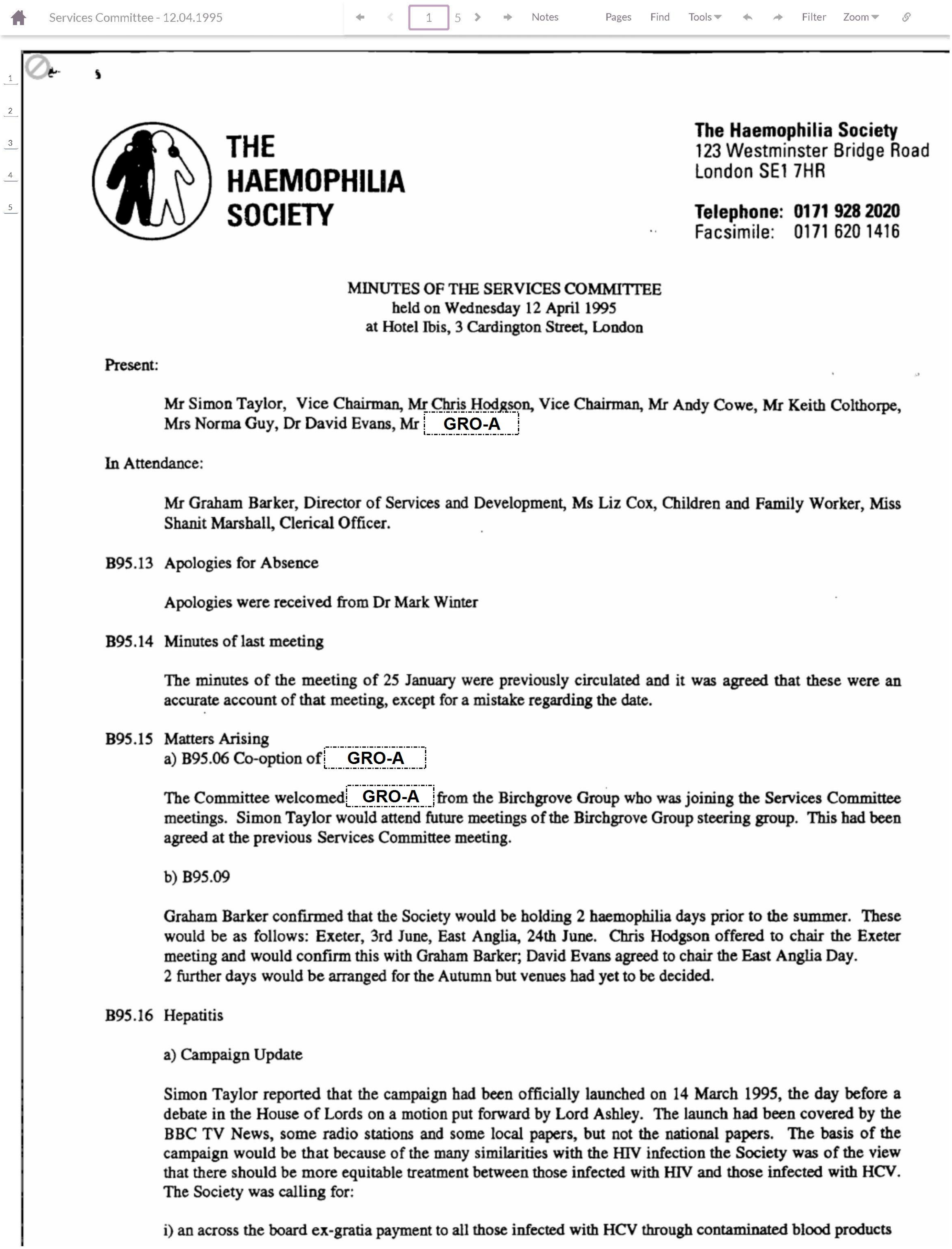
THE INFECTED BLOOD INQUIRY

EXHIBIT WITN45000024



THE HAEMOPHILIA SOCIETY

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MINUTES OF THE SERVICES COMMITTEE
held on Wednesday 12 April 1995
at Hotel Ibis, 3 Cardington Street, London

Present:

Mr Simon Taylor, Vice Chairman, Mr Chris Hodgson, Vice Chairman, Mr Andy Cowe, Mr Keith Colthorpe, Mrs Norma Guy, Dr David Evans, Mr GRO-A

In Attendance:

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

B95.13 Apologies for Absence

Apologies were received from Dr Mark Winter

B95.14 Minutes of last meeting

The minutes of the meeting of 25 January were previously circulated and it was agreed that these were an accurate account of that meeting, except for a mistake regarding the date.

B95.15 Matters Arising
a) B95.06 Co-option of GRO-A

The Committee welcomed GRO-A from the Birchgrove Group who was joining the Services Committee meetings. Simon Taylor would attend future meetings of the Birchgrove Group steering group. This had been agreed at the previous Services Committee meeting.

b) B95.09

Graham Barker confirmed that the Society would be holding 2 haemophilia days prior to the summer. These would be as follows: Exeter, 3rd June, East Anglia, 24th June. Chris Hodgson offered to chair the Exeter meeting and would confirm this with Graham Barker; David Evans agreed to chair the East Anglia Day.
2 further days would be arranged for the Autumn but venues had yet to be decided.

B95.16 Hepatitis

a) Campaign Update

Simon Taylor reported that the campaign had been officially launched on 14 March 1995, the day before a debate in the House of Lords on a motion put forward by Lord Ashley. The launch had been covered by the BBC TV News, some radio stations and some local papers, but not the national papers. The basis of the campaign would be that because of the many similarities with the HIV infection the Society was of the view that there should be more equitable treatment between those infected with HIV and those infected with HCV. The Society was calling for:

i) an across the board ex-gratia payment to all those infected with HCV through contaminated blood products

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ii) access to a hardship fund for those who become ill and the dependants of those who die

iii) as a matter of urgency, payments to those who are already ill and the dependants of those who have died.

In addition the Society would be calling for adequate resources for haemophilia centres and for research, and for a public education programme.

Members of the Medical Advisory Panel had been asked for their views on possible criteria to trigger the access to payments from any hardship fund that may be set up.

The press release was sent to over 500 MPs and an all party meeting would be held in the Commons on Wednesday 26 April. Graham Barker also reported that the response from MPs to the letter from the Society had been a good one, and that over 100 had given indication of support, and 150 letters had been sent to the Secretary of State on the matter. As well as this, members who had written to their MPs had also been responded to positively.

Simon Taylor went on to raise the issue of there being a lack of members ill from hepatitis C who would talk to the media. It was agreed that an infected individual who appeared to be well would not generate the right publicity for the cause.

Andy Cowe asked whether the Campaign Group had a specific figure in mind relating to the amount of 'recompense money' it was seeking or whether it was prepared to negotiate. Simon Taylor's response was that the Society would have to await what was offered.

b) Hepatitis Task Group

The Hepatitis Task Group held a meeting on 7 April chaired by Andy Cowe in Simon Taylor's absence.

Graham Barker reported that Mandy Cheetham had been appointed as the Hepatitis Worker. The Group was informed that she would be attending the Hepatitis Day on May 6th. Her role would include researching the use of Interferon treatment, as well as the issue of the extent to which centres were following the guidelines set out by the HCDO. She would be talking to people with hepatitis to find out how they were affected and what problems they were experiencing. This information would help define exactly what a hardship fund would be used for.

Graham Barker reported that the Hepatitis Road Show being organised by Bayer had yet to be arranged, but he confirmed that he hoped these meetings would be held after the summer, and was pressing Bayer for a speedy resolution of any problems.

The Hepatitis booklet had also been discussed and it was reported that the final draft was currently being circulated with a 2 week response deadline. Schearing had agreed to produce a print run of 8000 copies.

The Manor House Group had raised the question of funding for their activities but had not indicated any specific figure. Funds would be used to cover meetings, the newsletter and sundry costs. Norma Guy stated that some of the activities that they wished to organise would be incorporated into current Society events such as Hepatitis Days. Simon Taylor stated that the Society would consider any formal proposal for funding from the Manor House Group.

Andy Cowe had raised the issue of incorporating the Manor House Group into the Society's constitution. This

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would be discussed by the Manor House Group at a meeting on 25 April. Norma Guy stated that the Manor House Group had invited the Hepatitis Worker to attend its future meetings. She also informed the Committee that the Group would discuss the possibility of one of its members talking to the media.

B95.17 HIV

a) Report from Society/Birchgrove meeting on 9 March 1995/HIV Task Group 27 March 1995

Representatives from the Society (Alan Tanner, Simon Taylor and Graham Barker) met with 4 representatives of the Birchgrove Group (full details of the meeting to be circulated) to discuss a paper prepared by the Birchgrove Group. During the discussions a number of areas of broad agreement emerged. These included the need for the Society to demonstrate its commitment to people with haemophilia and HIV, the need to look at the Bulletin and its coverage of HIV, the need for improved communications between the Society, the Macfarlane Trust and the Birchgrove Group, the need to give the Birchgrove Group recognition within Council and the need for joint work between the Society and Birchgrove, and where appropriate, the Macfarlane Trust.

The editor had met with representatives from the Birchgrove Group and agreed that future editions of the Bulletin would have a page devoted to HIV issues. The Society would work more closely with the Birchgrove Group on its conferences. It would also consider how to improve its information and advice resources, and the referral of appropriate calls to the Birchgrove Group. It was also agreed that the Macfarlane Trust, the Birchgrove Group and the Society would produce a newsletter on information resources. The editors would be GRO-D Simon Taylor, and GRO-D Graham Barker reported that the Society was co-operating with the Birchgrove Group on commissioning a consultant to look at the needs of long term survivors and also ways of meeting their needs. The consultant would report on how best to improve access to information and services for HIV positive members and their families.

GRO-A expressed the view that the Society should produce a charter outlining its aims and current activities relating to all areas of work, so that members would know what to expect from the Society, and this was agreed to.

Andy Cowe raised the issue of the constitutional relationship between the Birchgrove Group and the Society. It was agreed that the Constitutional Working Party should meet with representatives of the Birchgrove Group and the Manor House Group as a matter of urgency.

C) Memorial

Discussion took place regarding commissioning a monument in memory of people with haemophilia who died of AIDS. The Committee was in favour of this. Simon Taylor expressed the view that the memorial should be situated in London as it would be the most accessible area for people to reach from other parts of the country. He also suggested that the memorial should be secular, possibly in a park or gardens with a place for people to sit and reflect. Simon Taylor suggested the Embankment Gardens or College Green might be suitable.

David Evans supported the idea but suggested that a sculpture might be very expensive, and that members should not be approached as this could be seen as competing with funding for the Birchgrove forest project.

GRO-A suggested that the Society choose a sculptor who had a personal commitment to HIV and Haemophilia. He expressed that view that the Society should aim more for accessibility than prestige.

Andy Cowe supported the idea of having an open air monument, but was not in favour of the locations suggested by Simon Taylor. He suggested that all possible sites be considered, including the Royal Parks.

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Simon Taylor agreed to look into these suggestions.

B95.18 Parent Support Group

Graham Barker reported that the Parent Support Group met on 16 March and progress had been made in the following areas:

a) Contact Network

The Parent Support Group accepted a proposal for setting up a parent support network. Initially there would be three or four parents acting as co-ordinators for a small team of volunteer parents that they already knew. Any parent ringing the Society seeking contact with other parents would be put in touch with one of the team of volunteer parents by a parent co-ordinator. Four parents had expressed a strong interest in becoming co-ordinators. A meeting would be held in early May for them to look at how the system would work and what training and support structures would be needed. The parent support network would complement not replace the work already done by Local Groups who put new parents in contact with others.

b) Video

The Northern Group had produced a video of young boys with haemophilia playing and talking about haemophilia. The video would be of considerable help to parents of newly diagnosed children. The Society had initially purchased 50 for distribution to Local Groups and centres. The Parent Support Group still felt the need to produce a video that showed young children with haemophilia growing up and discussed the possibilities of doing this themselves. Edie Threadgold had volunteered, and Liz Cox suggested that she may have a contact who would produce the video at the cost of materials only. Simon Taylor felt that information concerning the Society's activities should be included in the film, so that it could also be used for a wide range of purposes.

c) Resource Pack for Parents of Newly Diagnosed Children

This pack was reported to be in its final stages and would be available in May. The pack would come in a ring binder so sheets on specific issues could be photocopied and additional material added. Bayer would distribute some copies to centres and the Society would hold some. The pack would be given to the parents of a newly diagnosed child by the centre staff. It would contain material about the Society, including an application form, and the parents would be encouraged to join the Society. The Committee agreed that in order to encourage newly diagnosed people and parents of newly diagnosed children to become members of the Society, Groups should build contacts with centres and ensure that information displaying Society activities should be available at all centres. GRO-A suggested that each Centre held a copy of the binder for display purposes and then applied for a copy when they had a newly diagnosed child.

Liz Cox pointed out that the drawings featured in the pack did not reflect ethnic diversity, and that the Society should take note of this in future publications.

B95.19 Publications

Graham Barker reported that the Society had received 20,000 copies of Introduction to Haemophilia. The cost of this had been met by Bayer. Copies had been sent to all centres and would be distributed to Local Groups.

Work had begun on the new Centre Directory and all centres had been asked to provide details on a standard form of inclusion. The directory would be funded by BPL.

Drafts of the Blood Products guide and the Benefits guide were currently being circulated for comments. Neither had sponsorship but both would be produced in house if necessary.

A publication on von Willebrand disease had been produced by the Centre Directors' Working Party and may be used in the future for a Society publication.

The Annual report was circulated for comments. All agreed that it was a great improvement on previous editions from the point of view of presentation and content.

Keith Colthorpe raised the issue of the language used in the Bulletin, stating that he had received complaints about the high level of scientific language in some of the features. David Evans supported this comment and expressed the view that articles needed to be simplified further. Andy Cowe said that he felt there had been considerable improvement in recent issues. Simon Taylor agreed with this.

GRO-A suggested that a new approach to the design and language of the Bulletin be considered. He also suggested that a publications list be made available.

B95.20 Blood Products

Simon Taylor reported on the correspondence from the Deputy Chief Medical Officer on recombinant factor VIII and a letter from Dr Christine Lee in the Lancet about the risk of parvovirus B19 and the need for recombinant factor VIII. He said the Society should not compromise on safety issues. The Society's policy was that everyone should have access to the highest possible purity products including recombinant products.

It was agreed that the Society should look for opportunities to raise this issue and continually push for people to be on purer products. It was noted that many still received intermediate purity products and it was agreed that people should be moved off intermediate purity products as soon as possible.

Graham Barker stated that Dr Mark Winter would be speaking at the AGM about prophylaxis and recombinant products and that an article based on his talk could be published in the following Bulletin.

B95.21 European Haemophilia Consortium

Simon Taylor reported on his discussions with Terkel Anderson of the Danish Haemophilia Society, also chairman of the EHC steering group, about the programme and funding for the meeting. It had been agreed that the EC would contribute approximately £5000 towards the meeting. A finalised date for the meeting would be provided within the next week or so. The theme of the meeting would be 'Rehabilitation and Incorporation of People with Haemophilia in Employment'. He stated that a research project on this issue would be undertaken by the Danish Society. Sessions on medical issues associated with this subject would be organised as well as sessions on prophylaxis and new products.

B95.22 Future Staffing Requirements

Simon Taylor reported that following Kate Richards' departure, the staffing requirements for the Services Department were being reconsidered. He outlined a proposal that had been prepared by Graham Barker and Susan Archer, which was accepted by the Committee. The matter would be discussed further at the Resources

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Committee.

B95.23 Any Other Business

Simon Taylor pointed out to the Committee that this was the last meeting that Liz Cox would attend as her contract ended in June. He thanked her for all her work, in particular her role in raising the level of awareness of the needs of children and families within the Society.

B95.24 Date and Time of Next Meeting

The next meeting will be on 5th July 1995. Andy Cowe and Keith Colthorpe offered their apologies for absence at this meeting.

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