DRAFT

(1)

RESTRICTED – Need to know basis only

Mettings of Skipton Fund Teleconference – 29 September 2004

Date: Wednesday 21st September 2004
Attendees: Christine Lee (Royal Free Hospital), Bob Stock, Aileen Keel (Scottish Executive), Caroline Lewis, Mike Simmons, Caroline Lewis (Welsh Assembly), Richard Gutowski, Hugh Nicholas, Mike Brannan (Department of Health, England)
Apologies: Gerry Dorrian (Department of Health & Social Service, Northern Ireland)

1 INTRODUCTION

1.1 Although Gerry Dorrian was unable to attend, Northern Ireland will agree to abide by the points agreed during the teleconference.

2. 'NATURAL CLEARERS'

2.1 Prof Lee was invited to speak to the group regarding her concerns about inconsistency in the reviewing of natural clearers (NCs)by clinicians. Clear instructions are required for clinicians in order to eliminate this disparity.

2.2 The Fund was set up by Ministers for those who have endured physiological suffering / damage by contracting Hepatitis C and not for the 'worried well' or asymptomatic. Most NCs clear very soon after infection patients (i.e. during acute phase) and never become symptomatic, hence, according to the terms of the Fund, they should NOT receive payment.

2.3 The only accurate methodology to determine at which stage (i.e. acute or chronic) that patients cleared is to backtrack to the time of infection by PCR testing samples. However most hospitals do not hold samples for patients back to 1977 (i.e. average time patients contracted Hepatitis C) and so this will not be possible.

2.4 Prof Lee recalled an unusual case in which one of her patients took 25 years to clear. PCR tests of samples from during this period fluctuated between positive and negative, and the patient remained asymptomatic and gave normal transaminases throughout. The group disagreed with Prof Lee's analysis that the patient was ineligible, as the individual must have cleared in the chronic phase and so is eligible.

2.5 It is unlikely that the doctors completing patients' forms were treating them at the time and so will be unlikely to be capable of accurately reporting whether they were asymptomatic during the relevant period (and asking the patient is not viable given the £20,000 at stake). A

number of cases supported by clinicians may therefore be based on sympathy rather than medical evidence.

2.5 Blood transfusion patients are unable to be traced, but it is probablye that a number may come forward in the future. Testing is likely to show patients to be PCR negative (even if antibody positive) and probability suggests that they will have cleared during acute phase while asymptomatic; in such a case, patients would not be eligible.

2.6 Although Part 2(a) is not entirely robust, the criteria cannot be changed at this stage.

2.7 Setting up a medical (appeals) panel to help adjudicate on cases is of paramount importance, as the current system of ad hoc teleconferences is not a viable solution.

2.8 Conclusions:

- Original criteria defined by Ministers must be adhered to (i.e. physiological damage).
- Acute stage clearers are **not** eligible.
- Chronic stage clearers **are** eligible.
- PCR positive samples required for eligibility.
- Skipton Fund to be advised accordingly.

TO DO:	**Who**	**By**
Inform Skipton Fund Directors of conclusions.	*RG / HN*	*1/10*
Reiterate to Prof Lee that patients who clear in the chronic phase are eligible for payment.	*HN*	*?*

3. APPEALS PANEL

3.1 The panel should be relatively small, consisting of relevant experts preferably with representatives from each territory with a balance of Haemophilia Society members and non-members. Ensuring that the Panel includes the correct people overrides issues of affiliations however. Membership should reflect the requirements of the panel (e.g. include two haematologists and two hepatologists) and a further meeting would be required to determined the exact.

3.2 Prof Lee would be an ideal member due to her background and strong views on adherence to the criteria. Individuals that provided valuable contributions to the previous Expert Panel would also be potentially beneficial panellists, e.g. Prof Thorn, Prof Deshaker and Prof Bascahli [DN: spelling?]. Representation from a professional capable of elucidating on risk issues would be valuable, e.g. a haematologist from the transfusion services such as Ian Franklin.

3.3 Legal advice has recommended that an appeals panel should be appointed via a public process, which would aid transparency and independence from government. New directors and executive officers could be appointed simultaneously.

3.4 The NHS Appointments Commission (England) could perform the appointments process. The Welsh Assembly found this approach acceptable when selecting candidates for the HPA.

3.5 There are 50 cases currently on hold, hence the Appeals Panel should be instituted as soon as possible. In the interim period, an expert medical panel should be set up to provide adjudication.

TO DO:	**Who**	**By**
Investigate the viability of Panel appointments through the NHS Appointments Commission for the Scottish Executive.	*BS*	*1/10*
Inform Frank Hill of suitability of Prof Lee for Panel.	*RG*	*1/10*
Consider potential panellists in the context of wider participation (i.e. beyond haematologist and hepatologists).	*RG / HN*	***?***
Investigate instituting a provisional medical board.	*RG / HN*	***?***
Liaise with NHS Appointments Committee regarding the selection process.	*MB*	*1/10*

4. SKIPTON FUND QUERIES

4.1 Enquiries from Skipton Fund regarding specific cases were reviewed. Responses were decided for a number of these cases [see below], while a holding response that the Appeals Panel will consider cases was recommended for the remainder.

TO DO:	**Who**	**By**
Draft reply to Prof Foster at Barts to explain that doctors should be considering time spent living in an area with a high prevalence of Hepatitis C (e.g. Egypt) under "other possible sources of infection".	*RG*	*?*
Advise Fund that: ➢ *Patient C - Naval hospitals abroad receive same blood stocks as the NHS, therefore patient is*	*RG*	*1/10*

eligible for consideration.

- *Patient B – 35 day rule should be applied and so patient is eligible for consideration.*
- *Patient F – Alternative arrangements should be sought to enable Patient to see a health professional and give sample.*
- *Evidence of cirrhosis is required for second payment, hence should be requested (e.g. Colvin case).*
- *Remaining Patients on hold should be advised that their cases will be considered by the Appeals Panel.*

5 October 2004