with hepatitis C were what were called 'healthy blood donors'. These blood donors were healthy people, they wanted to give blood and they were altruistic et cetera. A group of them had hepatitis C. He never saw liver transplant patients or patients with liver cancer, so his view of the disease was very biased in the same way that a liver transplanter's view would be very biased.

**CHAIR**—Professor, I want to follow up on a comment you made in a previous answer about compensation. Your understanding was that in Canada compensation moneys were essentially taken from programs for hepatitis C.

**Prof. McCaughan**—That was an anecdotal comment. I do not have a primary source for that but, from talking to some liver specialists in Canada recently, there is certainly a view. I do not know whether it is a substantiated view.

**CHAIR**—Is that a concern about what could happen in Australia.

**Prof. McCaughan**—Yes, it is a concern, and that concern has already been expressed unofficially. I do not have all the evidence from people who have been affected by this illness, which could have been prevented with surrogate testing—those who received a blood transfusion or whose husband, father or mother died from hepatitis C rapidly progressive cirrhosis over a four- or five-year period following a blood transfusion in 1988 from a core antibody positive donor whose ALT was elevated. I know it has occurred—I have had patients to whom it has occurred—but I do not think I am in a position to say whether compensation should or should not be paid. However, if compensation is paid some consideration should be given to ensuring this does not affect ongoing funding for the current problem.

**CHAIR**—Do you have any view or comments that you would like to make about the National Hepatitis C Strategy, including the review process, in terms of what we should be doing not just for those who have hep C as a result of the blood service but in a broader sense?

**Prof. McCaughan**—It is good that we have a national strategy. I think we were one of the first countries, if not the first, to develop one. New South Wales was the first regional service to develop it. I have been very supportive of the development of the national strategy. I do not have the full national strategy in front of me to comment on all the aspects. My only general comment, which I put to the national strategy interviews, is that I do not think the stakeholders at the interface of looking after these patients are represented well enough.

**CHAIR**—The health sector?

**Prof. McCaughan**—Yes. I do not think that the people who deliver care to these patients on a day-to-day basis are represented well enough, and I do not think the molecular virology of this disease is represented well enough in national strategy decisions.

**CHAIR**—What does that mean, to an ordinary person like me?

**Prof. McCaughan**—That means the research scientists who can investigate the virus directly in laboratories I do not think are well enough recognised in this country. It is somewhat ironic that currently there are three major groups in Australia which have NIH funding to investigate various aspects of hepatitis C but none of those groups can get support from the NHMRC for their work.

**CHAIR**—There are three groups who can get NIH funding?

**Prof. McCaughan**—Who currently have NIH funding—two in Sydney and one in Melbourne—who have been consistently frustrated by the peer review system in the NHMRC for hepatitis C research.

**CHAIR**—Are you suggesting that hep C research should be taken out of the NHMRC model?

**Prof. McCaughan**—I am not suggesting that; I am just making a statement. It should be put in context with the stakeholders trying to investigate this disease in the laboratory, particularly at the viral level. The stakeholders who are delivering clinical care I do not think get enough input into decision making in the national strategy.

**CHAIR**—Finally, because we have only got a few minutes left, community understanding and awareness of hepatitis C, however acquired, has been raised with us on many occasions. Is that something where the National Hepatitis C Strategy could be improved? How do we as a country try and break down that misunderstanding, not only in the community but also in the medical profession, of what hep C is, so that people can get over the discrimination a lot more quickly?

**Prof. McCaughan**—It is very difficult. It was very disturbing to hear during the New South Wales inquiry on discrimination that the major discrimination of patients was in the health services. That is a major concern. Recently we had a horrendous anecdote—which I will not give to you—from within our own institution of medical discrimination by someone who should have known better. It is very difficult. It requires more exposure about the issues. One of the areas that does concern us is the non-English-speaking communities, particularly the Middle Eastern community, particularly Egypt, where we think the disease may be a significant burden. Access to education in that community, for example, is very difficult. We have no handle on disease burden in that community, really.

I will mention one of the disappointing things about the national strategy. A lot of our data comes from projections from measuring infection, which we can do very well. So our projection data comes from modelling and our infection data comes from the test. But we really do not have a structure to analyse disease burden. The only disease burden structures we have are the liver

transplant units data. There is a huge hole between measuring the infection and having a projection and then measuring what actually happens and how many people with this disease are dying of liver failure. Education is very important. The other group where education is a major issue is the Vietnamese community, where significant drug use has led to significant infection. Also there is a longstanding infection in that community from Vietnam itself.

**CHAIR**—Professor McCaughan, it has been very useful to our committee to have you come this afternoon. Your paper in particular is very useful. If you have got anything further you would like to add—

**Prof. McCaughan**—I just wish the inquiry well in trying to understand this infection, and the people that it has affected. I would encourage you to talk to as many people as you can.

**CHAIR**—We are trying to do that.

**Prof. McCaughan**—Thank you very much.

**CHAIR**—Thank you, Professor McCaughan. I thank everybody for their attendance and assistance today. I have been asked by a number of people if, on hearing other people's evidence, they can write supplementary submissions. We are very happy for that to occur. I have also been asked if people can send in submissions through the mail. Yes, we would like them, however they are received.

**Committee adjourned at 5.31 p.m.**