Scotland & Northern Ireland Haemophilia Directors Group

Minutes of meeting held on 12th January 2004 at 11.00am
Board Room 1,
New Royal Infirmary
Edinburgh

Present: **Prof C Ludlam (Chair), Dr C Tait, Professor I Walker, Dr H Watson, Dr R Kerr, Dr J Anderson, Dr E Chalmers, Dr A Thomas, Dr W Murray**

Apologies: Prof G D O Lowe; Dr L Horn; Dr P Cachia

Action

1. Minutes of Meeting held 3rd November 2003 were accepted.
It was noted that the Mannucci paper from JTH circulated with the Agenda had been the incorrect article. The intended article had been the one discussing an historical perspective on HIV and Hepatitis C in haemophilia. CAL indicated that he had given a copy to Dr A Keel and all Haemophilia Directors were encouraged to read the article.

2. **Matters Arising**

Recombinant FVIIa use out with haemophilia patients
It was clear that use of rFVIIa out with haemophilia was continuing at most Centres, albeit at a low frequency. Audit Forms were being collected but it was agreed these would be collated locally for future discussion. CT was asked to recirculate electronically copies of the protocol and 1 page audit proforma. **CT**

UKHCDO Genetics Guideline
CAL noted that a final pdf file had been completed for this guideline and should soon be circulated by Dr Hay. It was suggested that this guideline be a major topic for a future Haemophilia Directors Meeting.

Feedback from meeting with Haemophilia Patients and Haemophilia Society on 3rd November 2003
It was noted that a date for the next annual meeting was still to be arranged and further discussion is required on the topic of a spring/summer meeting. It was uncertain whether this should have a primarily educational theme or whether it would be more political (e.g. Scottish Haemophilia Alliance). CT was asked to write to Mr Dolan regarding the patients' expectations from such meetings and also to consider possible dates. It was agreed that a weekend slot was not suitable for medical staff however an afternoon or early evening meeting in a central position (e.g. Dundee or Perth) should be manageable. **CT**

3. **Home Delivery Pilot**

AT and LC presented their findings from the questionnaire audit of parents of haemophilia children. In general there was a very positive view on home delivery. It was agreed to discuss this further with NSD and SHS with a view to initiating a pilot in this patient group in the near future. It was noted that some data was missing and therefore Dr W Murray will forward some additional information to LC. **WM**

It was agreed that a fairly detailed specification would be required with a delivery company both with regard to delivery arrangements, patient obligations and documentation. It was noted that several English Haemophilia Centres had recently

tendered for a delivery service and CT was asked to obtain copies of their specifications. **CT**

The potential volume of product for home delivery (circa 10 million units per year) could yield a significant cost saving. Some of this saving would ultimately fund the delivery service however it was important that some of the residual monies to be reinvested in the haemophilia service (e.g. providing extra nursing or genetic counselling support). It was also noted that the administration involved around home delivery may require more data manager resource. The home delivery item would be discussed further at the February meeting.

4. Hepatitis C

CAL reported that there was likely to be a Department of Health announcement within the next month or so regarding ex gratia payments for haemophilia patients with Hepatitis C. At present however specific details were not available.

2nd Scottish Meeting

CAL indicated that HW had reviewed the proposed topics for further study under the Hepatitis C banner. Although there were between eight and ten such topics it seemed sensible to focus on one or two and try to take them forward. HW indicated that many of the topics were not worthwhile while some of the topics should ideally be addressed at UKHCDO level. It was agreed to update data from each Centre regarding numbers diagnosed with Hepatitis C, numbers treated and their outcomes. HW will design a data collection template For discussion at the next meeting.

HW

5. vCJD

CAL updated the group. There were no further developments from the Incidents Panel. However the incident reported in December where there may have been a case of transmission of vCJD by red cell transfusion certainly raised the possibility that this condition could be transmissible through blood and blood products. It seemed likely that the Panel would shortly announce details of categories of patients who would require notification and be subject to special precautions should they require invasive procedures. . At present time it remains unclear how the notification process would work and who would provide counselling. For some categories of patients it was perceived that Public Health physicianswould undertake this, however it was agreed that for haemophilia patients this would be inappropriate. It was agreed that discussions would be required between Haemophilia Directors and SCIEH.

Draft Patient Letter

Some time was spent reviewing the letter prepared by CAL. Various suggestions were made and the letter shortened. Further refinements were subsequently made during the CFWP Meeting. CAL will circulate letter for final comments with a view to all Centres posting out the letter (1st Class Post) on Monday 2nd February 2004 to all haemophilia-centre-registered patients who have received plasma derived coagulation factor concentrates. It was noted that Northern Ireland may delay such action as they are currently implementing recombinant factor for all policy. IDW also raised the issue as to how we should tackle non-haemophilia patients who have received implicated products (e.g. DeFIX and I.V. Immunoglobulin). It was agreed this would require further discussion at CFWP level.

ALL

6. FVIII and FIX usage and projections

It was reported that usage in the West was slightly over target while in the East FIX use was significantly under target while FVIII use was just slightly below target. Overall for the whole of Scotland the projections were probably roughly on target and therefore it was agreed that 2004/2005 projections should be based on 2003/2004 usage + 10%.

3rd Generation Baxter recombinant FVIII product (Advate) is expected to be licensed early in 2004. Discussion followed as to how patients may be prioritised for receiving this product. Although there was limited data on the use of the product in previously untreated patients, it did seem likely that this would be a priority group. There would also be special cases (e.g. Jehovah's Witness patients) who would merit treatment with this product but thereafter the logical approach may be to give this product to patients who are already in the lowest risk category for transfusion transmitted infections. This topic would require further discussion with NSD and SHS and would be influenced by the potential differential cost between Advate and Recombinate.

7. Haemophilia Databases

It was noted that the East Coast system was rolling out well. CT inquired as to how critical it would be for GRI to hold specific data on usage of individual patients from RHSC. The recently circulated NSD contract had implied this requirement. However it was agreed that such detail would not need to be held at GRI.

CAL reported that some haemophilia staff had raised concerns regarding the UKHCDO database particularly in light of recent GMC guidance on patient confidentiality. CAL offered to raise this specific issue with Rod Muir at ISD. **CAL**

8. AOCB

CT enquired as to the status of the report being produced by a student (under CAL guidance) on use of FVIII and FIX in haemophilia patients over the last 20+ years. CAL indicated the report was now complete and he would endeavour to circulate a summary once the student's project had been marked. This information should be discussed further at a future Haemophilia Directors Meeting.

SNBTS four factor DeFIX study protocol.
It was noted that a study for the above product was due for discussion at CFWP. Once modified, this protocol should be discussed further at the next Haemophilia Directors Meeting in February.

Date of Next Meeting

Wednesday 18th February 2004 at 1.30 pm in the Seminar Room, Haemophilia Centre, Glasgow Royal Infirmary.