# Minutes of the Meeting of the Board of Directors of The Skipton Fund Limited held at 14:00 on 10 March 2015 at Alliance House, 12 Caxton Street, London, SW1H 0QS

| Present:       | Mr P Stevens<br>Mrs E Boyd<br>Professor G Dusheiko<br>Mr P Spellman<br>Professor H Thomas | Chairman<br>Director<br>Director<br>Director<br>Director |
|----------------|---|--|
| In attendance: | Mr N Fish<br>Ms Joyce Materego  | Scheme Administrator<br>Finance Manager                  |

B1.15 Apologies for absence There were no absentees.

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#### B2.15 Welcome to new Director and Finance Manager

The Chairman welcomed Professor Geoffrey Dusheiko to the Board of Directors and Joyce Materego to the role of Finance Manager and thanked them both for their work to date.

#### **B3.15** Minutes of the previous meeting The minutes of the meeting held on 14 February 2014 were signed as a correct record.

#### B4.15 Matters arising

164 – The Scheme Administrator reported that he had liaised with the Macfarlane Trust (MFT) shortly after the last board meeting about the possibility of there still being widows of deceased MFT primary beneficiaries who would be entitled to apply for payments through the scheme. There had been a handful of such widows found and paid in the current financial year as a result of this contact and efforts by MFT were ongoing to try and find others who may be eligible.

165 – The Scheme Administrator reported that, since the Fund had greater board level medical expertise, the success rate at the more recent Appeals Panel meetings had been less than the overall average of circa 50%. It was agreed that the appointment of Professor Dusheiko meant it was no longer deemed necessary to appoint another medical director, especially as there was often good medical data published online to assist with applications where records of a medical procedure were provided but not specifically that referenced treatment with blood or blood products.

167 – The email from the Department of Health (DH) was noted and that the Skipton Fund's assistance in helping to find patients

eligible for early access to new hepatitis C (HCV) drugs would not now be required. Professor Thomas reported that he had recently attended a British Association for the Study of the Liver/British Society of Gastroenterology meeting about the new HCV treatments during which he summarised the Skipton Fund's assessment process for determining if cirrhosis was probable for the stage 2 payment. The data supported a Fibroscan score of 14.5kPa as an indicator of a greater than 50% probability of cirrhosis in the absence of other markers. At the meeting the clinicians had recommended a Fibroscan score for advanced fibrosis (Ishak 5/6) of 11.5 kPa, which was lower than that used for Skipton Fund stage 2 assessments, as they wanted to make sure the sensitivity for offering treatment was high (>80%). Although a good approach from a treatment point of view, as it limited the chance of missing a patient with cirrhosis, from the Fund's point of view it would mean that cirrhosis would be overestimated in many cases. Professor Thomas would make the Department of Health aware of this difference in approach and that, unless requested otherwise, the Fund would continue to consider applications for evidence of a greater than 50% probability of cirrhosis.

168 – The Scheme Administrator reported that the DH had not been in contact again regarding this matter and that people who had been compensated elsewhere for HCV infection remained free to apply for an ex gratia payment through the Skipton Fund. 171 – The Chairman reported that he had met with the Chief Executive of the charitable trusts and it was agreed that, due to her lack of involvement with the Skipton Fund, it was not considered appropriate that she provide a supervisory and control function for Skipton Fund payments. Subsequent to that meeting, procedural changes had been made whereby all online payment batches required authorisation by a director along with the Finance Manager with online authorisation cards currently being held by the Chairman and Mr P Spellman. The Board were content that this was far more secure than the previous method of having the Finance Manager as the sole authority.

#### B5.15 Unclaimed stage 2 'top-up' payments

The Scheme Administrator provided up to date figures on the number of unclaimed 'top-up' payments, with 72 being due to the estates of deceased people and 26 to people who may still be alive. In the case of the 26 people who may still be alive, the Scheme Administrator felt that Traceline might be able to help, even though this service usually required the person's NHS number. Traceline would hopefully be able to confirm if the person was alive and which health authority they were registered with. In the case of the 72 payments due to estates, it was reported that there were a few doctors who had not responded to previous written requests and that this could be followed up. However, in many cases it was not known if the deceased person had a next of kin and, if they did, who this would be. It was resolved that, provided the DH did not object, the Scheme Administrator would make further efforts to find people eligible for the top-up payment, especially the 26 people who may be alive and entitled to regular payments.

#### B6.15 Payment statistics to 31 March 2015

The Board noted the payment statistics for the year ending 31 March 2015 and that the total number of new stage 1 and 2 payments would be similar to last year. It was noted that there had been a spike in stage 2 payments at the start of the year which the Scheme Administrator felt had been partly due to the exercise to update the contact details of people at stage 1.

## B7.15 Application statistics to 31 December 2014

The Board discussed the number of declined stage 1 applications and were informed by the Scheme Administrator that roughly 200 of these were 'natural clearers' and of the remaining 500, roughly 200 had also been declined at appeal. The remaining 300 were declined for various reasons with the main one being a lack of evidence of treatment with blood or blood products.

The Board noted the slow but steady percentage increase in stage 1 applicants progressing to stage 2 which Professor Thomas felt, at 30%, was about the level that would be expected. The Board were hopeful and expectant that the upcoming new HCV treatments would help to prevent as many people from developing cirrhosis in the future. In response to a question, the Scheme Administrator reported that no deferred applications had ever been overturned at appeal and that the majority of successful stage 2 appeals from the estates of deceased applicants were as a result of the creation of the predictive formula to estimate progression to cirrhosis amongst people co-infected with HIV.

B8.15

#### 5 Payment forecasts for 2015/16

The Scheme Administrator explained the difficulties in forecasting Skipton payments and that the estimated levels for 2015/16 were therefore based on current levels less a few payments as per the general trend from previous years. Unknown variables such as the Government's response to the Penrose Inquiry and how successful the latest attempt to find people eligible for 'top-up' payments could cause the forecasts to vary greatly from actual payment levels.

#### B9.15 Appeals Panel

The Board felt that the Appeals Panel statistics had been covered in sufficient detail during the course of discussions of other agenda items but asked that the Scheme Administrator pass on the Board's thanks for all their valuable work via the Chairman.

B10.15 Expenses policy

The Chairman reported that, as the sole employer of staff of the 'Alliance House entities', the Caxton Foundation had a variety of policies to cover all areas of employment but that the Skipton Fund, with its own independent Board, required a separate expenses policy. The Board were content with the proposed policy and it was formally adopted.

B11.15 Draft Directors' report

The Board were content with the current draft and felt it read well. The Chairman reported that he would be adding a paragraph about the appeals process and would circulate an updated version shortly

# B12.15 Updating contact details for recipients of the Stage 1 payment

The Scheme Administrator reported that he had been approached by the Department of Health in September 2014 and asked to update contact details for people who had received only the stage 1 payment as a result of infection in England and who were recorded as being alive on the database. The process involved contacting circa 2000 people by email, telephone or by writing to their doctors and 2 temporary members of staff had been employed to provide assistance. Responses from doctors were still being received but at 9 March, 1350 people had been found, 93 people had been found to have died and 559 people had not been found. In January the Department of Health then asked that the same exercise be carried out for people whose infection came about through treatment in Northern Ireland, Scotland and Wales. At 9 March, 371 of this group of people had been found, 56 people had been found to have died and 183 people had not been found. The Department of Health had not made it clear why they wanted these details updated other than to say that they were reviewing the scheme and if there were changes made in the future they wanted the Skipton Fund to be in a position to let everybody know in writing.

## B13.15 Penrose Inquiry

The Board noted that the Penrose Inquiry was due to report on 25 March and that the Government would provide an interim response before Parliament was dissolved at the end of the month. Although the Board felt the report could have implications for the Skipton Fund it was not known what these might be.

#### B14.15 All-Party Parliamentary Group (APPG) report on Haemophilia and Contaminated Blood

The Scheme Administrator reported that there had been a number of factual inaccuracies contained within the APPG report and that the Chief Executive of the Caxton Foundation and Macfarlane Trust had coordinated a response which included inaccuracies concerning the Skipton Fund highlighted by the Chairman, Professor Thomas and the Scheme Administrator. The report, which to date had not impacted on the Skipton Fund, was noted.

**B15.15** House of Commons debate on contaminated blood It was noted that the debate focussed mainly on the sad circumstances of individuals and their families and how they had been affected by contaminated blood. The Scheme Administrator reported that there had been few mentions of the Skipton Fund but one of those had been by an MP speaking on behalf of a constituent who had been declined on the basis of 'natural clearance' and another whose stage 2 application had been delayed due to a lack of evidence of progression to cirrhosis.

### B16.15 Letter before claim from Leigh Day Solicitors acting on behalf of three Skipton Fund payment recipients to the Secretary of State for Health

The Chairman reported that the Skipton Fund had received a letter from Leigh Day Solicitors questioning the legality of the Government funded companies and charities which require that HIV and HCV be treated as separate viruses with different payment arrangements available for each. The letter had been sent to the Skipton Fund for information only, it had been carefully checked by the Chairman and Scheme Administrator, and only the Secretary of State for Health was required to respond. The Board noted the letter and that it may result in changes to the scheme in the future but that the decision was not for the Skipton Fund to make.

# B17.15 Management costs budget for the year commencing 1 April 2015

The Board considered the management costs budget for the year commencing 1 April 2015 and the latest costs forecast for the current year. The Chairman noted that management costs for the current year had risen by around £5,000 from the previous year but that this was more than offset by the agency staff costs incurred as a result of the Department of Health's request to update contact details for people at stage 1. The other notable variances were insurance costs and the cost of the Appeals Panel, both of which had fallen substantially. The Scheme Administrator explained that, due to timings of meetings, the Appeals Panel had met only twice in the current financial year and that both of those meetings had been tele-conferences. There was to be a meeting in Scotland in early

April and probably a further 2 or 3 meetings over the course of the next financial year so costs were expected to return to forecasted levels. Insurance costs had fallen as a result of a comprehensive review of insurance policies across the Alliance House entities which had resulted in the removal of duplicated or unnecessary cover and a more accurate apportionment of premiums across the entities. The management costs budget for the year commencing 1 April 2015 was approved.

#### B18.15 Any other business

The Chairman asked if the Department of Health had informed the Skipton Fund of the 2015/16 regular payments increase. The Scheme Administrator responded that he had received an email that morning informing the Fund that the payments were to be increased by 1.2% from £14,574 to £14,749. The Company Secretary of MFET Limited, whose payments benefit from the same increase, felt that it would be necessary to wait until official written directions had been received from the Secretary of State for Health before relaying this information to payment recipients. The Skipton Fund would comply with this request.

Due to the potential for change to the Skipton Fund after the Penrose Inquiry had reported and the Government's response to the letter before challenge from Leigh Day it was felt that a board meeting might become necessary sooner than usual and one could be called as and when necessary after 1 April.

There being no further business the meeting closed at 15:05