Scotland & Northern Ireland Haemophilia Directors Group

Minutes of meeting held on 26th August 2004 at 10.30am
Seminar Room
Haemophilia & Thrombosis Centre
Glasgow Royal Infirmary

Present: **Prof G Lowe, Prof C Ludlam, Dr C Tait, Dr W Murray, Dr E Chalmers, Dr A Thomas, Dr O McNulty**
Apologies: Prof I Walker, Dr S Dempsey, Dr R Kerr

Professor Lowe opened the meeting by welcoming Orla McNulty from the Belfast Haemophilia Centre to our meeting.

Action

1. Minutes of meeting of 10th June were approved

2. **vCJD Issues**

CAL and GL updated the group on the current UKHCDO position on vCJD and discussions they had had with Frank Hill and the vCJD Incidents Panel.

It is understood that Haemophilia Doctors will receive a letter from UKHCDO (in early September) updating them on notification and management strategies for Haemophilia patients. It is then expected that we should send a letter to all our bleeding disorder patients informing them of the situation and the fact that any patient who has received UK sourced pooled plasma product between 1st January 1980 and 31st December 2003 should fall under the umbrella category and be managed (from a public health point of view) as 'at risk' of onward transmission of vCJD. It is understood the communication from UKHCDO will include draft patient letter, draft letter to patient's GP and clinical information for patients and medical staff.

Specific public health measures will be required for any surgery involving CNS, eye or lymphoid tissue (e.g. tonsillectomy or splenectomy). However most other major surgery may be unaffected. The situation with endoscopy remains unclear although it is assumed dental work will need no additional precautions. Basically all invasive procedures should follow the ACPD guidelines available on the web site. These will obviously be updated as time goes by.

It is understood that recipients of red cells, platelets, cryoprecipitate or FFP would not count as having been exposed to UK sourced pooled plasma products. Exposure to IV Immunoglobulin is medium risk and the classification of individual patients who have been exposed to IV Immunoglobulin during the above time frame will need to be made on a case-by-case basis.

There was considerable discussion as to which of our patients should be sent the patient information letter (e.g. ? exclude mild von willebrand's disease,

mild carriers of haemophilia, patients with acquired haemophilia, patients who have never received any pooled plasma product). No decision was agreed, however if the patient letter is to be posted on 20th September, further discussion on this topic will be required. **ALL**

Haemophilia Directors were conscious of some patients who, following our previous correspondence, had indicated that they did not wish any further notification about vCJD. However given that this notification is a public health issue then such patients will have to be notified (particularly if they fall under the umbrella category) that they will require extra precautions for specific invasive surgical procedures. Patients will also have to be informed that details of their exposure to pooled plasma products in general and specific implicated batches in particular will be recorded in their medical records. Furthermore, such information will also be recorded centrally (UKHCDO) as part of a surveillance programme.

Review of the draft patient letter resulted in some suggestions being forwarded to CAL. In particular it was felt that the Patient Reply Sheet would require modification. CAL will discuss potential modifications with Nicky Connor at the HPA as well as members of Scottish Executive, SCIEH and Professor Frank Hill. He was however keen that the patient letter for Scotland and England were fairly similar. **CAL**

Regarding identification of patients who have received pooled plasma products at our Centres, it was perceived that the easiest approach was to review our UKHCDO Returns dating back to 1980. If such a review identifies patients no longer at our Centre then it would be our duty to forward this information on prior treatment to the Centre now responsible for that individual patient. **ALL**

CT asked if surgeons and dentists would also be notified about this new policy. CAL was uncertain but it was felt that we should have discussions with the local Director of Infection Control who could then in turn inform the relevant specialist.

It was agreed that the above vCJD issues would be discussed further at our next meeting on 6th September.

3. Matters Arising

Annual Meeting with Scottish Haemophilia Patients Group and Nurses
This meeting has now been arranged for Tuesday 28th September in Glasgow. The precise start time has still to be finalised although it is anticipated Haemophilia Directors may meet for an hour or so before the meeting with the patients. It is likely that the agenda will be dominated by vCJD and hepatitis C issues.

~~Role out of~~ Advate in Scotland
Various Centres are now issuing this product while at GRI in Glasgow old stock of Recombinate is still being used up before Advate is issued. With regard to use in young PUPs AT and EC agreed that, at present, they would recommend the use of Helixate or Kogenate in such patients until further information on use of Advate in PUPs under 6 years of age is available. EC suggested that we review our use of Refacto before the next contract renewal.

Summary Report on Coagulation Factor use in Scotland (1989-2003)
The Group are requested to forward any comments or questions to CAL who can discuss these with the student who prepared the report when he returns to Edinburgh for graduation. **ALL**

Northern Ireland representation
It was noted that Orla McNulty (+/- Dr F Jones, Dr S Dempsey) will represent haemophilia interests from Northern Ireland. GL informed the Group that we are soon due to undertake our Scotland & Northern Ireland Audit of Haemophilia Centres. However it was agreed that this should be deferred until early 2005.

Four Factor DeFIX Trial
It is understood that the study is currently with MHRA.

Audit data for non haemophilia use of Novo seven
CT indicated that he had received some audit report forms from Inverness and Aberdeen but as yet none from Edinburgh. It is understood that CAL will forward around 20 returns from Edinburgh while AT can forward 1 from Edinburgh Children's Hospital and EC will forward some from Yorkhill. OMcN also offered to forward data from Northern Ireland. CT is due to make a presentation on this audit data towards the end of September at the Scottish Haematology Society meeting in Carnoustie, so he requests all returns to be sent to him by 6th September.

4. Hepatitis C

This topic was deferred to the next meeting.

5. Database Issues

GL indicated he had received letters from Glasgow Caldicott Guardians indicating that they were happy with the use of the database as described but uncertain about it's use in research. Specifically such research uses may require individual patient consent.
He reiterated our proposal to produce a 5-year audit plan.

6. Home Delivery Pilot

EC and AT tabled responses from SHS from 3 of the commercial suppliers. There remained uncertainty as to where funding for any pilot exercise would come from and at present AT and EC felt that we could not proceed any further without some sort of resource commitment from NSD or SHS. It was agreed this matter should be discussed further at our Autumn meeting with NSD and SHS.

Date of Next Meeting

The next meeting will be held on **Monday, 6th September** at **2pm** in the

Postgraduate Centre
Royal Infirmary Edinburgh
Craigmillar Room, Room 8125.

The Postgraduate Centre is off the main hospital concourse at the north end. (Chancellor's Building end).

Lunch will be available from 1.30pm