Scotland & Northern Ireland Haemophilia Directors Group

Minutes of meeting held on 6th September 2004 at 2pm
Craigmillar Room, Room 8125
Postgraduate Centre
Royal Infirmary Edinburgh

Present: **Prof C Ludlam, Prof G Lowe, Prof I D Walker, Dr R Kerr, Dr H Watson, Dr A Thomas, Dr F Jones, Dr O McNulty, Dr C Tait, Dr W Murray.**

Apologies: **Dr L Horn**

Action

CAL opened the meeting by announcing the appointment of Philip Cachia to the post of Post Graduate Dean in Tayside. He acknowledged the significant input made by Philip Cachia to the Group over many years. It was agreed that CT should write to PC indicating the thanks of the group and wishing him well in his new post. **CT**

1. Minutes of the meeting of 26th August were accepted after minor amendments to Item 3.2 relating to use of Advate in Scotland to indicate that PUPs should be treated with Helixate-Nexgen and Kogenate Bayer.

2. **vCJD Issues**

There was further discussion around the forthcoming vCJD announcement and the various letters which could be sent to patients and their General Practitioners. The following were agreed:

- Haemophilia Centres should be writing to all their currently registered patients with congenital bleeding disorders and antithrombin deficiency (this would exclude patients with FXII deficiency or platelet disorders).
- Patients for whom there was a record of treatment with UK sourced pooled plasma product 1980-2001 would be sent:
  - Scottish covering letter from haemophilia Centres indicating they had received pooled plasma product.
  - Copy of HPA letter to patients (p1-6).
  - Scottish Patient Reply Sheet (modified page 7 of HPA letter to patients)
  - Patient information document from HPA.
  - Stamped addressed envelop
- Patients for whom there was no record of being treated with UK sourced pooled plasma product 1980 – 2001 would be sent:
  - Scottish covering letter indicating there was no record of treatment with pooled plasma product.
  - Copy of HPA letter to patients (p1-6)
  - Scottish Patient Reply Sheet (modified page 7 of HPA letter to patients)
  - Patient information document from HPA.
  - Stamped addressed envelop.

- General Practitioners of patients who have been treated with pooled plasma product 1980-2001 would be sent:
  - Copy of Scottish Centres covering letter to patient.
  - Standard HPA GP letter, modified for exposed Scottish patients
  - Copy of HPA letter to patient.
  - Copy of Patient information document from HPA
  - Copy of HPA vCJD clinical information document for doctors.
- General Practitioners of patients for whom there is no record of treatment with UK sourced pooled plasma product 1980 – 2001 would be sent:
  - Scottish GP letter for Non Exposed patients
  - Copy of Scottish Centres covering letter to patient
  - Copy of HPA letter to patient.
  - Copy of HPA Patient Information document

It was also agreed that:

- Patient letters should be posted in the Hospital mail system at 9am on Tuesday 21st September, 1st class mail. This is 1 day later than scheduled because 20th September is a holiday in Edinburgh.
- The patient reply sheet will be modified as discussed at the Directors meeting. All letters to patients will be accompanied by a stamped addressed envelope for patients to reply to the Haemophilia Centre. **ALL**
- Copies of all correspondence with patients will be filed in the Hospital Case Record along with a copy of the standard GP letter if the patient had received treatment 1980 – 2001. The case record will also contain an HPA Table recording whether patient had received any implicated batches. **CAL,GL, CT**
- Where a Centre identifies a patient who has received UK sourced pooled plasma products 1980 – 2001 but is no longer treated at that Centre then efforts should be made to pass this information on to the Centre where the patient is now registered. If this were a Scottish or Northern Ireland Haemophilia Centre then such information could be sent in a simple email over the NHS Net.

CAL/GL/CT will prepare updated versions of the Scottish covering letter and the patient reply sheet and circulate these to Haemophilia Centres.

CAL intimated that the information we were about to receive from UKHCDO was only a recommendation and each Haemophilia Centre did have the option of handling the situation as they wished. However it was hoped that all Scottish Haemophilia Centres would follow the above plan. FJ and OMcN intimated that they would hope to follow the same system as in Scotland although some of the paperwork would need modified.

Several Centres indicated that the whole process of searching records and issuing letters to patients along with multiple copying of information sheets would prove a significant resource issue. This is particularly true in Glasgow and Dundee however Royal Infirmary Edinburgh have already been promised whatever resources were required. CAL indicated that if any Centre felt there was going to be great difficulty in achieving the deadline of 21st September then they should intimate this to GL or CAL in the near

future who could raise the issue with Dr Aileen Keel.

If individual Centres have incomplete Oxford Returns then they were at liberty to request information from the National Haemophilia Register, although it was anticipated that the Register could be inundated with such requests.

It was agreed that if patients ask if they have been exposed to implicated batches then they in turn have to be asked whether they mean batches where the factor concentrate included a donation from a donor destined to develop CJD or simply where the albumin exipient for that factor concentrate was prepared from donations including one from a donor who subsequently developed vCJD.

3. Matters Arising

Agenda for Annual Meeting with Scottish Haemophilia Patients and Nurses 28th September 2004

CT indicated that those attending the meeting would include members of the Scottish Haemophilia Forum who represented the Haemophilia Society in Scotland. It was also anticipated that the new Chief Executive of the Haemophilia Society would attend, as would Haemophilia Nurses in Scotland. There was discussion on how other patients could be represented and whether in fact the whole meeting could be made open to any Haemophilia patients. It was agreed that it would be impossible to organise this for this year's meeting however discussions on this topic should be included in the meeting on the 28th September. Other agenda items should include:

- Minutes of previous meeting
- vCJD
- Hepatitis C/Skipton Fund issues
- Recombinant coagulation factor treatment
- Home delivery of treatment

CT will write to Haemophilia Nurses asking if they wish any additional items on the agenda. **CT**

Four Factor DeFIX Trial

HW reported that MHRA have indicated that a pilot study is required with 10 patients in each arm. CT will write to SNBTS enquiring as to when the pilot study will roll forward. **CT**

Audit data for non-haemophilia use of Novo Seven

CT received further forms from Edinburgh Children's Hospital and Northern Ireland and it is understood another 5-8 forms will be sent from Royal Infirmary Edinburgh in the near future. **CAL**

4. Hepatitis C

Update on proposed audit exercise

HW outlined the key fields of the simplified audit tool (document attached). All agreed that this should be easily manageable given time. Data could be collected in each Centre on an excel spread sheet and forwarded electronically to HW for collation and analysis . A completion date will be

agreed at the next meeting. Northern Ireland agreed to consider participation and CAL offered to forward a minute from the hepatitis meeting which was held in Edinburgh last year. **CAL**

Ex-gratia payments
These appear to be progressing smoothly. Apparently Part 2 forms are not yet available.

5. Database Issues

CAL and GL reported on their responses from Caldicott Guardians regarding the use of National Haemophilia Database and Scottish Haemophilia Database. As yet Aberdeen and Dundee had not had any response. There remain concerns both among Caldicott Guardians and among the Directors Group of the potential use of database information for research without properly informing patients. AT reminded the Group that the information sheet did specify that research involving additional information from specific patients would require their consent although anonymous data may be used without their further consent. CAL has written to Charlie Hay asking for clarification as to exactly what fields are included in National Haemophilia Database. CT also reported that he had a response from Charlie Hay indicating that the Database Group would review the patient information sheet in light of the anomaly reported by Nancy Brodie.

CAL reminded the Group that Dr Charles Swainson, Medical Director, RIE has suggested that each Centre have a protocol/SOP clarifying which individuals can access the database and how they should do this. **ALL**

Audit Haemophilia Scotland
CAL reminded the Group of our proposal to prepare a list of audit exercises undertaken over the last 10 years as a preamble to a document outlining our future 5-year plan. This would then hopefully form the basis of a bid to the Scottish Executive for appropriate funding. Each Centre was asked to forward brief details to CT about any audits they have undertaken over the last 10 years (e.g. as reported in their CCC or Scottish Haemophilia Centre Audit Reports). Further discussion will be required on proposed future audit projects. **ALL**

CAL is now liasing with Dr Eisa Hamid, MSc student, about the 1989-2003 audit and hopefully its publication

6. AOCB **ALL**

Haemophilia representation on bi-collegiate physicians quality of care committee
AT indicated that she was having to demit her office and it was agreed that Ron Kerr would take on this role meantime. AT will inform the quality of care committee about this change.

Supply of Antihistamine to patients **AT**
S&NIH Nurses Group have written to the Directors Group asking for guidance on their ability to prescribe antihistamines and in particular whether there would be benefit in a written guideline to advise nurses on management of patients with reactions to FVIII or FIX concentrate. The Group considered several situations where use of antihistamines required

clarification:

Prescription/Administration of antihistamine to patients by haemophilia nurses

It was understood this would probably require nurses to have a PGD for specific use of antihistamine (particularly intravenous antihistamine) in patients with previous reactions to coagulation factor concentrate. If any Centre had or was developing such a PGD then it was agreed that the paperwork should be circulated to all Centres for their use.

Treatment of patients with acute reaction

This was thought to be a separate situation and management should follow the National Anaphylaxis Guideline.

Supply of antihistamine to patients for use along with home treatment

This was felt to be an individual physician decision. Patients could be advised to take oral antihistamines sometime before treatment or intravenous antihistamine along with or shortly after their treatment Presumably however, a prescription would be required for the antihistamine from pharmacy.

This item could be discussed further at a future meeting.

Charges for Genetics Testing

Aberdeen and Glasgow reported that they had received several invoices for payment to Royal Infirmary Edinburgh for haemophilia genetic investigations. These invoices had been unexpected. CAL reported that these had been issued because the RIE, as yet, had not received funding from NSD despite relatively strong assurances that this would be forthcoming in the current year. This now seemed unlikely and therefore the hospital was issuing invoices. CAL suggested that the recipient hospital considered forwarding these to NSD indicating that they had been under the impression that the Genetics Service would be nationally funded.

New Consultant Contract

GL asked if all consultants had their haemophilia duties, including on-call, included in their new contract/job plan. Directors from Edinburgh, Dundee and Aberdeen as well as Prof Walker and Dr Tait from Glasgow confirmed this to be the case. Consultants in Northern Ireland were still negotiating regarding their new contracts.

Date of Next Meeting

Tuesday 28th September 2004
Glasgow Royal Infirmary

12 noon Meeting of Haemophilia Directors
Seminar Room, Haemophilia & Thrombosis Centre
2 pm Meeting with Haemophilia patients and nurses
Board Room