Mann Pat (RQ3) BCH

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Sent: 18 August 2004 09:49
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Subject: CJD Risk Notification - Plasma Products - Update on Process

Importance: High

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Dear All,

CJD Risk Notification - Plasma Products - Update on Process following meeting at DoH with Health Minister

This meeting, held yesterday afternoon, was chaired by Lord Warner (Health Minister), and attended by Aidan Halligan (Deputy CMO), Angela Robinson (Director NBS), Graham Whitehead (CE Haemophilia Society), David Watters (CE PIA), Michael Clarke (Press Officer DoH), Gerard Hetherington (Head Health Protection DoH), two private secretaries, and I.

There was complete agreement that it was desirable for the notification process to be conducted in two stages - stage 1 to allow clinicians to prepare to notify patients, stage 2 the actual notification of patients coupled with public information. It was agreed that an interval of about two weeks should be aimed for between the two stages.

Monday Sept 6th was repeatedly mentioned as the target date for disseminating information to the Health Service, and Monday Sept 20th as the date by which Haemophilia and PID patients should have received their letters, and the date when the DoH would schedule a proactive public announcement, supported by both the Haemophilia Society and the PIA.

There was a general view, lead by Graham Whitehead, that the batch details should be made available at the outset of stage 1, and I agreed that the HPA would coordinate the necessary minor change in arrangements to make this happen.

Aidan Halligan repeatedly expressed his view that a dedicated national help line for Haemophilia and PIA patients would be a great help (over and above current plans for the general public to be directed to NHS Direct). Subsequently, however, I ascertained that neither Graham nor David thought this necessary - they would always refer patients to the local clinical centre where they were known and they expected that such an arrangement would be adequate. They were also skeptical that anyone could lay-on the sort of skilled help-line that would be necessary for such a particular group of patients, and were certain that it was not a role either of their societies would attempt to undertake. Apart from being available for the week of Sept 20th, this help-line would also need to be able to swing into action anytime during the previous two weeks.

It was also generally agreed, that a contingency plan 'to go public' had to be in place throughout stage 1 in case the press heard of the development prematurely and began pressing for information. The DoH would take the lead on preparing this contingency response, that would probaly involve both the Haemophilia Society and the PIA in a supportive role, as well as the HPA.

We did not dwell too long on the issue of when precisely Medical Directors of all Trusts should be written to, but it was noted that a) Haemophilia doctors had expressed the desire that Medical Directors should be put in the picture and asked to provide support, and b) that if they were not written to as part of stage 1, many would be informed piecemeal by their Haemophilia clinicains. Also, it has occurred to me since that if we are to initiate the batch notification as part of stage 1, then we must provide Medical Directors with the information if their Blood Banks and Pharmacies are to be properly informed.

Subsequently, talking with Graham and David, I ascertained that they agreed wholeheartedly with me that patients should not be written to immediately before a weekend. The target date for letters to be sent out should be a Monday. So we need to agree with the DoH the precise timetable.

Therefore, the actions from now are as follows:

1. Make the necessary alterations to the documentation for the Batch details to be disseminated from Day 1, and liaise with BPL and PFC to inform them of this.

2. Agree with everyone the precise dates upon which event should happen. I recommend the following:

Tuesday Sept 7th : Letters and information pack to Clinicians and Medical Directors - including Batch details
Batch details notification by BPL and PFC.

Monday Sept 20th: Letters to be posted to haemophilia and PID patients from clinical centres>

Tuesday Sept 21st: Public announcement co-ordinated by DoH.

We also should improve the emphasis within the documentation of the need to avoid releasing information publicly until after the most affected patients have been written to.

The issue of a dedicated national help-line for haemophilia and PID patients is unresolved - any comments would be welcome. Could the wording at the conclusion of the letter to patients about contacting one's local centre be strengthened?

Noel

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