



2 June, 2004

Mr Charles MacKenzie
Administrator, Tainted Blood Product Action Group

By facsimile
02 9565 0359

Dear Mr MacKenzie,

On behalf of ARCBS I would like to thank you personally for attending the meeting facilitated by Sir Laurence Street last Thursday May 27th.

Although the matters covered at the meeting included some very difficult ones and we acknowledge the very different views of participants, I believe that we made some progress in sitting down together and talking. There were a number of ideas put forward which ARCBS can consider and I undertake to get back to you about these before July 2.

One result of the meeting has been that ARCBS has made a further submission to the Senate Inquiry about the meeting and, with the permission of the Senate Committee, we attach this for your information.

We look forward to building on last Thursday's meeting in future and hope that by working together we can address what Sir Laurence described as the "breakdown in communication".

Yours sincerely

Dr Brenton Wylie
National Blood Products Manager

Cc: Sir Laurence Street
Members of the Senate Committee
Senate Committee Secretariat

The Australian Red Cross Blood Service (ARCBS) is a humanitarian organisation, committed to saving lives through sharing life's best gift.

The ARCBS has recognised that, in the past, some blood-transfusion recipients contracted the hepatitis C virus from blood transfusions. This is a terrible fact and we are sorry that this occurred.

The ARCBS is sorry that for some blood recipients, contracting hepatitis C has resulted in often debilitating physical symptoms, and in some cases, unfair discrimination. As individuals and staff of the ARCBS, we have been distressed to hear of these situations. ARCBS in its submissions to the Inquiry has argued that people with hepatitis C should have improved access to personal, medical and social support, through the existing health care system in Australia.

Having heard the concerns of the many who have acquired hepatitis C through blood transfusions, the ARCBS has been searching for a means by which it could acknowledge its sorrow to all those impacted by this tragic disease.

On 27 May 2004 at NSW Parliament House in Sydney, the ARCBS convened a meeting chaired by a highly respected Australian and experienced facilitator, Sir Laurence Street AC KCMG QC. The meeting was in part a result of the ARCBS having listened and learned from the appearances of those who spoke at the hearings of the Inquiry into hepatitis C and the Blood Supply about their own experiences of living with the consequences of blood transfused hepatitis C.

The intention of the ARCBS in convening this meeting was to assemble representatives of organisations who had appeared before the Inquiry, speaking on behalf of those with hepatitis C who have acquired the virus from transfusions. With this objective in mind, the following people were present at Parliament House:

- Rev. Bill Crews (Exodus Foundation)
- Mr Charles MacKenzie (Administrator, Tainted Blood Product Action Group)
- Mr Niel Lake (Independent)
- Mr Stuart Loveday (Executive Officer, Hepatitis C Council NSW)
- Mr Peter Matthews (Vice President, Haemophilia Foundation of Australia - HFA)
- Miss Maria Romaniw (Co-ordinator, TRAIDS)
- Ms. Miriam Reja (Representative, TRAIDS Support Group)
- Dr Tony Keller (National Donor and Product Safety Manager, ARCBS)
- Dr Brenton Wyllie (National Blood Products Manager, ARCBS)

An invitation was extended to all Inquiry Committee members to attend as observers.

Senators McLucas, Knowles and Moore, together with the Committee Secretary, Mr Elton Humphery attended in this capacity. Apologies were received from the other members of the Committee.

In gathering these individuals, the ARCBS expressed its sorrow to all who had contracted hepatitis C as a consequence of a blood transfusion.

The ARCBS stated its clear desire to establish an ongoing dialogue with those affected by hepatitis C to move forward an agenda to meet the needs of blood transfusion recipients with hepatitis C.

The ARCBS proposes to establish a steering committee to review donor- and recipient-triggered Lookback programs with a view to making improvements in communication and engagement with

blood donors and recipients. As a result of today's meeting, we will seek the participation of stakeholders representing groups such as those who appeared before the Inquiry.

The meeting recognised continuing concern about low levels of awareness of hepatitis C and in particular the likelihood that some blood recipients who received transfusions prior to the introduction of specific hepatitis C testing may still be unaware of their potential exposure to hepatitis C. The meeting supported improved education and awareness programs that were culturally appropriate for non-English speakers. The meeting also saw a need to address continuing discrimination against those with hepatitis C.

As we have stated before, we extend our sympathy to each Australian who has acquired hepatitis C, including those who have contracted it through blood transfusions. We recognise the impact that this disease can have on a person and their family.

However, as we said at the Inquiry we maintain that we have always acted in good faith, taken decisions responsibly and in accordance with the best available contemporary scientific knowledge. Accordingly, we do not accept liability at law.

However, we do acknowledge specific circumstances raised during the Inquiry hearings where it is clear the ARCBS has not always met the expectations of people with hepatitis C in terms of how the ARCBS has interacted with them. We hope that we have learned from these experiences and intend to implement improved systems wherever practicable in our day to day dealings with those affected by hepatitis C.

In making this submission, the ARCBS expresses through the Inquiry its sympathy and genuine sorrow to all who have suffered the impacts of transfusion-transmitted hepatitis C.



2 July 2004

Mr Charles MacKenzie
Independent Blood Council

By facsimile
02 9665 0359

Dear Mr MacKenzie,

As I indicated in my letter of 2 June 2004, I am writing to progress some of the issues raised in our meeting of 27 May at NSW State Parliament House.

In the interim, the Senate Committee has released its report and ARCBS has publicly stated that it welcomes its recommendations.

There are however a number of initiatives that ARCBS believes can be discussed and progressed ahead of the adoption of any recommendations by government.

As discussed at the meeting, ARCBS had decided to review the process of Lookback with a view to identifying ways to both further standardise existing processes and endeavour to improve the system in the future, including investigating ways of making the process more user-friendly. It is our intention to seek input into this process from a wide range of interested organisations groups including your group. The Committee's first two recommendations if adopted would also be of great benefit in this area.

The remaining issues discussed at our May meeting, are largely encompassed in the Senate Committee's recommendations. ARCBS will be writing to Government in the near future to state our support for a practical examination of the recommendations. ARCBS will emphasise its willingness to participate in discussions with government regarding the effective implementations of the recommendations for the benefit of people who have received hepatitis C from a blood transfusion or blood product.

Yours sincerely,

Brenton Wylie
National Blood Products Manager

Cc: Sir Laurence Street
Committee Senators
Committee Secretariat



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2 August 2004

Dr Brenton Wylie
National Blood Products Manager
Australian Red Cross Blood Service

Dear Dr Wylie,

Thank you, for your letter dated 2nd July 2004. Your offer to include the Independent Blood Council in the process of improving the 'Lookback' system is welcomed. We hope that improved communication between our organizations will be of benefit to the thousands of recipients of hepatitis C contaminated blood and to their loved ones.

As you would be aware from the public submissions made to the Senate inquiry into Hepatitis C and the Australian blood supply, improving or changing the 'Lookback' system is very much in the interests of people who have acquired hepatitis C as a result of blood transfusions.

We propose a series of monthly meetings through which we can discuss our recommendations for the future of the 'Lookback' system.

We look forward to the commencement of ongoing meetings between our organizations and trust that you will arrange them at your earliest convenience.

Yours Sincerely,

Charles MacKenzie
President
Independent Blood Council

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Australian Red Cross

BLOOD SERVICE

30th August 2004

Mr Charles MacKenzie
President
Independent Blood Council
PO Box 1595
ASHFIELD NSW 1800

Dear Mr MacKenzie

Thank you for your letter of the 2nd August 2004. ARCBS is continuing to view Lookback as an important issue to progress as quickly as possible and I again take this opportunity to stress that we view your input into the process as important to its outcome.

We are currently engaging a consultant to carry out the review and we will be in touch with you in the near future once this appointment is in place.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Brenton Wylie'.

Dr Brenton Wylie
National Blood Products Manager



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28.02.2005

Dr Brenton Wylie
National Blood Products Manager
Australian Red Cross Blood Service

Dear Dr Wylie,

Just under one year ago the Independent Blood Council received an apology from the Australian Red Cross Blood Service (ARCBS) to the thousands of Australians who received blood transfusions tainted with Hepatitis C. The ARCBS admitted to a Senate Inquiry into the Australian blood supply that there are as many as 8 764 Australians living with the potentially deadly virus, Hepatitis C, as a result of receiving contaminated blood. The ARCBS also confessed that to date you have failed to directly notify the majority of those victims who received contaminated blood.

In May of last year the former chief justice of NSW, Sir Laurence Street, facilitated a mediation meeting between our organizations. Sir Laurence Street determined that your failure to communicate more effectively with victims of the tainted blood tragedy was due to a 'break down in communication'. Your response to Sir Laurence Street's concern came in the form of written and verbal undertakings that you would engage with, and seek to work with, victims and organizations such as ours in the future.

When the ARCBS failed to initiate meetings in August of last year, the Independent Blood Council wrote to the ARCBS and proposed a series of monthly meetings. To this day, and nearly one year on from your apology to our organization for the Hepatitis C contamination of the blood supply, you have failed to meet or otherwise communicate with us.

We must now remind you of your promise to the victims of the tainted blood tragedy, and specifically to the IBC as witnessed by Sir Laurence Street. We trust that the undertakings to which the ARCBS committed itself amounted to more than just rhetoric, and would like to take this opportunity to remind you of the very real harm that your organization may cause victims and their loved ones by choosing to renege on your agreements.

With a view to enabling the fulfillment of your promises, we propose that our organizations agree to meet on a day not later than the close of June 2005, and that the facilitator for this meeting be an individual who is agreeable to both parties.

We anticipate your favourable response to our invitation, and look forward to meeting with you personally at a time of your convenience.

Yours sincerely,

Charles MacKenzie
President



Australian Red Cross

BLOOD SERVICE

26 May 2005

Australian Red Cross Blood Service

Mr Charles MacKenzie
President
Independent Blood Council
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ASHFIELD NSW 1800

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Dear Mr MacKenzie

Thank you for your letter of 1 March 2005 to Dr Brenton Wylie. As Dr Wylie is on extended leave, I am replying on behalf of the Australian Red Cross Blood Service (ARCBS). I apologise for the delay.

As discussed at our meeting last year, the ARCBS undertook to review the processes and procedures involved in donor triggered and recipient triggered lookback. I can inform you that an external consultant has now been appointed, and is undertaking a full review of internal processes and procedures and identification of external constraints, with a view to making recommendations for improvement. The consultant has been briefed and will be contacting all relevant external stakeholders, including the Independent Blood Council.

I would like to address some incorrect perceptions that may arise from interpretation of some of the contents of your letter. Firstly, the ARCBS did make estimates on the potential number of Australians who might have been infected by hepatitis C, but this should be seen as an 'estimate' and not an 'admission'. In reference to notification of potentially infected recipients, the ARCBS, in a detailed written and verbal submission to the Inquiry, indicated the reasons why such direct notification was impossible in many cases.

The ARCBS has not broken any promises to the Independent Blood Council. A number of recommendations were made in the report of the Senate Inquiry, and the ARCBS has only recently been informed of the outcome of government consideration of these recommendations. We have acted on the one recommendation which ARCBS was able to directly impact, through the establishment of the consultancy to review our lookback processes. As stated above, you will be contacted in the near future by the consultant. I trust that this is an avenue that will be beneficial in outlining the concerns of the Independent Blood Council with respect to Lookback and communication issues and in documenting any remedial action where appropriate.

Yours sincerely

Dr Anthony Keller
National Donor & Product Safety Manager



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2 August 2005

Dr Anthony Keller
National Donor & Product Safety Manager
Australian Red Cross Blood Service
97 Great Eastern Highway, Rivervale, W.A, 6103

Dear Dr Keller,

Thank you for your letter dated 26 May 2005.

In 2004, the Independent Blood Council, in the interests of communication, proposed a series of monthly meetings to be held between our organisations. Communication at this time was of paramount importance. Your organisation had advised that thousands of Australians were infected with the deadly Hepatitis C virus as a result of receiving contaminated blood transfusions. Your advice also included alarming news that the bulk of hospital patients effected have still not been traced and warned of the potential danger to their lives. In February of this year, noting that your organization had not agreed to monthly meetings, we proposed that our organizations have a single meeting to be held prior to July of this year. We have been disappointed that the Australian Red Cross Blood Service (ARCBS) to date has chosen to ignore our invitations to meet and work together for the benefit of the blood supply and victims of Australia's worst medical tragedy: Tainted blood.

We must insist that the issue of tracing infected blood donors and recipients of their blood be given more attention. If you are unwilling to meet with the Independent Blood Council and other patient advocacy groups, we urge you to at least communicate through other means. Of immediate concern for the Independent Blood Council is the continued failure of tainted blood tracing programs. Of equal concern is whether these continued failures are as a result of the ARCBS' policy of accepting blood donations from visiting US Naval personnel. Presumably US Navy Personnel are difficult to trace due to the transient nature of their work and the fact that they reside overseas.

We are alarmed that a policy to accept donations from US Naval personnel could ever have been conceived. It seems logical that donors such as this would be harder to trace and manage because they are foreign and, whilst overseas, beyond Australian law, the very mechanism that protects the safety of Australian recipients of blood donations. We are also concerned about the incidence of drug use and sexual promiscuity within the US Navy. These are major factors in the spread of the Hepatitis C virus. Could you advise us as to how many US Naval personnel have made blood donations in Australia whilst their ships are in port? Have all of their donations been traced? If not, when does the ARCBS expect that this will be completed? Will you advise the public of this problem?

We must stress that seeking blood donations from high risk sources be avoided at all costs. Thousands of Australians are now tragically infected with life threatening viruses as a result of blood transfusion. We must all work together to ensure that the safety of the blood supply be of the highest possible standard.

We hope to be provided with more information soon from the ARCBS, regarding what is being done to improve the vital process of tracing contaminated blood. We also hope that you will be able to answer some of our questions.

Yours Sincerley,

Charles MacKenzie
President