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Dear Liz

Thank you for your letter of 6th March and the enclosed letter from Graeme.

As you say, a number of issues are raised by Graeme's letter. I fully understand the concern to establish as clearly as possible the source of hepatitis C infection in patients who have hepatitis C related liver disease. I am not sure that I understand, but I would be happy to hear further reasons, why the source of the infection would necessarily influence the management of the patients once hepatitis C related liver disease was diagnosed.

We all know that a number of cases will be solved by the hepatitis C look-back programme. We have never pretended, however, that the look-back programme would identify all those individuals who were infected by blood transfusion before the start of screening in 1991. What Graeme would like to do is to turn the problem on its head and investigate every case of hepatitis C infection, in which there is a history of blood transfusion, as a formal "posttransfusion hepatitis" or "transfusion transmitted infection" investigation. A number of issues obviously arise. Firstly, none of us disputes the need to investigate donors where hepatitis C infection has been apparently transmitted since the start of routine screening of blood donations. We know that there were deficiencies in the early tests used and suspect that, although the specificity and sensitivity of the screening tests have improved immensely, they will still not be 100% correct all the time. For these cases, I do not think there is any dispute.

The problems arise in patients transfused with unscreened blood. If no possible source of infection has been revealed through the look-back, then we are into a law of diminishing returns. As we all know, a proportion of donors will have lapsed from donation and will not therefore have been tested for hepatitis C. We can, providing hospital records are available, identify the donors whose blood was transfused to any individual recipient and ascertain whether those donors have been tested. This we have done on a number of occasions. Although it may not give the complete answer, in those cases where all the donors have been tested, it can at least point to another source of hepatitis C infection.

Our difficulties lie in the area where one or more donors have lapsed and not been tested for HCV. The clinician who is caring for the patient will no doubt have explored other possible sources of hepatitis C infection and may have to reach a

view on whether the history of blood transfusion is the most significant factor. Obviously, in a multi-transfused recipient who received unscreened blood, the likelihood of infection through blood transfusion is quite high. The reverse is not always true. There are huge ethical and operational difficulties in attempting to contact donors who lapsed from donation before 1991. It might be useful to list these difficulties, in no particular order of priority.

- 1. The donor may have died.
- 2. The donor may have moved.

  This is not insurmountable, since we have become very adept at tracing donors through the FHSA and general practitioners.
- 3. The donor may have developed a serious illness and received medical treatment, including blood transfusions. We have had more than one example of donors who have received multiple transfusions for leukaemia, in whom one could question the validity of now testing for hepatitis C infection as an indication of the status before the medical treatment.
- 4. The donor may have excluded himself/herself for a valid reason and not wish to respond to our attempts at contact, for the very reason that the donor knew himself/herself to be ineligible for donation. This is particularly an issue in those donors who may have been at risk of transmitting HIV infection before 1985.
- 5. The donor may have retired from donation having reached the final retirement age.

We are always treading a delicate balance between the needs of the recipient and the caring clinician to have questions answered versus our duties to the donor. Where there is a long time interval between the donation and the attempt at tracing, the chances of any positive contact with the donor diminish dramatically. Furthermore, the damage which could be done to that donor becomes significantly greater. The counter argument is that the identification of someone who was infected with hepatitis C infection 10 years ago could be to their benefit, but this must be a secondary issue otherwise we would have large scale testing for hepatitis C in the general population.

We must be careful not to be seen to be seeking out individuals to "blame" who then have a burden of guilt for the very reason that they have been sought out as possible sources of hepatitis C infection. This is very different from identifying donors during routine screening of blood donations and notifying them of these results. These individuals are never informed that they might have transmitted infection to others. Those donors who have been recalled for posttransfusion hepatitis investigations very often are seriously concerned that their voluntary act of blood donation could have caused harm to others. This is a very heavy burden to give an individual and we must bear this in mind, without being paternalistic.

You and I share views on this subject. I am sure that Graeme would like this issue discussed more widely and I would like to take this to SACTTI, to ascertain whether our views are shared, or whether our colleagues would feel that Graeme's question should be actively pursued.

This is a very long reply, because I wanted to set out some of the many issues that concern us all. It is not an easy subject and I would welcome a wider discussion at SACTTI, for the reasons outlined.

With best wishes.

Yours sincerely

Patricia E Hewitt Consultant in Transfusion Medicine