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"Skipton Fund claim handling - the 'PCR' issue"

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<Bob.Stock@GRO-C GRO-C>
09/09/2004 09:17

To: Richard Gutowski/PH6/DOH/GB@GRO-C
cc: <Caroline.Lewis@GRO-C>, <gerry.dorrian@GRO-C>, <Aileen.Keel@GRO-C>, <Sandra.Falconer@GRO-C>, <Andrew.Macleod@GRO-C>, Gerard Hetherington/TRRO-PERFC/DOH/GB@GRO-C
bcc:
Subject: Skipton Fund claim handling - the 'PCR' issue

Richard

1 Re the two messages from Peter Stevens. I think we need either to hold a meeting or a video conferenceinvolving MOs as well as officials to resolve this matter– since we currently

have different views on how best to proceed coming out of Scotland and Wales, and none as yet from England or NI. And weprobably need to do this fairly urgently before this becomes the next Sunday Heraldissue. We also need to decidewhether it would be helpful toinvolve thisChristine Lee from the Royal Free for the technical part of that discussion.

I worry that we have boxed ourselves into a corner with this by accepting the inclusion of the group that supposedly clear spontaneouslyafter chronic infection– but that is all water under the bridge. It is all very well for Peter to carry on aboutthe principles behind the scheme but that is not his role. And if webelievethe statistics, then inclusion of the whole spontaneous group will increase the number ofeligible applicants by 20%.

2 I note that Peter alludes tothe absentAppeals system. Dolan is constantly badgering me about this and thatalsocouldbecome an issue up here in themedia or parliament soon. Haven't heard anythingon this since about the end of July– when it wasestablished that appeals panel members (and directors Ibelieve?) would need to be publicappointments. Where are we this?

Bob

<<Skipton - first payments>> <<More on Skipton>>

Re-emerging blinking into the daylight after a few weeks rustication in Dorset, I find that progress continues at Alliance House. I shall have some detailed figures for you at the weekend, but I note that we have paid about 20% of those from whom application forms have been received, and at present seem to be paying more each week than the rate if inflow of new applicants. Phew!

There have been two factors determining the rate of progress:

- my insistence that each payment is signed-off by a director. With (for a time) only 2 London-based directors available, and with that sign-off entailing quite a lot of checking, that has been a limiting factor. We now have the third London-based director available and have transferred more of the data-checking to the staff, so this sign-off is no longer a constraint

- my parallel insistence that the actual payments, involving the computerised transfer of funds, are made by a member of the Macfarlane finance team - a permanent employee in whom we have total confidence - rather than by somebody on a short-term contract. This function is both tedious and time-consuming, and we have settled on a target of 250 payments a week. This is the determinant of our speed of progress. The more detailed figures will confirm that, at the moment, we have some 12 weeks' worth of payments to be made by this person.

We only have one other person on the MFT finance team and cannot spare him off that job to make Skipton payments. We are training another MFT person on the payments process, but her capacity will always be limited because she, too, has other MFT work to do.

I will be looking at the payments process to see if it can be speeded up, but I am not optimistic.

Now, some questions:

- we have an application from somebody who was transfused, while visiting his parents who were RAF personnel in Gibraltar, at the Royal Naval Hospital there. Please would you confirm that that establishment is effectively part of the NHS?

- the part 2A questions continue to cause great difficulty, and I trust that you are hard at owrk consulting on these. Some further illustrations of the problems (Bob already has some stuff form me on this):

  - a clinician said that a patient was PCR positive, but added that he had not been tested since 1998. We took this as a qualifying.
  - the 2A questions were answered "yes", "no", "no" and "no", but the clinician went on to say that the app[licant had had persistently abnormal ALT tests.
  - after a similar set of answers, the clinician said that a liver biopsy (on a haemophiliac) showed him to have cirrhosis
  - in another similar case, the evidence of cirrhosis comes from CT scanning and ultrasound.
  - in yet another case, the second question (PCR negative?) was unanswered, but the clinician said chronic Hep C had been diagnosed.

Finally,we have a case from Brian Colvin, at the Royal London, who has signed off lots of applications but on this one cannot complete the form. From a long and detailed letter the position appears to be

- the applicant is a long-term Hep B carrier with partial immunity to that virus
- he is also HCV antibody positive and in 1995 and April 2003 had positive HCV PCR test (but in 1991 had had a negative one, which Colvin believes to be a false result)
- HIV treatment casued a flare-up in his Hep B infection which then resolved spontaneously
- as his HIV treatment led to an improved immune system, his HCV PCR test became negative spontaneously in October 2003 and remains so.

Colvin concludes that the applicant clearly is and was chronically infected with Hep C (and nearly died of liver disease) and should qualify for the 2nd stage payment, but appears to be of doubtful eligibility for the first stage payment. This has to be nonsense.

These all show that the 2A questions are not leading us (or the clinicians) to clear conclusions.

Furthermore, one of the London-based directors is Elizabeth Boyd, who is a DOH-appointed MFT Trustee who works at the Royal Free. Her understanding, based on Christine Lee's knowledge of Hep C, is that "nobody who is PCR negative without receiving Interferon based treatment would have experienced any of the symptoms mentioned in 2A(iv)." She is, therefore, not passing any "natural clearers", which forces the rest of us to follow suit - but until she made this plain I had already passed quite a lot of such cases.

So we have inconsistency of treatment on this point within Skipton, matching that from the clinicians, about which I have already told Bob.

My belief is that this is not a major problem in terms of numbers and can be resolved by taking a different view of this point that was much debated earlier this year; in other words, I think we shoudl abandon the distinction of viral clearance between those whose clearance followed treatment (the majority of clearers) and those who did so "naturally". I do not believe that the cost to the scheem would be significant.

But we do need greater clarification on this point at the very least, and should not be distinguishing between those whose clinicians only tick the boxes and those who add sufficient arguments as to indicate that being PCR negative without taking interferon and without clear evidence from the acute stage is not, in fact, a sound or fair reason for withholding payment.

I could suggest "Appeals Panel", but think that we actually need a re-definition of eligibility - the Panel would be similarly stymied by the rules of the scheme, which are themselves the root of the problem since we did not find a set of questions in part 2A which sufficiently defined how to discriminate against this small group of people.

Your swift resolution of this would be much appreciated. I will be happy to come into Skipton House to talk about it if that would help.

Peter

We now have about 50 "natural clearers" applications on hold. (One of them is from Chris Hodgson, former Society Chairman and MFT Trustee). They include MFT and non-haemophiliacs. A few answer the 4th question in 2A "yes" - ie there is evidence of chronic phase infection - but on the model of Christine Lee at the Royal Free, who is holding 32 such cases and does not believe that many of those infected early have any reliable means of getting this question answered, we are holding these as well.

But we have certainly paid some who now would be in the "hold" pile.

Keith is beginning to receive phone calls from this bunch, so the matter is beginning to press. As I said before, I do not think this is a matter for an Appeals Panel, but results from a flaw in all theng leading to the questionnaire and an ill-judged and unfair attempt to exclude a small minority on the basis that somehow their infection did not matter. As some of the cases have shown, some of those who have cleared naturally have evidence of cirrhosis, which makes their exclusion an especial nonsense. I think we need a shrug of political shoulders and an acceptance that this rule is not workable because the viral impact is more complicated than was understood.

On another matter, we have had an application from a guy who now lives in France and has no access to a British GP or hospital. His infection arose from treatment here for aplastic anaemia, on which he seems to have been quite a campaigner. He now refuses to go near hospitals except for absolute emergencies, believing them (with evidence of learned papers to support this stance) to be a major risk of further infection that his compromised immune system should not be exposed to. Most of the claim looks fine but his PCR status is not known. This possibly could be a case for an Appeal Panel, were it to exist.

Parliaments are clearly back, judging by Keith's phone calls. Anything you can do to hold back the questions until next week, by when we shall have some decent post-holiday figures for you, would enable us to process more.

Peter

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