Lord Hunt

From: Gwen Skinner
HSD
Date:19 June 2000
Copies: Dr McGovern
Mr Lister

MEETING 10.00 WEDNESDAY 21 JUNE WITH UK HAEMOPHILIA CENTRE DOCTORS - DR FRANK HILL (CHAIRMAN) AND DR CHARLIE HAY

Purpose of meeting

Initiated by us, to build up a relationship with UKHCDO and discuss ideas for strengthening haemophilia services.

UK Haemophilia Centre Doctors Organisation (UKHCDO)

- registered charity with a secretariat in the haemophilia centre at Oxford.
- Dr Hill fairly new Chairman - Haemophilia Centre Director, Birmingham Children's Hospital. (Wants to "take the angst out of haemophilia.")
- Dr Hay - UKHCDO Deputy Treasurer. Haemophilia Centre Director, Manchester Royal Infirmary (adults). A number of his patients are from the campaigning and litigious arm of the Manor House Group.
- UKHCDO is part of the Haemophilia Alliance. Dr Hill has been working on the service specification in recent weeks.

Suggested format for meeting

You may wish to begin by asking Dr Hill to give a pen picture of haemophilia services and the people who use them.

Service specification

Dr Hill may be able to say whether completion in the summer looks likely. You may wish to ask him if it would be sensible for you to meet with the Alliance in the summer.

Counselling

The service specification includes counselling. You might want to ask Dr Hill/Dr Hay for their views on current counselling provision, and whether those infected with hepatitis C are amenable to it.

(Background on counselling - the Haemophilia Society has focussed on maintaining social work posts. Broad 1998 survey information is available. UKHCDO takes a broader view of counselling - differing needs at differing times in a haemophiliac's life. Counselling is carried out by clinicians, clinical specialist nurses, social workers, physiotherapists, departments of clinical psychology.)

Mapping current provision (as a prelude to performance management)

How to set out the baseline/starting point to monitor a system of improving services? The UKHCDO collects audit information on a 3 yearly basis to re-designate Comprehensive Care Centres. Current information has just been gathered and will be collated by September. You might want to ask them to describe the information and whether it is confidential within UKHCDO. (Some centres will fall short of the mark).

We have asked the Haemophilia Society to propose a mapping project for counselling. (The UKHCDO know this.) The Society was already working on an HIV & hepatitis C treatment questionnaire for haemophilia centres which UKHCDO has seen.

Performance management

How would UKHCDO see a system of performance management developing?

Extension of supply of recombinant Factor 8

Could Dr Hill/Dr Hay give us some more information about this? We understand that Wyeth are expanding their production of RF8 and in theory this will make enough available for all. RF 8 has not been in plentiful supply, there has not been enough for haemophiliacs in all age groups. Dr Hill may recommend an extension of provision, as a means of building the confidence of all haemophiliacs, especially those who have hepatitis C.

(Though this sounds attractive, there would be consequences for BPL, who work with human plasma only. Additionally, recombinant Factor 2 is twice the cost of the plasma derived product, which would take the annual cost for a person with moderate/severe haemophilia from £20k to £40k. You might want to say that you will consider a referral to NICE, and ask Dr Hill when the increased supplies are likely to be available.)

Issues which Dr Hill/Dr Hay may raise/mention

Collection of data on haemophilia/hepatitis C
The UKHCDO collects annual data on haemophilia but to date this has not included data on the incidence of hepatitis C infection. Such data would be helpful for mapping and performance management. However, data protection requirements mean that individual haemophilia centres can hold data but the consent of the patient has to be obtained before it can be transferred to the UKHCDO central register. This consent may be difficult to acquire in the case of haemophiliacs with hepatitis C.

The UKHCDO have been assessing ways of overcoming this. They make suggestions which involve us; we would need to assess the implications. They may also request further financial support to provide standard computer software to haemophilia centres for data collection. (A grant of £30k has already been given, a further sum could be considered if resources allow.)

Product developments
When new products appear on the market, the commercial suppliers rapidly withdraw the predecessor, leaving only the higher price new product. England has the second highest price for recombinant Factor 8, Germany being the highest. The UKHCDO have been given the contact point at NHS Supplies, for initial discussion, as currently Trusts purchase blood products individually.

Interferon with Ribavirin
The UKHCDO want to hear NICE's view as soon as possible and they may believe that it is not due until next year. In fact the initial appraisal is scheduled for 13 July (when all who submitted evidence will receive a copy) and the final appraisal 27 September.

Genetic services
The laboratory connected with Dr Hill's haemophilia centre provides the genetic services for the West Midlands. The service around the country is mixed. Dr Hill would like to see a more organised system of carrier and antenatal detection. There is apparently increasing an tendency to terminate the pregnancy if the child is male (females being carriers but much less likely to show actual symptoms.)

GENERAL BACKGROUND

Recombinant Factor 8

This Government required Health Authorities and Trusts to provide recombinant Factor 8 for new patients and children under 16 from April 1998 (and Factor 9 from April 1999). The UKHCDO had pressed hard for this and were pleased with the outcome. The decision was not based on general acceptance of the greater effectiveness of the recombinant product, but the fact that a synthetic product was more reassuring to people with haemophilia than a human plasma derived one.

Recent requests to UKHCDO

We have made several recent requests to UKHCDO in the light of concerns expressed by the Haemophilia Society. We have asked them to ensure that hepatitis C testing is carried out for all haemophiliacs who might be at risk, if the individuals wish, and to ensure that there are links between haemophilia centres so that all have access to counselling.