

# Scotland & Northern Ireland Haemophilia Directors Group

## Minutes of meeting held on 14<sup>TH</sup> June 2002 at 1pm SNBTS (PFC), Ellen's Glen Road, Edinburgh

Present: Professor C A Ludlam (Chair), Dr C Tait, Dr I D Walker, Dr A J Thomas, Dr J Anderson, Professor G D O Lowe, Dr P Cachia, Dr H Watson and Dr L Horn.  
Apologies: None received

1. Minutes of the meeting of 29<sup>th</sup> April 2002 were approved with the following amendments: Action
  - I. Previous meeting had actually been held on 28<sup>th</sup> January 2002 (not 8<sup>th</sup> June 2001).
  - II. Item 3. Para 3. "a draft response for Trust to be released in the event of publicity relating to this incident."
2. **Matters arising:**

GL identified an error in the minutes from December 17<sup>th</sup> meeting with the Haemophilia Society. Under Item 8 it had been stated that the Scottish Haemophilia Centre Audit had highlighted concerns from individuals attending the Inverness Centre. This was not in fact the case. Concerns had been raised by Mr P Dolan following conversations he had had with patients. PC agreed to amend minutes and circulate revised version. PC
3. **vCJD:**

The group reviewed their position with regards to patient notification of possible exposure episodes. Advice from the vCJD Incident Panel clearly stated that patients should not be contacted until the panel had advised on their individual risks. This required anonymous data on the numbers of vials received being forwarded to Philippa Edwards at the Incident Panel. CL indicated that he had forwarded data from Edinburgh area about 1 month ago but as yet had had no response. It is anticipated that advice will not be forthcoming until the Panel have re-run their risk assessment exercise. Data from Aberdeen and Glasgow should be forwarded to the incident panel in the near future. GL,CT  
HW

GL informed the group that he had finalised the draft press statement and circulated it confidentially to his Trust Medical Director. CL will forward copy of final press statement to the Haemophilia Directors so that they can give confidential copies to their individual Medical Directors. It was noted that as yet the Haemophilia Directors have not received a copy of the SNBTS press statement. CL  
HW,  
PC,CL,  
EC

JA highlighted clinical problems which were arising because of previous patient exposure. Despite the request for urgent advice from the CJD Panel none had been forthcoming.

It was agreed that no letters should be sent to patients at present, pending response from the vCJD Panel. Final versions of Trust press statement should be circulated to individual Trust's Medical Directors (confidentially). Should a copy of an SNBTS statement become available it too could be circulated confidentially to Trust Medical Directors. All
4. **Audit**

GL reported that all UKCCC Audit Reports were now submitted and he would be preparing a final report in the near future. This would be forwarded to Dr Frank Hill. Scottish Haemophilia Centre Audit Reports would all be copied to GL by the end of June and a final report would be prepared. GL

It was agreed that the much-postponed questionnaire audit of patient's perceptions of recombinant factor therapy could be undertaken over the summer. GL would circulate the final version of the questionnaire to Haemophilia Directors who would then post out to all current users/parents of recombinant FVIII and FIX products. The questionnaire should be circulated along with a local covering letter. GL  
All

5. **FVIII and FIX supplies**

Apart from continuing problems with small vial sizes of Kogenate there were no new problems. AT indicated that some patients had been switched from thrice weekly to twice weekly prophylaxis because of the lack of small vials, and that there would be considerable patient/parent resistance to revert to a thrice weekly prophylaxis regime.

6. **UKHCDO Database**

There remains some uncertainty to data protection issues around the proposed UKHCDO database. Advice from Department of Health (London) and a letter from Aileen Keel would seem to suggest that implicit patient consent would not be required. However there was concern that Scottish Law differed from English Law and that certainly in Scotland patients would have to be given the opportunity to opt out of the database. Because of this the proposed UKHCDO information sheet would need some minor alterations to be suitable for Scottish Haemophilia patients. GL suggested sending a copy of the information sheet to Aileen Keel with proposed Scottish amendments.

GL,CL

It was agreed that GL would circulate information on a view from CSAG.

CL will write to Dr C Hay suggesting changes required on the information sheet.

GL

JA indicated that she had sent copies of the information sheet to the Irish Parliament but as yet had received no reply.

CL

Scottish Haemophilia Directors were still awaiting notification of a date when they could view the proposed UKHCDO Database and have a question and answer session with Mr Rob Hollingsworth. CL to circulate proposed date when details available.

CL

PC enquired if patients also should be informed of local databases in operation at Edinburgh Royal Infirmary and Glasgow Royal Infirmary? Since these databases represented part of a managed clinical network it was thought they were probably justified in law.

7. **National Haemophilia Specification**

GL indicated that he had sent a copy to Mr Harry Burns as a member of the West of Scotland Health Boards Consortium. It was suggested that copies also be sent to a relevant member of North East and South East Scotland Health Board Consortiums. NSD have supplied names of potential contacts which are as follows:

HW,  
PC, CL

Mr Malcolm Finlayson,  
Secretary,  
South East and Tayside Regional Planning Group (SEAT)  
C/o Tayside Health Board  
P.O. Box 75,  
Luna Place  
Dundee Technology Park  
Dundee DD2 1TP.

Mr Neil Campbell  
Chief Executive  
North of Scotland Regional Planning Group  
Grampian NHS Board  
Summerfield House  
2 Eday Road  
Aberdeen AB15 6RE

8. **PCC for Warfarin Reversal**

It was noted, with some dismay, that NSD had withdrawn funding for commercial PCCs for this indication. It was agreed that it was now up to local Hospitals to look at their policies and purchase and issue commercial PCC if they felt it appropriate.

All

9. **Haemophilia Genetics Service**

CL reviewed the progress with the new UKHCDO Working Party and the establishment of a network of labs within the UK providing Haemophilia Genetic Services. It seemed likely that the main referral lab in Scotland would be Edinburgh Royal Infirmary with the common

Inversion 1 and Inversion 22 mutations also being assessed in the Duncan Guthrie Institute at Yorkhill, Glasgow. GL and CT indicated that they had still not had any communication from Professor Mike Connor regarding the new proposals.

GL asked if there would be any charge levied for samples from the West of Scotland analysed at Edinburgh Royal Infirmary. CL indicated that there would need to be an assessment of workload in the first instance and this may be followed by a request for central funding.

CT and GL will clarify the situation in the West of Scotland and liaise with CL.

CT, GL

10. **Platelet Transfusion Requirements for Patients with Inherited Platelet Disorders**  
There was general agreement that HLA-matched Platelets were probably not necessary for patients with inherited platelet disorders. LH indicated that this sort of policy was in place in Trent however SNBTS in the East of Scotland had not been keen to provide such a service. Even in those patients with Bernard Soulier or Glanzmanns Disease the benefit of HLA-matched platelets was unclear. The main risks were in fact development of GPIIb/IIIa antibodies in Glanzmanns patients, rather than HLA antibodies. Obviously should patients develop a degree of platelet refractoriness associated with HLA antibodies then HLA-matched platelets would be indicated.

11. **AOCB**  
Nil

12. **Date of Next Meeting**  
Monday 23<sup>rd</sup> September, 2pm, Glasgow Royal Infirmary (Time to be confirmed). CL will investigate the possibility of combining this meeting with a nurses/patients/NSD meeting.

CL

NB 28 August 2018