Witness Name: Charles MacKenzie
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INFECTED BLOOD INQUIRY

EXHIBIT WITN3939022

P561

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.

COMMUNITY AFFAIRS

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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.