HAEMOPHILIA WORKING PARTY

North Thames (East & West) Regional Haemophilia Centre Directors

Minutes of the meeting held at the Haemophilia Centre, Royal Free Hospital,
Thusday 16th February 1995, at 2.15 p.m .

Present:

Dr C.A. Lee (Chairman)
Dr M.E. Wood (Secretary)
Dr M.A. Laffin
Dr E. Miller
Dr B.T. Colvin
Dr D. Keeling
Dr J.E. Pasi
Dr S. Allard
S/N M. Cox
S/N J. Smith
Sister P.Lilley
Sister D. Cohn-Brown
Sister C. Woosey
Mr A. McCraw

Apologies:

Dr O. Eden
Dr J. Harrison
Dr M. Mills
Dr N. Simpson

Minutes of the last meeting, Royal Free Hospital, 3rd January 1994, were accepted without amendment.

1/95 Matters arising:
1/94: Regional Haemophilia Domiciliary Nursing Sisters
It was confirmed that the funding for these posts was now secure, being held by the Royal Hospitals & Royal Free Hospital Trusts.

5/94: High Purity FIX Concentrate
The BPL product was now marketed, under the name Replinine.

10/94: Prophylaxis
A protocol for the management of children had been circulated and was being used as far as possible by all those treating children with Haemophilia.

2/95 Hepatitis C Litigation
Dr Colvin reported that this was ongoing. So far there is a small number of cases and it is felt that few of these are likely to succeed since there is thought to be little likelihood of evidence of "negligence" in the majority of cases.
There are at present two firms of solicitors acting for the Plaintiffs, their respective approaches appear to be rather different. Although individual Hospital Trust's would need to involve their own solicitors, the firm of Wilkinson Maughan in Newcastle had been proposed as "co-ordinating" solicitors for the defence.

3/95 Involvement of Haemophilia Centre Directors Organisation with NBA
The National Blood Authority has a Regulatory body to advise it. Since the NBA is involved with BPL and hence with the production of Factor Concentrates, it seemed appropriate for there to be a representative from the HCDO on the Regulatory body. This suggestion was being taken up by the NBA.

4/95 HIV/AIDS funding and indications for High Purity Factor concentrates.
Some regions were apparently arguing again about the appropriateness of using AIDS money to fund the additional cost of High Purity Factor concentrates for HIV positive Haemophiliacs. There is no evidence to support any view other than that the use of High Purity concentrates delays the fall in the CD4 count in infected individuals
However since AIDS funding is to be withdrawn in the future, this arguement seemed likely to become academic.

5/95 Report from meeting with Dr A Rejman and Officials from The Department of Health.

This meeting had been held as a result of the suggestion by Dr Paula Bolton-Maggs at the 1994 HCDO meeting, that there was a need to address issues about the funding of Haemophilia Care at a Government level
Dr Colvin said that the opportunity had been taken to draw the attention of the Government to two issues in particular:

i) the likely increase in the use of Interferon in the treatment of Hepatitis C
ii) the likelihood that the use of Factor concentrates would increase; this had implications not only of cost but also with regard to the ability of producers to meet demand.

On both matters the Department said that there would not be any more funds made available; it was up to Providers to negotiate suitable contracts with their respective Purchasers. The department also recommended that Purchasers might form "consortia" in order to cushion themselves against the effect of 'expensive' patients such as those with inhibitors.
Dr Colvin said that although he felt that the course of the meeting had been entirely predictable it had still been a "useful exchange of views".

6/95 Recombinant Factor VIII
Dr Lee reported that she had written to Kenneth Calman expressing the opinion that experience had shown that plasma derived products could never be guaranteed to be completely safe and pointing out that the availability of a recombinant product could overcome doubts about such concentrates. A reply from "a senior DoH official" gave the view that Plasma derived concentrates were "no less safe" than the recombinant product and added that the current Recombinant product contained plasma derived albumin and " was not without side-effects".

During the discussion which followed it was felt by all those present that all children under the age of 10 years and any previously untreated patients (ie: those who were likely to have not been exposed to any known virus by factor concentrates) should be given the opportunity to have treatment with recombinant factor VIII. The UKHCDO was likely to be considering the issue in the near future.

It was understood that the Oxford centre had persuaded Purchasers to buy Recombinant FVIII for use in treating children; they had apparently argued that the cost might be accounted for by the "savings" made in no longer having to treat older patients who had died. Dr Colvin suggested that it might be possible to negotiate a price reduction if several Comprehensive Care Centres (eg: Oxford, Cambridge, RFH, Royal Hospitals) joined together to purchase in bulk.

7/95 Designation of Haemophilia Centres
i) All those centres which had previously been designated as Comprehensive Care Centres had been approved and would continue in this role. Three further centres that had applied for CCC staus had been selected for Audit; Nottingham and Cambridge had been approved, the third centre was yet to be visited. It was anticipated that the Haemophilia Society would be issuing a new booklet detailing all centres. Dr Colvin commented that it was clear that there were still areas of the country where there was poor access to a Haemophilia CCC.

ii) There was little enthusiasm for a National Audit of non-CCC Haemophilia centres. One other centre was to be visited in order to provide support for the conntinuation of the level of service provided although they did not meet criteria for a CCC.

iii) Discussion of the value of a regional audit of non-CCC units followed. It was generally agreed that it would be helpful to such units to develop a set of Standards or Guidelines against which the level of service that was provided could be audited. Dr Wood agreed to produce a draft, based on both the protocol which Mark Winter had drawn up (which it was felt was rather large and unwieldy for smaller centres) and HSG 93/30. Dr Colvin and Dr Lee agreed to comment on this document when it was prepared; once accepted it could be used annually to audit the non-CCC units within the North Thames region.

8/95 Consent to Treatment
The idea of informed consent to the use of Factor concentrate treatment was gaining momentum. The issue of informed consent to Blood Transfusion was under discussion by the Royal College of Pathologists. Dr Pasi has been asked by the UKHCDO to produce a set of guidelines for counselling patients/parents of children about to commence treatment with plasma derived products.

9/95 Annual Returns & Data Collection

The new computer is now in use in Oxford. Future Data collection requirements are likely to change. It may become possible to access central records via a modem link eventually.

10/95 Working Party Reports

a) Acute Adverse Events

The current main area of concern related to Factor XI concentrate, in particular its thrombogenic potential. Revised guidelines have been issued Dr Lee expressed reservations about the use of Fresh Frozen Plasma and drew attention to experience in other countries where Tranexamic acid alone had been successfully used as cover in Heterozygous FXI deficiency. Dr Colvin commented that the situation was still under review and it was likely that further revised guidelines would be issued soon.

b) Chronic Liver Disease

Guidelines had recently been drawn up and were about to be circulated These were to be considered as the "State of the Art" but might not be entirely practicable in every case; in particular a liver biopsy was not essential but the guidelines contained advice on the management of this procedure for those who required them.
The cost of genotyping the virus was likely to be approx. £60/patient. This procedure is valuable in identifying those patients with subtypes 2 & 3 which appear to be very responsive to Interferon. Because of the possibility that a new subtype may appear during treatment, follow-up genotyping should be considered.

c) Genetics

A National Database for Haemophilia B has now been established. Professor Gianelli and colleagues were being asked if they would consider establishing a similar database for Haemophilia A. The working party is looking at the issues of carrier detection and of gene therapy.

d) Paediatrics

Guidelines on prophylaxis are already available. The working party was looking at the insertion of Portacaths and also at the variety of literature available for parents and children - it was planning to try to co-ordinate a 'common' approach to this.

e) von Willebrand's Disease

A document about diagnosis and management, including patient information sheets, had been produced and was shortly to circulated to all Consultant Haematologists.

f) HIV

Consensus treatment guidelines had been sent out. An MRC grant application to fund two nurses to gather information in order to improve the national database had been turned down. Alternative sources of funding were to be considered. A suggestion to look into the heterosexual spread of HIV within the Haemophilia population had met with little enthusiasm.

g) Inhibitors

Guidelines for management were in production. The national survey of the 4 years 1990-93 is expected to be published in the BJH later this year.

Dr Lee concluded this review of the Working Parties by saying that it was hoped to produce a definitive volume of the various guidelines soon.

Dates of future meetings:

1) 1995 UKHCDO 1-day business meeting is to be held in Manchester in October, arranged by Frank Hay.

2) April 1996 BSH meeting: Eric Preston is President and is planning a 1 day session devoted to Haemophilia

3) WFH: the next meeting will be in Dublin in June 1996; Ian Peake is Scientific Director.
Because of this meeting the next UKHCDO 2-day meeting will not be until 1997 and is to be held in Cardiff.
A 1-day business meeting is planned for autumn 1996 at the Royal Free.

4) The next meeting of the North Thames Working Party will be held in February 1996 - date to be confirmed.