



THE HAEMOPHILIA SOCIETY

The Haemophilia Society
123 Westminster Bridge Road
London SE1 7HR

Telephone: 071 928 2020
Facsimile: 071 620 1416

MINUTES OF THE SERVICE COMMITTEE held on Thursday 10 November 1994 at Central Office of Information, London SE1

Present:

Mr Simon Taylor, Vice Chairman, Mr Chris Hodgson, Vice Chairman, Mr Andy Cowe, Mr Keith Colthorpe, Mrs Norma Guy, Dr Mark Winter, Dr David Evans.

In Attendance:

Mr Graham Barker, Director of Services and Development, Mrs Kate Richards, Member Services Officer, Ms Liz Cox, Children and Family Worker, Miss Shanit Marshall, Clerical Officer.

B94.72 Apologies for Absence

Apologies were not necessary as all were present

B94.73 Minutes of last meeting

The minutes of the meeting of 8 September were previously circulated and it was agreed that these were an accurate account of that meeting.

B94.74 Matters Arising

There were none

B94.75 Report from Hepatitis Task Group

It was reported that the Group met on 12 October 1994 and that copies of notes of the meeting would be circulated. The progress outlined in this report had been submitted to the Executive Committee on the 21st October. The main points included:

- a) Letter sent to Brian Colvin outlining Society concerns
- b) Agreement at MAP that Centre Directors Hepatitis Group would update and re-issue its guidance on HCV to all Centre Directors.
- c) Agreement that Centre Directors would produce in consultation with Society a patients charter setting out what service a person with haemophilia and HCV could expect.
- d) Meeting in December for Centre Directors and liver specialists to which the Society was invited.
- e) Letter to be sent to all Centre Directors expressing Society concerns on HCV
- f) No consensus amongst solicitors on the question of medical negligence (no confirmation in writing of position of J Parks & Co).

The hepatitis task group recommended that the Executive Committee discuss a proposal for a hepatitis C publicity campaign whose objective it would be to gain better treatment and care for those infected and financial help from the Government as and when those infected became ill. The Services Committee was invited to comment on these proposals.

Andy Cowe expressed the view that the damage that such publicity would cause to the Haemophilia community would outweigh any gains. A high profile campaign was not a suitable solution. He stated that a 'halfway house' solution may be the best way forward. It would be necessary to define what the Society wished to acquire. He suggested that the answer may lie in a Macfarlane Trust type of organisation. He underlined the necessity for a dialogue between the Society and the government.

Chris Hodgson felt that it would be difficult to place the blame on anyone as the HCV infection has been taking place since the 1970's, and that therefore it would be difficult to win compensation.

Mark Winter raised the issue of the complexity of HCV and stated that there is not sufficient knowledge about it. His view was that increasing public awareness creates a risk of causing panic and discrimination. The Society should discuss the issue with the Department of Health, and its priority should be to seek the best medical advice for its members, which should include funding research and making sure that members are counselled on diagnosis.

Norma Guy suggested that the Society would have to be seen to be actively dealing with the issue of hepatitis otherwise members such as the Manor House Group may approach the press themselves.

Dr Evans felt that the Society needs to put pressure on doctors to provide those infected with information about the virus. Compensation was not, in his view, a feasible option at this early stage. The Society should gradually feed the population with information regarding hepatitis, which would be both informative to the general public and satisfactory action for the Manor House Group.

Keith Colthorpe expressed the fear that in the public eye hepatitis would take on the same dimension as HIV, and stated that the Society should discourage people from pursuing the idea of litigation.

Simon Taylor concluded the discussion by suggesting that the Society should make it clear to ministers and the Department of Health that it takes the situation extremely seriously. Pressure should be put onto them, possibly through occasional media coverage. A high profile campaign was not yet appropriate.

Andy Cowe strongly expressed the opinion that once the media had a story they could not be controlled.

Norma Guy expressed concern regarding the dissatisfaction of the Manor House Group, if the Society was not seen to be doing something. In response to this David Evans stressed that the Society was clearly attempting to provide more information and promote better treatment for its members.

It was agreed that this topic would be considered further at the Executive and council meetings in Coventry.

B94.76 Report from Parent Support Task Group (meeting held on 20th September 1994)

Graham Barker reported that the Group had met on 20th September 1994. He specified the main points that arose from the meeting as being the following:

- a) The production of an information binder for parents of newly diagnosed children which would contain material written from the perspective of parents. Funding for this would be sought from Bayer.
- b) A video of the developmental stages of a person with haemophilia, containing parents and children. There would be further discussion on how this would be compiled and presented.
- c) A database of parents who wish to contact other parents in similar situations. It had been agreed that local Groups would be contacted, and they themselves would be in a position to identify parents with an interest in and knowledge of specific issues.
- d) A parent helpline was discussed. The Group had agreed that this would require further discussion because details such as training of helpline staff would have to be taken into account.
- e) A proposal for two prophylaxis conference in the same format of the Haemophilia Days had been agreed.
- f) The proposal for a Children and Family Worker was endorsed as essential to carry out the proposals to support parents.
- g) The Group had agreed on the importance of improved links with centres in order to ensure that parents receive greater support.
- h) The need to cater for teenagers was discussed but no solutions had been identified.

Finally, the Committee was informed that the Executive Committee had given its approval for seeking funding for the post of Children and Family Worker.

Some members of the Committee felt that teenagers would not be interested in the Society but Liz Cox stated that the Society should provide opportunities for teenagers with HIV to meet, as there was an identified need for this

Graham Barker informed the Committee that the option of compiling an information binder was definitely tangible.

A discussion on the possibility of prophylaxis conferences ensued. Graham Barker stated that many parents wished to learn more about it. Mark Winter suggested that a more general 'Children's Day' would be a better idea as it could cover various other relevant issues.

B94.77 HIV Report

The Committee was informed that the HIV Task Group had not met since the previous Services meeting, but that the first half of the payment towards the Birchgrove Group's core costs had been made. A meeting had been held with the Macfarlane Trust on 12 October, attended by Simon Taylor, Chris Hodgson and Graham Barker. Issues covered included support for the Birchgrove Group, the needs of widows and the needs assessment survey commissioned by the Trust.

Simon Taylor was of the view that the needs assessment survey would be extremely useful to the Society.

Mark Winter raised the issue of providing a memorial for all those who had died of HIV. The Committee agreed that there was a need for one and that it should be considered.

B94.78 European Activities

- a) Regulatory Affairs Symposium on Quality and Safety of Plasma Products 27th September 1994, Brussels.

Graham Barker reported back from this meeting that was jointly organised by the European Plasma Fractionation Association and the European Association of the Plasma Products Industry. The main purpose of the meeting was for the profit and not-for-profit sectors to jointly call for the regulatory authorities to consult and listen to the manufacturers. There was agreement that the public's confidence in the system had been shaken and there was therefore a need for an enforcement policy within the regulatory system. He reported that an updated van Aken report had recently been published giving data for 1991. This report recognises the continued growth in demand for factor VIII and talks less about the need for rational or optimal use of blood products. In his view the emphasis seemed to have been placed on harmonisation of blood collection, donor screening etc with a view to reducing the disparities between countries and thus encouraging increased trade between member states. Attempts to blur the distinction between the definitions of paid and unpaid donors seem likely.

The Committee had noted this report.

- b) Report on European Haemophilia Consortium Meeting 28 - 30th October 1994, Budapest.

Simon Taylor and Graham Barker attended this meeting. Simon Taylor provided a verbal report of the meeting. He reported that following discussions at the previous Executive Committee Meeting, the UK Haemophilia Society had offered to host the next EHC conference. There was some discussion on the amount of time required to organise the meeting and also its cost. While sponsorship money was likely to be forthcoming, this was unlikely to cover the full cost.

Simon Taylor said that the UK Society, as the strongest in Europe should help other eastern European countries, in particular Russia. Andy Cowe suggested that any such involvement would require considerable commitment over a long period of time. As a first stage it was agreed that centres be approached to see if there were any existing links.

B94.79 Services for Ethnic Minorities

Following discussions on the matter at the Nottingham Haemophilia Day Graham Barker brought to the attention of the Committee the necessity to assess how best to meet the needs of people with haemophilia from ethnic minorities. Members of the Committee suggested that a number of members from ethnic minorities would not understand written information sent to them regarding haemophilia care and treatment even if it was in their own language.

The Committee agreed that the need for translation had to be assessed through centres. Another option would be to put parents from the same ethnic communities in touch with each other. Those centres with the largest ethnic groups should be consulted.

David Evans suggested that a letter be circulated to all centres enquiring about this issue.

Andy Cowe raised the possibility of making use of volunteers to assist with translation.

Simon Taylor requested that Graham Barker carry out the enquiries.

B94.80 Advertising

Simon Taylor instructed that all publicity material from the Society should be monitored by the Services Committee. The Society would have to be careful with the image that it was portraying of people with haemophilia. The Executive Committee had considered some fund raising proposals from an advertising agency. A brief for the advertising agency would have to be drafted, making clear the messages the Society wished to convey. In the meantime, no further action should be taken with regard to advertising without insutrecting Simon Taylor and Graham Barker.

B94.81 Report on Items for Information

a) Chairman's Conference

Graham Barker explained to the Committee how the Drop in sessions would work and the role expected of individual members of the Executive.

b) Publications

Graham Barker reported that the text for Introduction to Haemophilia had been finalised and production now lies with Bayer. A second draft of the publication on blood products had been produced by David Evans.

c) Kogenate

Graham Barker reported that following the Royal Free Hospital's decision not to allow **GRO-A** to continue to receive Kogenate after the clinical trial had ended, he had, at the request of the Executive Committee written a letter expressing the Society's disapproval at this decision, and requested that the Royal Free discuss with Bayer arrangements for securing the continued availability of the product.

B94.82 AOB

Kate Richards reported on the meeting with the Association of British Insurers. A briefing paper would be produced in due course.

B94.83 Date and Time of Next Meeting

To be arranged.