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Professor Frank Hill,  
Chairman UKHCDO

By email (hard copy to follow)

15 October 2003

Dear Frank,

Proposed ex gratia scheme for hepatitis

I am writing to follow up our earlier discussions about the government's proposed scheme and to ask for UKHCDO's support in seeking to achieve the best possible settlement for the affected patient group.

Although no details have yet been officially released, from meetings that have taken place so far with officials and with the Scottish health minister Malcolm Chisholm, the Society has a number of concerns about the level of payments and the eligibility criteria that are likely to be introduced. We want to work with UKHCDO – several of whose members have individually been involved already – to secure the most favourable outcome for your patients and our members.

As you know, the Society has campaigned for very many years for a financial assistance scheme for those infected with hepatitis through contaminated blood products similar to that available for HIV. Last year, doctors Makris and Giangrande took part in the Society's expert working group which developed costed proposals for a scheme modelled on that operating in Canada with levels of awards based on five stages of medical need. Their report was presented to government in July 2002, and we had hoped that it would form the basis of any future scheme.

This is currently looking most unlikely, as it appears government proposals will follow those announced by Malcolm Chisholm this year. That would mean two levels of payment: £20,000 for those living with the virus now; plus £25,000 for those who develop cirrhosis.

For your background information, our trustees recently agreed a set of key principles that should underpin any scheme and which we hope UKHCDO could support wholly or in part:

- a) The scheme cannot exclude HIV/HCV co-infected.
- b) It must include provision for those who have died.
- c) There must be no exclusions from future action (i.e. no waivers).
- d) We are aiming for implementation of Lord Ross's expert Scottish committee's recommendations as a minimum and ideally our own think tank's proposals - and reject Malcolm Chisholm's reduced level proposals as unacceptable.
- e) We want one scheme for the whole UK rather than different ones for each 'jurisdiction'.
- f) We want meaningful consultation with the Society on the basis for the scheme.
- g) We want a scheme that allows for future need as proposed by our expert group and Lord Ross in Scotland i.e. not just a one shot payment. If a one-shot payment is the only way forward it must be sufficiently generous to take account of future declines in health etc as shown in the Society's future projections of the health of the affected group.
- h) We want a benefits/tax disregard as applies with the MFT payments (and extending to income from investments).
- i) We expect the scheme to include some provision for those who cleared the virus as proposed by our expert group.
- j) We will not accept a scheme based on means testing.

On the positive side, it appears likely that several of these points may be met by the final scheme, and this is very welcome.

*However, we are very concerned that as formulated by Malcolm Chisholm, the scheme would provide nothing for some of those most in need who have suffered particularly as a result of hepatitis specifically*

- a) it would include no provision for those who have died of hepatitis

- b) it would provide nothing for those who have cleared the virus through treatment, ignoring the distress and suffering they have undergone
- c) by opting for cirrhosis as the trigger for the higher payment, the scheme excludes many who may be suffering advanced liver disease and liver damage
- d) it is unclear whether the scheme would properly include the HIV/HCV co infected group - despite the evidence that co infection presents a greater risk to health and liver disease has become the leading cause of death within this group.

I hope you share our concern that these are significant weaknesses in the proposals, and that you can support us in seeking to influence ministers to make improvements in recognition of these points. Much of the discussion, we are aware, centres on medical assessments of the affected population, and we were pleased that Professor John Pasi was able to attend the medical experts meeting on 14 October at the Department of Health as our nominee at such short notice.

However, we will be writing to the Department to express our concern that he was the only haematologist at the meeting, alongside five hepatology specialists. For any future meeting we hope that there would be at least three haemophilia experts, including yourself and others such as Jonathan Wilde, Mike Makris, Paul Giangrande with an interest in this area. I am sure John Pasi will support this when he gives you his own feedback about the meeting.

I am aware that the next UKHCDO executive meeting is not scheduled until late November, which could be some time after the government intends to publicly announce the details of their scheme. It is therefore very urgent to involve you and other UKHCDO members in these discussions before final decisions are made, and the opportunity lost to achieve any changes.

I look forward to hearing from you,

Best wishes,

Yours sincerely,

Karin Pappenheim  
Chief executive

Cc John Pasi