Message

From: Nick Fish [GRO-C]
Sent: 27/01/2011 16:43:02
To: 'Hay Charles (RW3) CMFT Manchester' [GRO-C]
CC: GRO-C; 'Chris James' [GRO-C]; Jecock Rowena DOH GSI DWP GSI [GRO-C]; 'Mike Makris' [GRO-C]; Dewhurst Lynne (CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST) [GRO-C]; 'Peter Stevens' [GRO-C]; Martin Harvey [GRO-C]
Subject: RE: Skipton Fund payments

Dear Dr Hay

Thank you for your email, I will address the points in order.

With regards to leaflets and posters, this has been brought to the attention of the Department of Health today and I understand that they are (and already had been) considering designing something which could possibly be distributed as early as next month. I agree this would be useful in increasing awareness of the scheme.

I share your concerns on some people not being able to furnish sufficient evidence for the purposes of the application. However we hope that with a combination of i) information printed on the death certificate (I have spoken to the Trustees of people whose death certificate specifically mentioned hepatitis C, which I assume would only have been done if the infection was chronic, rather than them being AB positive?) ii) records held at Haemophilia Centres iii) records retained by the estate and iv) records which still exist at the hospital and/or GP surgery, most people will be able to receive a payment where it is due. For applications which are declined there is always the appeals system whereby the medical knowledge and experience of the panel members may be sufficient to overturn certain unsuccessful applications.

You wrote:
"In the pre-testing era, NANB hepatitis was defined by exclusion of alcohol, hepatitis A and hepatitis B in patients with abnormal liver function tests for >6 mths. For some of the patients who died a long time ago, that, plus a history of treatment with a high-risk product may be the only evidence of chronic hepatitis C there is. That would persuade me. Would it be adequate for Skipton? What is your minimum dataset?"
We would need guidance from the Department of Health on this matter.

On the registration form we request a copy of the death certificate but in cases where the estate is unable to provide a copy we could approach you for one; this would be useful, thank you.

You wrote:
"The National Haemophilia Database does not currently hold HCV testing data though we are beginning to collect it. We do have treatment history data and mortality data however and I wonder if this could be helpful to patients. For DPA reasons we could provide this to patients themselves and already do so but could provide you with data only from patients who have sadly died"

For any living applicants who are struggling to obtain records of their treatment with blood products I will refer them to you (although for people with haemophilia this is very rarely a problem as opposed to one-off transfusion recipients). For people who were registered with the Macfarlane Trust the source of the HCV infection has always been assumed to be the same as that of the HIV infection so the only records the estate must supply is with regards to the HCV. For those people with haemophilia who have died and did not have HIV then a copy of their treatment history data on your headed paper would be very useful.

Kind regards

Nick Fish
Scheme Administrator
Direct Line: GRO-C
Email: GRO-C

THE SKIPTON FUND

From: Hay Charles (RW3) CMFT Manchester [mailto: GRO-C]
Sent: 25 January 2011 15:17
To: GRO-C
Cc: GRO-C ; Chris James; GRO-C ; Mike Makris; Dewhurst Lynne (CENTRAL MANCHESTER UNIVERSITY HOSPITALS NHS FOUNDATION TRUST)
Subject: FW: Skipton Fund payments
Importance: High

Dear Nick,

Thank you for the information earlier.

I attach my letter to DH. I have had no response to this yet but will probably follow up with a phone call because further questions have arisen since I wrote it. I also wish to specifically ask again about the deadline of 31/3/11.

I think we are all concerned that patients may fall through the net because they don't know about it or because of the deadline. We are trying to get haemophilia centres to bring it to their patient's attention and will be providing patients with lists of patients that they may or may not be able to contact. Have you thought of printing a public information poster which we could display in haemophilia centres and clinics?

We are also concerned that some applications may fail because of a lack of supporting documentation. This will be unavoidable to some degree, for the following reasons: -

1. The notes may have been destroyed or lost (though some relatives have copies of notes, which may be very helpful).
2. The patient may have died before the advent of HCV antibody testing in 1992 or HCV PCR testing several years later.

In the pre-testing era, NANB hepatitis was defined by exclusion of alcohol, hepatitis A and hepatitis B in patients with abnormal liver function tests for >6 mths. For some of the patients who died a long time ago, that, plus a history of treatment with a high-risk product may be the only evidence of chronic hepatitis C there is. That would persuade me. Would it be adequate for Skipton? What is your minimum dataset?

In some cases there is documented evidence of severe liver disease on the death certificate. We have death certification data from ONS that we can provide you with. Data Protection Legislation does not apply to the dead, by the way.

The National Haemophilia Database does not currently hold HCV testing data though we are beginning to collect it. We do have treatment history data and mortality data however and I wonder if this could be helpful to patients. For DPA reasons we could provide this to patients themselves and already do so but could provide you with data only from patients who have sadly died

With best wishes,
Charles Hay
Chairman UKHCDO.
