PS/MS(PH)

From: Brian Bradley HP S&L

Date: 7 July 2006

Copies: PS/CMO
Ms L Kendall
Mr M Swindells
Dr D Harper
Mr G Hetherington
Dr A Wight
Mr W Connon
Mr J Stopes-Roe

Macfarlane and Eileen Trusts – meeting with the Chair and Trustees on 12 July.

Briefing for MS(PH)

The meeting is scheduled for 14.15, following a briefing meeting at 10.15 on 11 July/

Agenda

1. Welcome and introductions
2. Funding for the Eileen Trust
3. Funding for the Macfarlane Trust

1. Welcome and Introductions

We have been advised that the following will attend from both Trusts:

Peter Stevens (Chairman)
Martin Harvey (Chief Executive)
GRO-A (Serving Registrant Representative)
Andrew Evans (Chairman of the MacFarlane Trust Partnership Group and registrant)
GRO-A - Registrant Trustee
Sue Phipps - Trustee on the Eileen Trust

Handling note

It is unusual for registrants of such a Trust to be directly involved in meetings with Ministers of the sponsor Department. However, the Trustees feel strongly that it is appropriate for registrants to be involved in the Trust which has been set up for their benefit and they say they have always conscientiously followed a policy of registrants attending meetings with the Department. We expect the registrants will make their case for increased funding powerfully but politely. We suggest that MS(PH) listens to what they have to say and conveys any decision to the chairman and chief executive,

possibly accompanied by GRO-A (the user trustee) after the formal meeting. We understand from Mr Harvey that this approach will be acceptable.

2. Funding for the Eileen Trust

The Eileen Trust is a relatively small Trust created to provide *ex gratia* payments to non-haemophiliacs who were infected with HIV as a result of contaminated blood products provided by UK health services. It is managed by the same administrators and most of the Trustees serve on both Trusts. It does, however have slightly different issues and some of those involved feel somewhat overshadowed by the larger and more vocal pressure group of haemophiliacs. You may wish to invite Mrs Phipps to make the case for the Eileen Trust registrants.

Mrs Phipps will leave after this item as she has no interest in the Macfarlane Trust

3. Funding for the Macfarlane Trust

My submission of 14 June addresses the claim presented by the chair of the Trusts for substantially increased funding and the options recommended. A further copy of the submission is attached at Annex A for ease of reference.

Mr Stevens would like to present an overview of the case, followed by a brief contribution from Mr Harvey and a view from each of the registrants present of how their lives have been affected by this infection.

It is possible that they may raise the case of GRO-A as an example of a much more favourable settlement than is available from the Trust. This is not discussed in the submission. Details of this case are at Appendix A. In brief, the case concerns a litigant who contracted a (relatively rare) infection from a blood transfusion in 1995. There was no recourse to any other payment scheme, the (then) National Blood Authority accepted liability and a settlement was negotiated.

The line to take here is that

- We deeply regret that patients were infected with HIV/AIDS through blood and blood products.
- However, In general, compensation is only given for those who suffer negligent damage from NHS treatment.
- In this case this Government does not accept liability.

Other business

There is no other business agreed with the MFT for this meeting. Briefing is, however, appended about several issues which may still be raised by registrants. Gerard Hetherington's submissions of 26 June and 26 May cover these issues in greater detail.

Appendix A

The GRO-A case

This is a recent case in which a litigant received a settlement substantially greater than the payment made by either of the Trusts. It may be cited as a precedent by advocates for the Macfarlane Trust. In summary, the case involved an award of £750,000 compensation to GRO-A after he developed HTLV-1 from a transfusion during surgery for pancreatitis in February 1995. It could be claimed that a similar payment should be made to those infected with HIV.

Since the judgement in the HCV litigation, there have been a small number of "defective product" claims brought under the Consumer Protection Act (CPA) against the NBA (now the NHSBT). These have included cases of transmission of infection, including one of bacterial contamination which was settled for a modest amount. There are currently claims proceeding against NHSBT for hepatitis B transmission (2001) and HIV transmission (2002). Both cases have been brought under CPA and are being managed by NHSLA as they are covered under the NHSBT membership of the Liability to Third Parties Scheme (LTPS). Mr GRO-A's blood transfusion predated the NHSBT membership of LTPS and was therefore dealt with by the NHSBT and its legal advisors.

Line to take

- We deeply regret that patients were infected with HIV/AIDS through blood and blood products.
- However, In general, compensation is only given for those who suffer negligent damage from NHS treatment.
- In this case this Government does not accept liability.

Background

This case relates to HTLV (human T cell lymphotropic virus) infection, which was shown on investigation to have been transmitted to Mr GRO-A by blood transfusion.

GRO-A was transfused during major surgery in 1995. He subsequently developed a neurological condition which was eventually diagnosed as a condition called HAM (HTLV-associated myelopathy). He was confirmed to be HTLV positive. He had no other risk for HTLV infection apart from the blood transfusion, and the case was reported to the NBS for investigation. Meanwhile, the recipient consulted solicitors and commenced litigation under the CPA. The NBS were able (after some delay, due to difficulties in locating one of the donors) to establish that the source of the infection was one of the blood donors. As soon as this was established, liability was admitted under the CPA and the NBA proceeded to negotiate a settlement. Part of the difficulty in this case is the rareness of the condition and therefore of medical experts in the UK who were able to give expert advice. Settlement was reached at a meeting between all parties on 7 July 2005.

Appendix B

Documents

There has been some recent correspondence with the Trust about a number of relatively early documents which are either missing from DH archives or are known to have been destroyed. Registrants may raise any of these issues as examples of poor management of their cases by the Department.

Handling of documents returned by solicitors

At the request of both MS(PH) and MS(R) officials are giving high priority to examining the files which have been returned to the Department by Blackett, Hart and Pratt (Solicitors). The work of existing staff in the Division has been reprioritised to accommodate this but the work required to examine the returned documents, together with several other related tasks, represents a major undertaking. This will require extra staff from elsewhere in the department, which are currently being recruited. We have also arranged with SOL to commission an initial analysis of what the returned papers contain, to be carried out by an independent legal expert (panel counsel). We will also pursue MS(PH)'s suggestion of seeking assistance from the Information Commission.

We have raised with SOL the question from Baroness Barker about what steps the Department would be taking to ensure that the returned documents would be adequately protected. They have given assurances that the returned documents are being held securely. SOL have arranged for independent Counsel to list the recently returned documents and undertake an initial evaluation of their contents as set out in the letter of 8 June 06 from Ministers to Lord Jenkins. A report from Counsel is expected imminently

Documents which have been destroyed

We know that there were two instances in the 1990's where papers were destroyed in error. The first instance was following the HIV litigation. Currently we do not know the full extent of what was destroyed. We propose to establish more information about these papers, and the circumstances of the destruction. In the second instance, we know that 14 volumes of papers relating to the Advisory Committee on the Virological Safety of Blood (ACVSB) were destroyed. An internal investigation was undertaken in April 2000 by colleagues in Internal Audit to establish why these files were destroyed. We have a copy of the report by Internal Audit, therefore in relation to these files we may be able to establish whether some of the papers recently returned include papers from the ACVSB. We will also list the documents (of which there are thousands) recently released in Scotland.

We have identified an additional member of staff who is expected to start work next week, to identify and analyse all the papers currently available, including the very large number recently released in Scotland. We anticipate that preparing a comprehensive inventory and report of all the papers may take up to six months (a recent similar, incomplete, exercise in Scotland took nine months).

Waivers of litigation rights

We have had several letters recently (one of them from Mr GRO-A asking for a copy of any waiver of their right to pursue litigation which they may have signed when they registered their claim with the Trust. We have been unable to locate the Department's copies of these waivers on our files – which is unfortunate, but not entirely surprising, given that the files in question are over 20 years old. We are confident, however, that all registrants were required to sign such waivers before their claims were processed and we have provided copies of the form of words used for some of the waivers at the time.

Lines to take

The purpose of this meeting is to discuss the funding of the Macfarlane and Eileen Trusts. However, we regret that any papers relevant to the Trust's work have been destroyed in error. I have explained on a number of occasions that there has been no deliberate attempt to destroy past papers.

During the HIV litigation in the early 1990's many papers from that period were recalled. We understand that papers were not adequately archived and were unfortunately destroyed following the litigation. Officials have also established that a number of files on the Advisory Committee on the Virological Safety of Blood (ACVSB) between May 1989 – February 1992 were unfortunately destroyed in error. These papers were destroyed between July 1994 and March 1998.

An internal investigation was subsequently conducted by the Department's internal audit team.

Appendix C

Demands for a Public Inquiry

It is possible that the Trustees may raise this, especially if they anticipate a negative response to the claim for increased funding. Gerard Hetherington's submission of 26 June considered the pros and cons of a public inquiry into contaminated blood products.

Lines to take

- We have considered the call for a public inquiry very carefully. However, as previously stated, the Government does not accept that any wrongful practices were employed and does not consider that a public inquiry is justified.
- Donor screening for hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time.

Appendix D

Long term funding for recombinant treatment

MS(PH) announced on 19 April that further funding for recombinant treatment will continue. For 2006/07 the monies previously included within central budgets for allocation to the NHS have now been included as a block sum for Strategic Health Authorities to manage. To ensure that the desired outcomes are achieved this is accompanied by a service level agreement.

We understand that there will not be a specific reference to levels of funding included in the bundle to the NHS. The SLA has been drafted dealing with outputs, this will include a statement "Provision of recombinant clotting factors to all haemophilia patients" .

We have not had confirmation of funding for future years.

The lines to take are

- the Government has already committed £88m over the past three years.
- Ministers have confirmed funding for recombinant treatment in this financial year.
- As a result, we will have made available significant funding for the provision of recombinant treatment.
- We are committed to this area of patient treatment and continue to consider the long-term funding implications

Officials will continue to monitor this programme, and assess the financial impact on PCTs over the coming year, through the Recombinant Roll-out: Forward Planning and Monitoring Group.