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Dear Colleague

Ex Gratia Payments for People with Haemophilia and HCV

I am aware that there was a meeting on October 14th to discuss the way forward with regard to the ex gratia payments which will be made to people with haemophilia who have been exposed to hepatitis C. I had hoped to attend the meeting to represent the Haemophilia Society, but was unable to do so because of the short notice and a prior commitment abroad. I am very pleased that Professor John Pasi was able to represent the Society, and he has kindly briefed us on the discussions.

I was surprised to learn that no apparent consideration has been given to a document submitted by the Haemophilia Society, which had been drawn up by a panel of experts, including three physicians, an experienced barrister and an actuary. I was one of these three physicians, and was joined by Professor Eric Preston and Dr Mike Makris from Sheffield. All three of us have a particular interest in hepatitis C infection in haemophilia, and have published important work in this area.

I would hope to attend future discussions myself to represent the Society, but in the meantime I am sending you a copy of our report which I would be grateful if you could distribute to members of the panel for their consideration. In advocating some form of financial assistance scheme, we took into account various models that have been adopted around the world and we were particularly impressed with the Canadian model which is relatively simple and straightforward to implement.

From briefing received from Professor Pasi, it would appear that there are some clear differences of opinion between our own group and that which met on October 14th.

1. Our group strongly felt that some form of payment should be made to patients who have simply tested positive for the HCV antibody, even if they subsequently cleared this and did not have abnormal liver function tests. It may be difficult for you to appreciate the tremendous anxiety that was generated in the early 1990s when patients were tested and informed of their results for hepatitis C. People with haemophilia were among the first cohorts to be investigated and tested systematically, and this group of patients was particularly mindful of problems related to AIDS only a few years beforehand.

2. We think it grossly unfair that patients co-infected with HCV and HIV should not receive additional compensation. It is certainly true that ex gratia compensation was offered to people with haemophilia in 1991, and that the agreement included a commitment not to seek compensation for any further infections that might be acquired through blood products. In fact, it is quite clear that many patients had already been tested for hepatitis C but not informed of their results when they signed away these rights.
3. Equally, we feel it grossly unfair that compensation should not be offered to the relatives of those who died from hepatitis.

Please do not hesitate to contact me personally by telephone if you would like to discuss the points raised in this letter and the accompanying report.

Yours sincerely

GRO-C

Dr. Paul Giangrande
Consultant Haematologist

cc Richard Gutowski, Head of Blood Policy division
Dr. Victoria King