

6

Falconer S (Sandra)

From: Stock RG (Bob)
Sent: 31 March 2004 16:26
To: David Reay; Gerry Dorrian; Richard Gutowski; Sue Paterson
Cc: Falconer S (Sandra); Keel A (Aileen)
Subject: Skipton Fund - outstanding issues [Communications strategy]

In preparation for the next meeting with patient organisations, I thought it might be useful to put down a few thoughts about the outstanding issues so that we can discuss them and come to the meeting with a common position.

Communications strategy (for informing potential applicants)

My initial thinking on this is as follows:

- Press release announcing 'doors open' for SF – giving contact details for SF (maybe reiterating scheme criteria) and flagging up the change since last announcement (effect of other awards)
- CMO Letter to clinicians. [We need to think about whether there should be two versions of this – one aimed at clinicians involved in treating the condition covered by the scheme (hepatologists; haematologists?; haemophilia centre directors) and a different one for GPs. I'm half inclined there might be a case for asking the former category to be more proactive in terms of bringing the scheme to the attention of relevant patients]
- Distribution of posters (just small A4 or A5 would suffice I would have thought). These could go out with the CMO Letter – with a contact point for obtaining more. Guess the patient organisations would want a supply. Would we go any wider than that?
- Full information on the SF website. Links set up to:
 - Patient organisation websites
 - NHS/Health Department websites
 - Government organisation websites?
- Write out to people who have registered an interest with us (just letting them know how to contact SF).
- Write out to patient organisations (you may wish to let your members know that)

Appeals

I think we have previously agreed that there will be a need for two different types of appeal (and associated panel).

We need one to deal with appeals against SF decisions on the **second payment**. This will only involve medical considerations and the panel need only be made up of medical experts. David has suggested that we could use some of the people currently on the medical trigger group. However, we need to have an idea about how many we would want and how we would choose them – and if we are going to offer the patient organisations a chance to suggest names, how we will do this (do we all vote on all the posts or do we offer one post for them to argue about between themselves)?

We need another to deal with appeals relating to **basic eligibility**. There will inevitably be medical issues here but I feel that much of the discussion will be around ordinary evidential issues and the assessment of the balance of probabilities. I therefore favour the model set up for Macfarlane where the panel was chaired by an experienced **lawyer assisted by two 'others'**.

We need to think about how we would select this lawyer in a way that would not attract any criticism. At least one of the others should be a medical person. We need someone who knows how the records system works in the NHS –

what is likely to be on a GPs notes, what is likely to have happened with hospital records etc. In the interests to appearing independent we could go to the BMA for a nominee. There will also be a need for medical expertise in understanding treatment regimes, not only for blood products but for transfusions (to be able to say for instance that it is highly likely that the bag attached to a patient's arm for a particular procedure was saline and not blood – or vice versa). So the 3rd person could be a medic too – to cover this different area of expertise. Patient organisations might make a stand for one of them to be the 3rd 'person'. I think we should resist that (at least on 3 person panel model) but maybe instead allow them a say in nominating the 3rd panel member.

BOB