

Agenda item 3  
1 March 2005

### **SUBMISSION FROM SCOTTISH HAEMOPHILIA FORUM**

The Skipton Fund arose only as the result of the campaigning in Scotland by the Scottish Haemophilia Forum, the Motion supported by 80 MSPs from all parties, the unanimous support of the 1999-2003 Health Committee of the Scottish Parliament and the decision of the then Health Minister Malcolm Chisholm who announced to Parliament in January 2003 that he was thinking making payments of £20,000 to those infected with Hepatitis C as the result of Blood Products or Transfusions.

Sadly since then, the work of the Scottish Parliament appears to have been hi-jacked by Westminster. On the 29<sup>th</sup> August 2003 Malcolm Chisholm announced that he would be making ex-gratia payment of £20,000 and a short time after this John Reid Health Minister announced that the Westminster Parliament would follow Scotland's example. Regrettably this announcement stated that the dependants of those who had died prior to 29<sup>th</sup> August 2003 would be excluded.

Following the announcement three meetings were held in London the first on the 14<sup>th</sup> October 2003 at the Department of Health Offices in Skipton House (thus the Fund has been named after a building rather than acknowledge the role of Scotland). These meetings consisted of a senior civil servant from each of the four countries of United Kingdom, the Chief Executive of the Haemophilia Society and myself as Chairman of the Scottish Forum, the Chief Executive of the MacFarlane Trust and representatives from two other organisations.

At this first meeting despite requests that a minute of the meeting be taken this was resisted by the civil servant from the Department of Health who undemocratically took the role of chairman.

From the onset it was apparent that there had been a dialogue prior to the meeting between the civil servants from the Department of Health and the Chairman and Chief Executive of the MacFarlane Trust thus the meeting was faced with a fait accompli that the MacFarlane Trust take on the responsibility of administering the now to be known as the Skipton Fund. At this meeting about two hours were spent on draft application forms that had been prepared by the MacFarlane Trust!

Prior to the next meeting which was held on the 26<sup>th</sup> March 2004 the Skipton Fund had been registered as a private company and without consultation had appointed four directors all who were trustees of the MacFarlane Trust. At this meeting there again was a request that minutes be taken given that there was a need of a record and an understanding how decisions would affect applicants.

The final meeting to my knowledge was held on the 17<sup>th</sup> May 2004. At this meeting notes relating to the meeting of the 26<sup>th</sup> March 2004 were circulated but the chairman was not open to questions regarding inaccuracies. It is our opinion that these notes were only made available as the result of a question raised by a MSP in the Scottish Parliament. Unfortunately no notes have been circulated in respect of this meeting.

It is our understanding that other meetings took place during the same period these consisted of Hepatologists (liver specialists) the Haemophilia Society at short notice was asked to nominate a Haematologist (blood specialist) it is uncertain whether this consultant attended more than the first meeting. We are uncertain whether there has been any meaningful consultation with the United Kingdom Haemophilia Centre Directors Organisation (UKHCDO) and the Government Departments drawing up the proposals for Skipton.

#### Issues of Concern

We have grave concerns regard the proposals regarding the "Appeal Panels".

It is uncertain whether the proposal in the next paragraph, regards Appeal Panels, announced had been made by Government or the Skipton Fund!

"The Appeals Panel would be constituted and convened consistently on each occasion that it met or deliberated on cases. The Panel would be Chaired by a legal professional such as a QC, and consist of lay representatives, a lawyer, a GP and a hepatologist. We expect the Appeals Panel to meet on a quarterly basis (at least for the first year or two) before a review of how the process has been working is carried out."

- 1) Why is there a need to set up a private Company limited by guarantee given that its function will only be to administer the Fund by sending out application forms, making payments based on a set criteria and rejecting others?
- 2) Given that Skipton will be funded by public finance, why is it not part of a Government Department thus ensuring that a Minister be politically responsible and answerable to elected members?
- 3) As a Private Company funded by public finance, how and who will monitor the Fund?
- 4) Why has the money provided as an ex gratia payment, to people infected with Hepatitis C through NHS Blood, being used to pay the staff of Skipton?
- 5) In the event of an Appeal Panel being set up how will the panel members be funded?
- 6) In other situations where a person has been refused a payment by for instance Disability Living Allowance by the Department of Works and Pensions, the Appeals Panel are appointed independently by the Department for Constitutional Affairs and funded by the Appeals Service.
- 7) Membership of the Panel, why a GP rather than a haematologist, given that most of the appellants will have been recipients of blood transfusions or products.

- 8) Generally the majority of patients, seen by hepatologists involved in the field of Hepatitis C are due to a choice of life style. ( Scottish Executives statistic state that there are 568 people in Scotland infected with Hepatitis C as the result of Blood) Therefore some concern has been voiced.
- 9) Will all members of the Appeals Panel be recruited in the same way?
- 10) Will the legal members be recruited acknowledging different legal systems in the UK?
- 11) Will there be recognition that lay member should have an understanding of the issues and experience of Hepatitis c. Rather than paid professional staff?
- 12) Where will Hearings take place?
- 13) Will the appellant be able to attend?
- 14) If the Hearings are being held for instance in London will appellants have their expenses met?
- 15) Will the appellant be able to have legal representation and who will meet the cost?
- 16) What expenses will be paid to Panel members and who will meet the cost?
- 17) How will appellants obtain expert opinion to challenge the decision of the medical panel?
- 18) Will all the documents used by the Skipton Fund in reaching a decision be made available to the appellant?

We note that within Part 5 of the "Bill" Section 24 sub section 5 "The Scottish Ministers may revoke or amend a scheme under this section" We would urge the Committee to recommend to the Minister that the proposed figure of £50,000 recommended by the Scottish Executive's Expert Group chaired by Lord Ross should substitute the proposal of £20,000 by Skipton.

We would urge the Committee to amend the "Bill" and remove the discrimination refusing payments to the dependants of those who have died prior to the 29<sup>th</sup> August 2003.

There are several concerns regards how different Consultants may deal with application to Skipton resulting in long delays for those who have applied.

We also are aware that some of the tests proposed to determine whether an individual meets the criteria for the second stage are flawed.

As previously mentioned we believe that the medical membership of the Appeals Panel should be a haematologist rather than a GP.

Philip Dolan  
Chairman – Scottish Haemophilia Forum  
24<sup>th</sup> February 2005