OXFORDSHIRE HEALTH AUTHORITY

OXFORD HAEMOPHILIA CENTRE

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Copy to JPC + KM only

JPC - ? Agenda Item 6 - bottom pg 6?
- that's not accurate is it?

To: UK Haemophilia Centre Directors, plus invited observers

From: Miss R.J.D. Spooner

Date: 11th December 1989

The point further was should we REMOVE any time barrier?

Re: Twenty-First Meeting of UK Haemophilia Centre Directors, held in Oxford on 9th October 1989.

Enclosed are Draft Minutes of the above meeting. Could you let me have your comments on the draft by not later than 15th January 1990, please.

GRO-C

Miss R.J.D. Spooner
Research Assistant
Administrative Secretary
UK Haemophilia Centre
Directors' Organisation

OH 3447

DRAFT

Minutes of the Twenty-First Meeting of Haemophilia Centre Directors held on Monday 9th October 1989, at the John Radcliffe Hospital, Oxford

Present

Dr. C.R. Rizza (Chairman)

Dr. K.H. Adamson
Dr. S. Al-Ismail
Dr. A. Aronstam
Dr. D.H. Bevan
Prof. A.L. Bloom
Dr. P. Bolton-Maggs
Dr. S.J. Bowcock
Dr. M. Chisholm
Dr. K.G.A. Clark
Dr. B.T. Colvin
Dr. A. Copplestone
Dr. J. Craske
Dr. E.R. Craven
Dr. R.G. Dalton
Dr. H. Dodsworth
Dr. J.A. Easton
Dr. D.I.K. Evans
Dr. E.A. French
Dr. B. Gibson
Dr. D.S. Gillett
Dr. Green-
Dr. I.M. Hann
Miss C. Harrington
Dr. J.P.L.A. Hayes
Dr. P. Jones
Dr. M.W. Kenny
Dr.P.B.A. Kernoff
Dr. H.E.T. Korn
Dr. R.S. Lane
Dr. C. Lee
Dr. R. Lee
Dr. J. Leslie
Dr. G.D.O. Lowe
Dr. C.A. Ludlam
Dr. S.J. Machin
Dr. P.J.F. McHugh
Dr. A.L. Miller
Dr. E. Miller
Mr. K.E. Milne
Dr. D. Mitchell
Dr. V.E. Mitchell
Dr. D.A. Montgomery
Dr. D.G. Oscier
Dr. L.A. Parapia
Dr. D.R. Pragnell
Prof. F.E. Preston
Dr. A. Rejman
Dr. C.L. Rist
Dr. G. Savidge
Dr. G.L. Scott
Dr. M.J. Seaman
Prof. N.K. Shinton
Dr. J.A. Shirley
Mrs. B. Simpson
Dr. J.G. Smith
Miss. R.J.D. Spooner
Dr. R. Stewart
Dr. L.M. Swinburne
Dr. C.G. Taylor
Dr. D.S. Thompson
Dr. E. Thompson
Dr. R. Vaughan Jones
Mr. D. Watters
Dr. R.T. Wensley
Dr. D.N. Whitmore
Dr. M. Winter
Dr. M. Wood

1. Apologies

Dr. R.S. Ardeman, Edgware
Dr. B. Attock, Barnstaple
Dr. A.S.J. Baughan, Ashford
Dr. J. Berhens, Carshalton
Dr. Bevan, Chichester
Dr. A.J. Black, Norwich
Dr. T.E. Blecher, Nottingham
Dr. M.A. Boots, Colchester
Dr. J. Cash, SNBTS
Dr. P.M. Chipping, Stoke-on-Trent
Dr. H.M. Daly, Truro
Dr. A.A. Dawson, Aberdeen
Dr. Dushciko, Royal Free, London
Dr. D.W. Gorst, Lancaster
Dr. P.A. Gover, Eastbourne
Dr. H. Gunson, B.T.S. Manchester
Dr. A. Hepplestone, Dundee
Dr. R. Hutton, Royal Free, London
Dr. J.M. Matthews, Oxford
Dr. E. Mayne, Belfast
Dr. S. Mayne, Derby
Dr. M. McEvoy, Harrogate
Dr.B.A. McVerry, Leeds
Dr. B. Murphy, Torquay
Dr. M.J. O'Shea, Shrewsbury
Dr. V.E. Oxley, Harlow
Dr. H.F. Parry
Dr. A.M. Patel, Wolverhampton
Dr. Peake, Cardiff
Dr. R. Perry, SNBTS
Dr. A.G. Prentice, Plymouth
Dr. C.D.L. Reid, Harrow
Dr. J.D.M. Richards, UCH, London
Dr. C.N. Simpson, Ipswich
Dr. R.J. Stockley, Worcester
Prof. I. Temperley, Dublin
Dr. Tew, Stevenage
Dr. D. Thomas, NIBSC, London
Dr. D.R. Triger, Sheffield
Dr. N.C. West, Whitehaven
Dr. A. Worsley, Poole
Dr. C.R.R Wylie, York

The Chairman welcomed to the meeting all the people present. A special welcome was extended to Dr. R.S. Lane (BPL, Elstree), Dr. R. Stewart (SNBTS, Edinburgh), Dr. A. Rejman (D.O.H., London), Miss C. Harrington (HNA Representative), Mr K. Milne and Mr D. Watters (Haemophilia Society Representatives) and Mrs B. Simpson (Cole & Cole, Oxford)

2. Minutes of the last meeting

The Minutes were approved and signed.

3. Matters Arising from the Minutes

Recommendations on choice of therapeutic products for the treatment of non-inhibitor patients with Haemophilia A, Haemophilia B or von Willebrand' disease.

The Chairman said that the document had been revised and sent to all Directors in May 1989. Prof. Bloom had written voicing his concern about the continued recommendation and use of certain products when other products perceived to be safer were becoming available. The Chairman said that Dr. Kernoff was preparing a new draft of the Recommendations and this would take account of recent advances and experience. Dr. Jones asked about the safety of desmopressin (DDAVP). In answer Dr. Lowe said this subject had been raised at the 15th meeting of ISTH in Tokyo, and that there were several reports of myocardial infarction following administration of DDAVP. As a consequence there had been some discussion about the advisability of giving DDAVP to people older than 40 years of age. Dr. Lowe suggested that the guidelines should give advice on the use of DDAVP, tranexamic acid and other synthetic materials. The Chairman asked Directors to write to Dr. Kernoff before the end of November to let him know their views about the contents of the proposed updated guidelines.

4. Report on Meetings of Reference Centre/Regional Centre Directors

The Chairman said that the last meeting of Reference Centre Directors was held on 13th February 1989 and the first meeting of the Regional Haemophilia Centre Directors' Committee had been held on 11th September 1989. The agenda at both meetings had been much the same as for the present meeting. Topics discussed and action taken included (a) Setting up of an Adverse Events Working Party (AEWP) under the Chairmanship of Dr. Peter Kernoff. (b) Dr. Gianelli of Guy's Hospital had attended the February meeting of Reference Centre Directors to present a proposal to

study gene mutations in haemophilia B patients in the UK and to set up a data base on gene mutations. It had been agreed at the meeting that Dr. Gianelli should write to individual Directors to ask for their collaboration in the project. (c) The Hepatitis Working Party had been discontinued and a new Chronic Hepatitis Working Party set up under the Chairmanship of Prof. F.E. Preston.

5. Report on 1988 Annual Returns

The Chairman said that many of the returns from Centres had come in very late this year, some not arriving until more than 5 months after the 31.03.89 deadline. It was therefore not possible to prepare a detailed report for presentation at the meeting. A brief verbal report was given. From the information received so far 86.5M Factor VIII Units and 15.9M Factor IX Units had been used by Centres in 1988. Dr. Rizza said that the full report would be sent out before Christmans 1989.

The question of changing the system so that the data were collected for financial years instead of calendar years was raised. During brief discussion there was no support for changing from the current system.

6. a) Progress Report on 8Y/9A Study

Dr. Rizza presented the report which had been pre-circulated (Appendix A). To date only one patient, a child had shown any elevation of AST. This was being investigated. The Study would probably continue until 30

patients had been entered and there were at least 20 with complete follow-ups. Dr. Rizza thanked Directors for their co-operation with the Study.

In discussion Dr. Craske recommended that the patients be followed up for 1 year. The questions of Hepatitis C antibody testing was raised and Dr. Craske suggested that all of the patients should be followed up for 1 year, although Hepatitis C antibody was usually detected by 3 months following infection.

6. b)

The Chairman invited Dr. Lane to report on Blood Product Laboratory's targets and plans for the future.

Dr. Lane said that the application for a Product Licence for Factor VIII was about to be submitted and the application for a Licence for Factor IX would follow. Progress was being made on the budget and production plans for next year for processing 500 tons of plasma. For 1990 the aim was to produce 100 M. i.u. of Factor VIII. BPL would produce 8Y in 500 i.u. vials as requested by Directors. Dr. Lane reviewed various production methods. A number of options regarding production were being considered and Dr. Lane would value the views of the Directors in these matters.

Dr. Colvin said that the new pricing structure was causing concern. Costs seemed to be increasing and Health Authorities might object to Directors

purchasing 8Y. Dr. Lane replied that under the new system BPL would pay Blood Transfusion Centres for plasma and the Regional Transfusion Centres would buy back the concentrates. In most cases RTC's passed the material to Centres free of charge but in some instances this did not happen. There seemed to be problems in arranging budgets in some Regions as well as some lack of communication. Dr. Savidge asked if this meant budgeting control of Factor VIII by Blood Transfusion Centres, not by Haemophilia Centres. Dr. Lane replied that this was up to each Region to decide. Dr. Kernoff said that he was concerned that Haemophilia Centre Directors were not involved in discussions about the supply arrangements from BPL and feared there might be a return to the situation where the BTS controlled haemophilia treatment. He did not think this was a good idea. He did not see the point of the BTS being involved and effectively controlling care. Dr. Savidge said he was concerned about the possible privatisation of the BPL and how this might affect the price of their products. Attention was drawn to the EEC directive concerning self sufficiency and in products prepared only from volunteer donors. Dr. Lane said that the UK Government policy was for self-sufficiency in blood products in line with other EEC countries. Dr. Rizza asked what the deadline was for the EEC self-sufficiency policy and Dr. Lane said it was likely to come in effect by 1992.

7. National External Quality Assurance Scheme (NEQAS) for blood coagulation.

Dr. Kernoff said he had no formal report to present but there were 3 points he wished to raise:

i) The standard of factor VIII assay at Haemophilia Centres was no different from that at non-Centres.

ii) NEQAS will be extended in scope to include new assays.

iii) He would like the views of the Directors about the format of the scheme.

Dr. Rizza asked Dr. Kernoff if he could prepare a report on performances for circulation to all Directors. After some discussion about the value of such a report, definition of poor performance and what could be done to help persistently poor performances, Dr. Kernoff agreed to write a report for circulation to all Directors.

8. Report from AIDS Group.

a) Update of Seroprevalence Study

The Chairman said that 2 papers had been published recently by the AIDS Group on behalf of the Directors. Reprints of the first paper had been sent to all Directors and reprints of the second paper would be posted to Directors within the next 2-3 days. The first paper was published in the BMJ in April (Br. Med. J. 1989, 298 1064-8) and the second appeared in the Philosophical Transactions of the Royal Society of London (Phil. Trans. B. Soc. Lond. B 325, 179-183 (1989)). The Chairman thanked Directors for their help with the Surveys. In the 1989 updating survey only 1 new anti-HIV+

patient was reported. This patient had not previously been tested.

b) Progression to AIDS/ARC in UK Haemophiliacs.

Reports of AIDS or ARC cases continued to come in. To date AIDS has been reported in 166 haemophiliacs, 108 of whom have died. 493 sexual partners of anti-HIV+ patients have been tested; 29(6%) of the partners were anti-HIV+. A full report would be prepared before Christmas for circulation to all Directors. In reply to a question Dr. Rizza said that he thought that the data were complete as far as reporting of AIDS was concerned. Oxford liaised closely with CDSC in Colindale and exchanged information with them at regular intervals.

c) Litigation

Dr. Jones said that the Secretary of State, Regional Health Authorities and Committee for Safety of Medicines were being sued; doctors were not being sued. Mr Justice Ognall wished to proceed with the trial quickly. Regional Health Authorities were being advised by in-house or private practice Solicitors. Broadly the claim was that the DHSS had failed to stop the use of imported concentrate and had been slow to produce heat-treated concentrates. A group on litigation had been set up by the Regional Haemophilia Centre Directors' Committee. Members of the group were: Dr. P. Jones, Dr. C.A. Ludlam, Dr. C.R. Rizza and Dr. G. Savidge.

Dr. Jones highlighted the damage being done to the doctor/patient relationship as the case dragged on and drew attention to the difficulty some patients were having in obtaining Legal Aid.

Mrs Barbara Simpson (Solicitor and partner in the firm of Cole & Cole Oxford) gave an outline of the progress of the defence to the patients' Statement of Claim. She said that she had been involved in trying to get an co-ordinated approach from Regions. The patients' claims were being dealt with as a Class action and Justice Ognall would preside at the trial. There had been 3 hearings so far. The Plaintiffs had put in a very lengthy Statement of Claim. The claim would be dealt with at 2 levels; (1) individual cases and (2) main action. There would probably be test cases covering each main issue.

The main Statement of Claim was already served and the main Defence would be served next year.

The patients had been asked to present a computerised list of all cases. A firm of private Solicitors, Messrs Wilkinson Maughan of Newcastle had helped them prepare the list. There was a total of 510 cases (66 in Oxford). All claims had to be in by February 1990; the Judge's authority would be required for late entries.

A co-ordinating Committee of lawyers were acting for the RHAs and had met 7-8 times. Mr Justice Ognall had asked for 1 firm to represent all the RHA's. Messrs Davies, Arnold & Cooper (London) would be the main firm and

would work with the Committee. It was hope to avoid duplication of work. Messrs Davis, Arnold & Cooper would work with the private firms who were as follows:-

London:	Tickle & Co.
	Beachcroft Stanley
	Capstick & Co.
Oxford:	Cole & Cole
Newcastle:	Wilkinson Maughan
Sheffield:	Oxley & Coward
Bristol:	Bevan Ashford

and with the in-house solicitors representing their regions. Generally the latter had little spare capacity to help. Mrs Simpson was liaising with Dr. Rizza to obtain copies of the minutes of the Directors meetings, Annual Returns etc. There was no need for other Directors to supply their Solicitors with the Minutes as Mrs Simpson would let all the Regional Solicitors have copies. The first meeting with Messrs Davies, Arnold & Cooper would be held on 16th October. Mr David Latham Q.C. had been retained as the Leading Counsel. He was very experienced in this type of work and was the Solicitors' unanimous choice as he had the capacity to deal with the vast amount of information. Also, he had a sympathetic approach to the case.

Experts had been approached and agreed to be witnesses. They are Drs. Pinching, Ludlam, Alder and Mortimer. Dr Aronstam and Dr. David Dane were acting as expert witnesses for the plaintiffs. A very detailed questionnaire had been prepared by Tickle and Co. and would provide a formal structure for the defence. Solicitors would be dealing with Centres in their locality. Only one manufacturer had to date been joined in the action. The Governemnt's barrister was Mr Justin Fenwick. Haemophilia Centre Directors were not defendants and the lawyers would like the Directors to co-operate fully and give as much help as possible.

Prof. Bloom asked if the Medical Defence Societies had seen the questionnaire drawn up by Tickle & Co. Mrs Simpson said no, but there would be no objection to their having a copy. Prof. Preston asked if Directors could be sued at a later date. Mrs Simpson couldn't see this happening, even if the present action failed. Dr. Colvin thought that individual Directors would be involved in defending individual cases but Mrs Simpson emphasised that the Health Authorities were the defendants, not the Directors.

Dr. Chisholm asked about cost to the patients of taking action and what the Directors could do to help them. Dr. Jones said the patients were now being asked to put down £7,000.

Mrs Simpson said that the defence lawyers would be looking at the possibility of striking out parts of the Statement of Claim at one of the hearings in the near future.

Dr.Jones asked what the Directors position was regarding talking to the Media. Mrs Simpson said there was nothing to stop them but she advised caution as each Director could well be a witness in the case.

A Director asked if action could be taken by patients at a later date. Mrs Simpson replied that if the patient had known about the present action and had not joined it would not be possible for him at a later date to sue.

Dr. Rejman, representing the Department of Health, stated that the Governments position was that there was no case for an out of court settlement and that compensation must be sought through the courts. He reminded Directors about the Macfarlane Trust. He said the government might consider giving more money to the Trust but felt that funds currently held by the Trust were apparantly not being allocated as charitably or as quickly as it might be. He drew attention to the problem that might arise with the Committe on Safety of Medicines (CSM) if individual members could be sued as this might lead to great difficulty recruiting people who would be prepared to serve on the Committee. It was not a simple problem. Dr. Jones said he was a Trustee of the Macfarlane Trust and disagreed with Dr Rejman's comments regarding the slow use of the funds. Dr. Green asked Dr. Rejman if the case could be settled out of court if the claim against the CSM was withdrawn. Dr. Rejman was unable to answer this question but said it was the policy decision of different Governments that was being challenged. Dr. Jones pointed out in response to a question concerning Legal Aid that the Macfarlane Trust could not pay fees to enable patients to take action.

The Chairman thanked Mrs Simpson for her helpful contribution to the Meeting.

8. d) Lymphoma

Dr. Ludlam asked Directors to let him know about lymphomas in both anti-HIV positive and negative patients. He and his colleagues could offer a range of investigations and had a good system for collecting samples from hospitals.

9. Future Meetings: format, locations and participants.

The Chairman said that after the Dublin Meeting several people had asked if the venue for the Scientific Meetings could go further afield, e.g. to the Channel Isles or to Holland. Also, it was suggested that there should be mega-meetings with simultaneous sessions and that more people should be invited to attend, e.g. all haematologists and nurses. After discussions it was agreed that all HCD Meetings would be held in the UK and the format would remain as now, 1-day and 2-day meetings being held in alternative years. After some discussion concerning the venues for the 1-day meetings it was agreed that for reasons of convenience the meetings should be held in London. The 2-day meetings should be held out of London preferably just outside a large city. Dr. Leslie suggested that haematologists not working in a Haemophilia Centre and haemophilia nurses should be able to attend AGMs. After a brief discussion Dr. Leslie withdrew his suggestion that haematologists not working in a Haemophilia Centre should attend as

it was generally thought that this would not be appropriate. The HNA were invited to send a representative to each AGM, so there would be feed-back from the meeting to nurses. Dr. Savidge suggested that notice of Scientific Meetings be published in the BMJ. This was agreed.

One Director said that some people were unhappy about the choice of date for the current meeting as it was being held on YOM KIPPUR and asked that the date of future meetings should be chosen more carefully.

10. Date and Place of next meeting

Prof. Preston said that arrangements were in hand for the next meeting, which was to be held in Sheffield on 20-21st September 1990. Full details would be sent to Directors as soon as possible.

11. Any Other Business

a) Dr. Savidge referred to press coverage about boycotting the WFH's meeting in Washington in 1990 and asked whether the Directors would consider boycotting it. Mr Milne (Haemophilia Society Representative) said that US regulations precluded HIV+ people from entering the USA. Haemophiliacs were particularly vulnerable because they carried Factor VIII, needles etc and were easily identifiable. The Haemophilia Society had decided not to send anyone to Washington and would like to see the meeting transferred to Canada. Dr. Winter proposed that the meeting should vote to boycott the Washington meeting and it was further suggested

that the Directors' Organisation should write to the US Government voicing their concern. Mr Milne suggested that the Directors should write both to the US Government and the WFH. Dr. Kernoff was concerned about boycotting the Washington meeting as it would be the National Haemophilia Foundation who would suffer as arrangements for the meeting were already far advanced He suggested a postal ballot of directors. After considerable discussion it was decided to draft a letter to be sent to the World Federation of Hemophilia expressing the Directors' concern.

The letter stated that:

> "The Haemophilia Centre Directors Group of the United Kingdom notes with dismay the visa requirements for entry to the USA. Unless these change to allow patients with haemophilia the same rights of access as other citizens the Group suggests that the venue for the meeting of the WFH in August 1990 be moved to another city outside the USA. If there is no change in the visa requirements or the venue then Haemophilia Centre Directors from the UK will be unable to attend the meeting"

It was agreed that the Chairman would convey this decision to the WFH.

b) Dr. Chisholm said it would be useful to have a discussion regarding managment of patients with inhibitors at one of the meetings. The Chairman agreed and suggested that she speak to Prof. Preston, who was organising the 1990 meeting.

c) The Chairman invited Mr Watters to give a report on the Haemophilia Society's views on the legal action being taken by patients and on the recently launched campaign for an out of court settlement.

Mr Watters reminded Directors that the Macfarlane Trust was totally separate from the Haemophilia Society although the Society was represented on the Trust. The Society's role regarding litigation was concerned only with advising people how to obtain legal advice and had started in 1986-7. The Society kept members informed of the steps they should take and of the progress of the court action.

He stressed that it would help the campaign for an out-of-court settlement if as many people as possible joined in. The Society had the support of the Sunday Times in the fight for an out-of-court settlement and series of articles were at present being published on the subject to heighten public awareness. A separate political campaign was also starting. MPs were being approached and a firm of professional lobbyist has offered to help free of charge. A letter would be sent to all MPs and he urged all those who were willing, to write to their MP.

12. Reports from Working Party Chairmen.

a) von Willebrand's Disease

Dr. Savidge said that the new Working Party had been formed 2 years ago. There were about 2,000 von Willebrands patients in the Oxford

register. Dr. Savidge had sent a questionnaire to all Centres last year asking about methods used for diagnosis of von Willebrands disease and presented the data collected from 70 completed documents. He planned to send out another questionnaire shortly so that the missing information could be collected. He felt that more information from Centres was required and quality control, perhaps via NEQAS. The results of the Survey would be published in due course when more data were available.

Dr. Kernoff said that it was not NEAQS's role to recommend best tests; that was a professional matter for the von Willebrand's Working Party to decide.

b) Inherited Platelet Disorders

Prof. Preston said that the Working Party had published guidelines in the Journal of Clinical Pathology. Some Haemophilia Centre Directors did not regard platelet disorders as being within their remit. At present there was 220 patients in the register. The Working Party would be meeting again next week.

c) Data Collection

Dr. Rizza said that the Working Party had now wound up and thanked Members for their help.

d) Chronic Hepatitis

Prof. Preston said that Dr. Craske had suggested last year that the original Hepatitis Working Party had run its course and that a new Chronic Hepatitis Working Party should be set up. This had been done and members of the new Chronic Hepatitis Working Party were Prof. F.E. Preston (Chairman), Dr. Dushciko, Dr. D. Triger, Dr. C.R. Rizza and Dr. P. Mortimer. He reported that Dr. Mortimer was willing to accept samples for Hepatitis C (HCV) testing. The Working Party would be looking at HCV testing in haemophiliacs. Dr. Rizza said that he had written to Directors at Dr. Mortimer's request informing them that Dr. Mortimer was willing to test serum samples for anti-HCV. Prof. Preston said he would send out formal information about the Working Party's activities within the next few weeks.

e) Reorganisation of haemophilia care

Dr. Savidge said that the document which had been circulated to all Haemophilia Centre Directors was the result of 3 years work since the Directors had taken the decision "to go Regional". The Working Party had tried to make the document as acceptable possible in the light of the White Paper. He had received a number of comments and objections but all had been resolved by slight modification of the wording. He would like the meeting to ratify the document so that it could be submitted to the Department of Health. The Chairman reminded Directors that the document was discussed in detail in Dublin.

Dr. R. Lee asked if it was mandatory for each Region to have a Regional Centre. Dr. Savidge said it was up to Centres in each Region to appoint Regional Centre. In reply to a question, Dr. Savidge said that for the time being the 4 Thames Regions would have only 2 Regional Centres (St. Thomas's Hospital in the South and the Royal Free Hospital in the North), although the situation might change in the future. Dr. Savidge proposed that he and the Chairman would formulate a letter to go with the document to Dr. Pickles at the Department of Health. The DOH would probably consult the Royal Colleges. Designation of Regional Centres would need to be agreed by Centres in each Region and then as the Regional Health Authority.

Dr. Leslie asked if there was to be a "Star rating" system for Centres. Dr. Savidge said that the list of centres published as a small booklet was mainly for the benefit of patients and should give an indication of the services available. Mr Milne said that following the discussion at the Dublin Meeting the Haemophilia Society was drawing up a new list of Centres. The Society had written to all Directors for information about their Centres and were collecting replies. In reply to a question Mr Milne said tha Society would not use the World Federation of Haemophilias 3-tier system for rating Centres.

Dr. Rizza suggested and it was agreed that representatives of the Society and representatives of the Haemophilia Centre Directors Group should meet to discuss the Society's list. After further discussion the document "Reorganisation of Haemophilia Care" was ratified.

f) Adverse Events

Dr. Kernoff presented a document prepared by the Working Party. He said there was a gap in the data on adverse reactions collected on behalf of the Directors and more effective mechanisms were needed. The document was the result of many discussions and was based on the method used by the British Paediatric Surveillance Unit. It proposed more active pursuing of information by sending a card to Directors 4 times a year requesting a positive or negative statement concerning adverse reactions. Dr. Kernoff asked for the meeting to approve the proposal and the forms. After brief discussion it was agreed that the Working Party should go ahead with its plans.

13. Carrier detection and antenatal diagnosis in haemophilia

Dr. Bolton-Maggs gave an account of the results of a Survey she had undertaken in 1988 at the request of the Haemophilia Society. A report on the survey had been published in a recent issue of the Haemophilia Society Bulletin (No.3, 1989). Questions were raised by the Survey regarding funding, location of test Centres and who should counsel the patients.

14. Report on behalf of the Haemophilia Nurses Association

Sister Harrington gave a short report on behalf of the HNA. The HNA was now linked to the Royal College of Nursing, which would help finance the Association, provide videos, accommodation etc. and organise courses. The

HNA had written to Centres where there were no nurses to see if they could recruit more nurses. Views of members regarding a boycott of the WFH's Washington Meeting were being sought. Two videos were planned:

1) "Growing up with Haemophilia", jointly with the HSIG.

2) "AIDS and Haemophilia: Questions and Answers".

15. Report on behalf of the Haemophilia Society/BASW Special Interest Group.

Miss Spooner presented a report on behalf of the Chairman of the group Shirley Mallon, who was unable to attend the meeting. The Group hold 3 meetings a year and they are all well attended. The Group were focussing on looking for good community care and were trying to solve Welfare Rights problems. They were also liaisng with the Macfarlane Trust.

In the future they were hoping to focus on the black and ethnic minorities, where many difficulties were comming to light. The Group would like to see medically trained interpreters available. They were planning to seek funding for a Research Project to uncover problems. They also wanted the Directors to know that the Group was recommending Social Workers to boycott the Washington Conference.

The meeting closed at 3.45 pm.