

Charles Lister
15/05/2003 15:22

To: Zubeda Seedat/PH1/DOH/GB@GRO-C
cc:
Subject: Letter from Frank Hill

Zubeda

Any comments?

Charles

----- Forwarded by Charles Lister/PH6/DOH/GB on 15/05/2003 15:27 -----



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GRO-C
15/05/2003 15:20

To: Charles Lister/PH6/DOH/GB@GRO-C
cc:
bcc:
Subject: Letter from Frank Hill

Dear Charles,

Re: Recombinant Clotting Factors Working Group and implementation for recombinant factor products for haemophilia

In order to facilitate the working of the group I would be happy to produce a few short (very short) papers. These could also be used to allocate tasks to members of the group with similar interests so that we develop a framework on which to put timescales for achievement.

The documents should be:-

1. a) Patient eligibility - including copy of Frank Dobson's statement of Feb 1998 + statement announcing current phased provision. What is not covered by roll-out (i.e. newly planned surgery).
b) Age related roll-out.
Issues still for consideration and planning - mainly to do with inhibitor patient treatment.
2. Document on how patients are to be informed of process of implementation and advice through UKHCDO and how patients should be contracted.
3. National contract for supply of recombinant. How this is to work etc.
4. How funding will be distributed - I believe this is money in lead PCT.
5. Presentation of existing data. Future data being collected and how this will be used to plan implementation.
This should also discuss what and how information will go to PCT.
6. Billing by Centres treating children and adults will be possibly at different costs and will need to be billed and ordered separately.

I am very conscious of the time constraints on you as you change posts. If you agree that this covers the main areas (add in any others) then I can liaise with Denise O'Shaughnesy and Zubeda Seedat to email drafts to the committee to produce a final action plan which would include any cascade of information other than on the web site.

Kind regards,

Frank Hill
Chairman -UKHCDO

P.S. I will liaise with Karin to produce a communication to patients once we have the above process clarified. FGHH.

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