

Tuesday, 18 January 2011

Rowena Jecock,  
Department of Health  
Wellington House  
135-155 Waterloo Road  
London  
SE1 8UG

Dear Rowena,

**RE: Review of support available to individuals infected with Hepatitis C and/or HIV by NHS supplied Blood or blood products and their dependants.**

This document was discussed at some length in the UKHCDO Advisory Committee. The committee have asked me to approach DH with some urgency to seek clarification on some issues and to make a plea for an extension of the deadline for registration of dependants of patients who died before the inception of the Skipton Fund.

The deadline set for registration of dependants of deceased patients appears arbitrary and does not give adequate time to trace these individuals, most of whom will have been out of touch with their Haemophilia Centre for years. That the date chosen is the last day of the financial year strikes a sour note in a report that was otherwise generally very much welcomed.

The National Haemophilia Database can help to facilitate this process by providing centres with a list of names, first of those who have died from liver disease (whose dependants should be eligible for a stage 2 payment). We hold death certification data and treatment data on such patients. Would I be right in saying that this NHD data should satisfy the Skipton fund should that patient's notes have been destroyed?

**UKHCDO Executive Committee**

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Many notes will have been destroyed, since there is only a legal obligation to retain notes for 6 years. We can also share this data with the Skipton fund, if they would consider this a valid form of preliminary registration

Tracing deceased patients who have died from other causes but who may, nevertheless be eligible for a stage 1 payment is even more challenging, since there are far more of them. I am not sure that this category of patient was fully considered in your estimates or our discussions. NHD can draw up a list of patients, now dead, who are known to have been exposed to blood components of blood products during the year of risk. Up to 30% of these patients will have cleared the virus spontaneously and a further proportion will have no documented abnormal liver function tests or destroyed notes. It would take centres a long time to review the notes (if they still exist). The HCV look-back exercise would provide all of this data, but not by the end of March! I am concerned that there may be many "speculative" registrations by dependants who do not know if they have a valid claim but who are anxious to beat the deadline.

I assume the Skipton Fund will contact patients already registered and/or their centres directly. Let me know what is envisaged.

I note no change in the criteria of eligibility for stage 2 payments other than B-cell lymphoma. Fibroscan was excluded?

I was interested to note that co-infected patients get two payments.

When will prescriptions become free?

Please provide me with contact details for the devolved administrations so that I can contact them. They are telling their clinicians that this announcement caught them by surprise, so a decision may not emerge before the end of the month. One wonders what deadline they will give for dependants of patients who died before the inception of the Skipton Fund? It would be unfortunate if a difference in conditions arose.

It may be useful to have a meeting to thrash out the finer details but in the meantime I would beg that the deadline be reconsidered.

Yours Sincerely,

**GRO-C**

**Dr Charles R. M. Hay**  
Chairman, UKHCDO