

**Minutes of the Meeting of the Board of Directors of The  
Skipton Fund Limited held at 10:30 on 14 February 2014 at  
Alliance House, 12 Caxton Street, London, SW1H 0QS**

Present:	Mr P Stevens Mrs E Boyd Professor H Thomas Mr P Spellman	Chairman Director Director Director
In attendance:	Mr N Fish	Scheme Administrator

**160. Apologies for absence**

There were no apologies for absence; Professor Thomas was involved via telephone link.

**161. Minutes of the previous meeting**

The minutes of the meeting held on 11 March 2013 were signed as a correct record.

**162. Matters arising**

155 - The Scheme Administrator reported that a total of 42 rejected stage 2 applications from the estates of co-infected haemophiliacs had been reviewed using the predictive formula for progression to cirrhosis amongst this cohort where records had been destroyed. As a result of the review, 25 applications had been approved and 17 had remained rejected. Further information had been sought in respect of 5 of these cases with 4 of them subsequently being approved and 1 remaining rejected.

156 – The Scheme Administrator reported that another attempt to find those people due a ‘top-up’ payment using telephone numbers and email addresses had been carried out in April/May 2013. As a result of this exercise a further 43 payments had been made to living applicants and a further 55 payments had been made to the estates of people who had died. Full backdating of the regular payments had been made to the 43 living applicants that had been found.

**163. Unclaimed Stage 2 ‘top-up’ payments, writing to doctors**

The Scheme Administrator reported that the exercise of writing to doctors had been a success with 28 ‘top-up’ payments and backdated regular payments being made to living applicants and 21 ‘top-up’ payments being made to the estates of people who had died. The exercise also highlighted that, as expected, a large number of applicants due a ‘top-up’ payment had sadly died, often

with no up-to-date contact details for a next of kin being held by the hospital. The Scheme Administrator informed the Board that there were now only 32 applicants who were potentially alive and due a 'top-up' payment and regular payments, with the remaining 70 or so being due to the estates of people who had died. Unfortunately, without the assistance of the Department of Health (DH), there now seemed little hope of finding these people.

164.

#### **Payment statistics to 31 December 2013**

The statistics to 31 December 2013 were noted. The Board noted that there were a large number of rejected stage 1 applications. The Scheme Administrator reported that around 200 of these 673 were with respect to 'natural clearers' and a further 168 had also been declined at appeal. Of the remaining circa 300, the majority would be made up of applications where there had been a lack of evidence of treatment with NHS blood or blood products, the rest being made up of applications with greater risk factors or the application fell outside the scheme's remit. It was felt that in future the Fund might consider a review of rejected applications to see if any might be cases that would stand a good chance of being overturned at appeal. Due to the potential costs involved, the DH would need to be consulted prior to any work being done on this.

The Board noted the steep rise in applications moving from stage 1 to stage 2 and that this would have been heavily influenced by the addition of applications from the estates of people who died prior to 29 August 2003, particularly in the case of deceased haemophiliacs and deceased co-infected haemophiliacs. The Scheme Administrator agreed to produce and circulate an alternative set of statistics which excluded 'pre-2003' applications.

Mr P Spellman asked if the DH had indicated what would happen regarding Skipton Fund applications if Scotland were to achieve independence in September's referendum. The Scheme Administrator had not been informed of the DH's intentions and would seek clarification and report back to the Board

Mrs E Boyd informed the Board that two widows of co-infected haemophiliacs who died before 29 August 2003 had recently qualified for Skipton Fund payments after the Macfarlane Trust had suggested that they apply; she felt that there would undoubtedly be others who would benefit if they knew about the scheme. The Scheme Administrator explained that the Fund's database would hold no information about these potential beneficiaries and it would be down to the Macfarlane Trust to attempt to contact them. It was agreed that the Scheme Administrator would liaise with the Chief Executive of the Macfarlane Trust regarding the possibility of contacting such people. The Scheme Administrator reminded the Board that the amendment to include the estates of people who died

before 29 August 2003 had been publicised in a past Macfarlane Trust bereavement newsletter but it was accepted that many people probably hadn't read this.

165. **Appeal Panel**

The Appeal Panel's statistics were noted. The Board felt the fact that over 50% of appeals were successful suggested that the Board would benefit from greater medical experience to be able to consider applications where some records existed but with no mention of whether blood or blood products were necessary as part of the treatment. This would ideally be a medical professional with knowledge of haematology and blood transfusions and the Scheme Administrator would approach Dr Patricia Hewitt of the National Blood Service to see if she could suggest anybody; if she could not then he would see if she had any ideas about how to find a suitable candidate.

166. **New Director**

The Board agreed in principal that Professor Dusheiko would be a very useful addition to the Board of Directors and would alleviate some of the pressure on Professor Thomas when it came to assessing borderline stage 2 applications. The Chairman reported that he had already contacted the DH regarding this matter but had yet to receive a response giving the go ahead to make the approach; it was resolved that he would telephone the DH to chase this up.

167. **Health Questionnaire**

The Scheme Administrator apprised the Board of the reason why the health questionnaire was being created. At a hepatitis C workshop with the DH in December 2013, Professor Dusheiko had given a presentation on the various new treatment regimens that were expected to be licensed in 2014, many of which avoided the use of interferon and had had promising trial results. He felt that those people who already suffered from decompensated liver disease would potentially benefit greatly from these new treatments and felt that the Skipton Fund would be best placed to find them; the DH agreed that this would be a good idea. The Directors reviewed the latest draft, which already incorporated changes suggested by Professors Thomas and Dusheiko, as well as the DH, and made further suggestions of how the wording could be improved. The Board also felt that it would be prudent to share the questionnaire with an interested party prior to distribution, such as GRO-A from the Hepatitis C Trust, or a patient representative, to ensure that the content and tone had been judged correctly. It was resolved that the Scheme Administrator would chase the DH for their latest version, would incorporate the Board's suggestions into the questionnaire and pitch the idea of involving GRO-A or a

patient representative, to the DH. The Board were in agreement that the questionnaire should be sent sooner rather than later once all interested parties had agreed to its content.

168. **Exclusion of applicants who have already been compensated for their HCV infection through the NHS**

The Scheme Administrator reported that the DH had indicated in a recent telephone call that it was their intention to exclude people from the scheme who had already received compensation for their hepatitis C infection through litigation. At this moment it was unclear if this would be limited to future applicants being asked to confirm that they had not already been compensated, or include existing applicants who were receiving regular payments. The Scheme Administrator had submitted draft wording for the application form and guidance notes to the DH and it was now with their lawyer for consideration.

169. **Draft Directors' Report**

The draft Director's Report was noted. The Scheme Administrator would fill in the missing data as soon after the conclusion of the financial year as possible. The Board accepted the draft Report.

170. **Article in the Times newspaper**

The Board agreed that the news article in isolation did not warrant a response and that the mention of Skipton Fund making insufficient payments to alleviate need was an issue for the DH to respond to since they determined the levels of payment. If further media coverage were to follow the Board would review their position.

171. **Any other business**

The Chairman informed the Board that the Annual Review meeting with the DH had taken place in August 2013 but that they had not circulated notes of the meeting. The meeting had been fairly standard in its content although it had resulted in receiving agreement to write to doctors in an attempt to find further unclaimed 'top-up' payment recipients and had resulted in the hepatitis C workshop taking place in December.

The Chairman reported that since the Finance Manager had left and been replaced by an interim, the Board should reconsider who had approval for Skipton Fund payment batches, particularly given the sums of money that were now involved following the introduction of the regular payments. It was resolved that the Chief Executive of the two charitable trusts who shared office space with Skipton Fund should be approached and given the necessary powers to supervise payment batches and act as the second signatory. The Chairman

would approach the Chief Executive and ask if she would be willing to exercise a supervisory and control function over Skipton Fund payment batches; a service level agreement may need to be drawn up in due course to cover the particulars of this role.

The Chairman informed the Board that he would be away from 3 March to 20 June but would be contactable by email.

There being no further business the meeting closed at 11:45.

GRO-C