

Mr A. Hollebon PS/PS(H)

From : Paul Pudlo CA-OPU2

Date : 16 June 1995

Copy : Mr Holden PS/SofS

REPORT OF MEETING WITH HAEMOPHILIA SOCIETY - 16 JUNE

HEPATITIS C CAMPAIGN

1. PS(H) asked for a note on above.

2. I met today with Graham Barker the Director of Development and Services for an off the record discussion of the Society's position. The Society are only concerned with haemophiliacs and have no official view on those infected through transfusion.

WHAT ARE THEY SEEKING?

3. It was evident that the Society had not thought through clearly details of what they want to achieve in the current campaign. In general terms they are being pressurised by members to obtain a settlement on par with the payments for HIV. The campaign is being fought on the grounds that there is no moral distinction between what happened to the two groups (HIV and HCV). HIV infected patients who signed away their legal rights to future compensation for HCV feel that they are equally entitled to any payments that may become available - save in terms of compensation already being paid for hardship. Thus the numbers involved could be 4,000 rather than 3,000. In broad terms they would like a standard lump sum recognition of the harm suffered and some sort of hardship fund. On the whole the impression was that the McFarlane scheme had worked well.

4. The Society do not accept the argument that settlement would open the flood gates. As they see it the HIV settlement was successfully contained. But they do recognise that the financial consequences in this case would be very much greater and over a longer period of time. They also recognised that trigger points for payment would be difficult to identify.

5. They will continue with the "moral" campaign until it is seen to fail. What the signal for this might be was not known but it would not be in the short term. The campaign would then shift to legal territory although the Society recognise that, on the basis of their current legal advice, they have little chance of success on grounds of negligence. A few cases have been settled out of court on the basis of "inappropriate treatment" - one for £145,000. These are likely to be very rare. One legal argument that is currently being explored is "the risk of hepatitis infection was known in the late 70s; why wasn't something done earlier?". This raises the question of what is a reasonable risk and could relate to current viruses that are not tested for such as Parvovirus.

6. The Society are also seeking :-

- DH endorsement of Haemophilia Director's Guidance on hepatitis.
- The development of central guidance on all aspects of the disease.
- More research into causation and potential treatments.
- Support for counselling of patients at haemophilia centres.
- Uniform access to PCR testing.
- Some sort of guarantee that Interferon will be available to those who need it.

This list does provide some scope for seen to be doing something for HCV infected haemophiliacs generally without acceding to payments but it would be very unlikely to stem the campaign for parity with HIV. The Department is already providing a S64 project grant of £91,937 (95/96) for the Society's Hepatitis Support project.

Paul Pudlo
Room 315, EH
Ext GRO-C