Scotland & Northern Ireland Haemophilia Directors Group

Minutes of meeting held on 18th February 2004 at 1.30pm
Seminar Room, Haemophilia Unit
Royal Infirmary, Glasgow

Present: Prof C Ludlam (Chair), Dr C Tait, Dr R Kerr, Dr H Watson, Dr L Horn , Dr E Chalmers

Apologies: Prof GDO Lowe, Prof I D Walker, Dr P Cachia, Dr A Thomas, Dr W Murray

Action

1. The corrected minutes of meeting of 12th January were agreed without amendment.

2. **Matters Arising**

Report on coagulation factor use in Scotland over 20 years
CAL indicated that he had still to hear if the Edinburgh student's thesis/report had been passed. Once this was confirmed he would forward a summary report to the group. **CAL**

Recombinant FVIIa use out with haemophilia patients
National audit is ongoing.

Future meetings with Scottish Haemophilia Patient Representatives
CT indicated that he had written to Mr P Dolan asking for possible dates for the autumn meeting and also suggestions of a possible remit for a summer meeting. It was noted that Mr Dolan represented the Scottish Haemophilia Forum but that the Scottish branch of the Haemophilia Society should also be included in this meeting. CT was asked to identify the Scottish Representatives and write to them as well. **CT**

Letter to ISD regarding UKHCDO Database
CAL tabled a detailed letter which he proposed we send to Dr Rod Muir at ISD, requesting confirmation that the UKHCDO database and our local Haemophilia Centre databases are acceptable within the Scottish interpretation of data protection and patient confidentiality laws. The letter would include a variety of enclosures, including UKHCDO patient information leaflet on the database, a recent letter from the Information Commissioner's office to UKHCDO indicating that it believed the UKHCDO database did comply with current legislation, and recent copies of GMC guidance and Medical Defence Union documentation on patient confidentiality. The letter would also include comments previously received from Dr Aileen Keel regarding a Scottish Executive view on the current National Haemophilia Register. **CAL**

Final copy of letter to Rod Muir is attached for your information.

3. **Home Delivery Pilot**

EC indicated that she had now received details of patient numbers and volume of product from all Scottish Centres. She had also reviewed the specifications kindly provided from Sheffield Children's Hospital and Bart's & the London NHS Trust (and Leicester). She would also make enquiries at Liverpool (Children's) and Royal Free Hospital who are also believed to have already agreed home delivery contracts. It was thought unlikely that a pilot could be organised which avoided

placing an advert in the European Journal although further discussions were required with Archie McEwan at Scottish Healthcare Supplies.

EC will also organise a meeting with Archie McEwan at Scottish Healthcare Supplies to establish how this process can be taken forward. EC & AT will modify the English specification template to draft a Scottish specification and circulate to Haemophilia Directors for comment.

EC

4. Hepatitis C

HW tabled a draft proposal for a project to review Hepatitis C management and success rate within haemophilia patients in Scotland. He thought this would not yield particularly novel information and therefore is unlikely to lead to a publication in a high quality journal. It would also involve a considerable amount of work for Glasgow and Edinburgh Centres who had the largest number of patients with Hepatitis C. The proposal was discussed at some length and some suggestions tabled. Further comments should be sent directly to HW who will refine the proposal for our next meeting.

HW, ALL

5. vCJD

CAL and CT reported on discussions around this topic at the recent UKHCDO Advisory Committee Meeting. Professor Frank Hill had attended a meeting with at CDC where he had stressed the impracticalities of calculating a vCJD risk score for each haemophilia patient – particularly since further batches of "implicated" coagulation factor concentrate are likely to be identified in the future. Within the Advisory Committee there had been a strong view that perhaps all haemophilia patients who had received plasma-derived products should be regarded as a potentially "high risk" group. The down side of such a strategy is that our patients may meet resistance when they come to require future surgical and other invasive procedures.

Professor Frank Hill indicated that the CDC plan to set up a sub-group to review plasma incidents (relating to vCJD). There was also discussion on the UKHCDO surveillance system. Dr C Miller who was heavily involved with this was now on maternity leave and the surveillance system appeared to be on hold. There was however a desire within some quarters of UKHCDO to record exposure information to implicated batches on the UKHCDO database. It was however clarified, among Scottish Haemophilia Directors, that no specific details had been sent to UKHCDO regarding patients exposed during the Scottish incident (1987-1989).

Given the above developments it was agreed that we would not forward a letter to our patients giving them an update on vCJD at present. The next UKHCDO Advisory Committee meeting was scheduled for May with a S&NIHCDG meeting shortly thereafter. The need to send an update letter on vCJD to our patients could be reviewed at that time. It was however noted that the Haemophilia Society had a very useful article on vCJD on their website and patients requesting further information could be directed to this.

6. FVIII and FIX

It was noted that the Baxter 3rd generation product (Advate) would be licensed within the next month or so. It appeared however that the licence might not initially include children under the age of 6 years - although like BeneFIX it might still be used in such patients. However, unlike BeneFIX, there were alternative licensed recombinant FVIII products available for this age group. At the present

time there was no clear view on a Scottish policy as to how Advate may be introduced.

7. Haemophilia Databases

CAL had written to Dr Charlie Hay requesting data on patients treated in Scotland with plasma products. There had been further discussion on this topic at the recent UKHCDO Advisory Committee meeting. CAL will check if information previously obtained from UKHCDO is still stored locally. If it is not, then Scottish Centres could write to Professor Frank Hill asking for copies of their patients' treatment at their centre. This information would be a useful resource if there is a future requirement to search for patients treated with particular products during particular time windows. **CAL**

CAL indicated that an electronic form of the information could also form a historical Scottish Haemophilia database, although it was unclear how this could be linked with our current database. CAL and CT will discuss with their respective Data Managers as to how the historical data from the UKHCDO database might be received and integrated with existing databases. **CAL,CT**

8. AOCB

Sequence and location of S&NIHCDG meetings

CT reminded the Group that the previously proposed sequence of meetings was as follows:

Wednesday	Edinburgh
Friday	Glasgow
Monday	Edinburgh
Tuesday	Glasgow

9. Date of next meeting

Wednesday, 5th May 2004 at 2pm in the Royal Infirmary, Edinburgh
[It seems likely this meeting may be followed by a meeting of CFWP]

Enc. Hep C study draft proposal (item 4)
Copy of letter to Rod Muir (item 2)