

Caring for people with bleeding disorders



THE
HAEMOPHILIA
SOCIETY
UNITED KINGDOM

William Connon
Manager, Blood Policy Division
Skipton House
80 London Road
LONDON
SE1 6LH

Petersham House
57a Hatton Garden
London EC1N 8JG
Helpline: 0800 018 6068
Admin: 020 7831 1020
Fax: 020 7405 4824
Email: info@haemophilia.org.uk
Website: www.haemophilia.org.uk

15 July 2005

Dear William

Thank you for your reply to my letter of 27 April 2005.

Whilst I am grateful for your restating of the eligibility requirements for patients infected with hepatitis C as a result of receiving contaminated blood products, I am aware that over 140 applicants have been identified as "natural clearers" for the reasons you have noted. I am equally concerned that many of these people will nevertheless have suffered greatly and compassionate payment criteria could be amended to reflect this.

With reference to the appeals panel, we would urge that the process be established and published by the end of July. Whilst we have some sympathy with the difficulties around consensus and the devolved administrations, we would be very concerned if there is not an appeals panel in place very soon. I am sure that the Haemophilia Society Board of Trustees would also be happy to nominate a patient representative to the appeal panel in the spirit of the Government's initiative towards patient involvement.

I look forward to receiving further information about the appeals process in the near future.

Yours sincerely

GRO-C

Graham Whitehead
Chief Executive



Mr Graham Whitehead
Chief Executive
The Haemophilia Society
Petersham House
57a Hatton Garden
London
EC1N8JG

Skipton House
80 London Road
London
SE1 6LH
Tel: 020 7972 2000
Direct Line: 020 7972

7th July 2005

Dear Graham

Thank you for your letter of 27 April about the Skipton Fund Stage One payments. I am sorry you have not had an earlier reply. Perhaps I should start by confirming which patients infected with hepatitis C as a result of receiving contaminated blood products are eligible for payments under the scheme.

The hepatitis C ex-gratia payment scheme is intended to make payments to help people living with hepatitis C infection. A proportion of people acquiring hepatitis C will eliminate the virus spontaneously in the acute stage and will not develop chronic infection. These are the people referred to as "natural clearers" and who are not eligible for payment. It was decided that people with chronic hepatitis C who, as a result of treatment, appeared to eliminate the virus – i.e. became repeatedly HCV RNA negative by PCR, would be eligible for payments from the scheme. Equally, people who, after a period of chronic infection, cleared the virus spontaneously, are eligible although the latter is not thought to be a common occurrence.

I cannot comment on individual cases. However where evidence exists which suggests an individual has had chronic infection, it would seem appropriate for them to make an application to the Skipton Fund. It does not follow that every application will be successful, but this allows all such cases to be considered.

I can confirm that the Department has no plans to amend the current position with regard to individual "natural clearers" who have eliminated the virus in the acute phase.

As you rightly state, the appeals process will be against determinations made by the Skipton Fund only, and not against the basic scheme. Any applicant who does not agree with the outcome of their application to the Fund will have the opportunity to apply to an appeals panel. We are currently working with colleagues in the devolved administrations to establish procedures for an appeals mechanism by the end of July, if possible.

Yours Sincerely,

GRO-C

William Connon