

*Caring for people with bleeding disorders*



THE  
HAEMOPHILIA  
SOCIETY  
UNITED KINGDOM

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**Minutes of Board of Trustees meeting**  
held on Wednesday 20<sup>th</sup> March 2002  
at Munro and Forster, 89 Albert Embankment, London, SE1

**Present:** Chris Hodgson (Chair); Alex Susman-Shaw (Vice Chair); Rona Macdonald (Vice Chair); Simon Taylor (Treasurer); Keith Colthorpe; Philip Dolan; Nigel Hamilton; George Levvy; Roddy Morrison;

**In attendance:** Karin Pappenheim (Chief Executive); Sue Rocks (PA to Chief Executive); Juliet Harris (Fundraising and Marketing Officer) – part of meeting.

**T02.12 Apologies for absence**

Apologies were received from Carolyn McGimpsey, **GRO-A** and Ian Hayes.

**T02.13 Minutes of the previous meeting held on 16<sup>th</sup> January 2002**

The minutes were agreed as a true and correct record.

**T02.14 Matters arising**

*(T01.79) (T02.03) Board/Governance*

It was noted that **GRO-D** had accepted the invitation to join the resources sub committee.

*(T02.07) WFH*

(a) *Congress 2002* : It was noted that the budget figures for the costs of sending delegates to the Congress in Spain had been miscalculated which meant there was an overspend of approximately £6.5K above the budget of £7K. This would entail extra fundraising and the need to ask local groups to help finance their own representatives.

b) *Elections 2002* :The ballot papers for WFH executive elections had been received. It was noted that the UK's two nominees Gordon Clarke (lay) and Dr Bruce Evatt (medical) were included. Since the member organisation can vote for two medical and two lay members, it was decided that the UK Society would vote for Dr Wolfgang Schramm (medical) and **GRO-D** (lay) in addition to its original nominees. The chairman would vote at the WFH Council meeting in Seville on 24 May.

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**T02.15 Finance**

**a) Audit progress – to note that audit is on schedule for approval of final report and accounts by board on 1 May.**

It was noted that the auditors had applied the latest SORP principles and the audit was on schedule. The resources sub committee would review the report and accounts at its meeting on 24 April, following which the final report would come to the board for approval at the meeting on 1 May.

**b) Salary policy – to approve proposals for annual increments**

As a result of the new salary policy agreed in 2001, trustees noted that it had been agreed to introduce new incremental salary scales in April 2001. The resources sub committee was asked to review the detail of implementation at their meeting on 24 April, and to report back to the board as to where existing staff would be placed within the grades.

**c) Non-salary benefits – to approve proposals**

The CEO had put to the board in November 2001 the introduction of additional staff benefits and since then had sought further advice from the Society's personnel consultant John Burnell. Having reviewed the proposals, the trustees approved the introduction of the non-salary staff benefits from 1 April.

**T02.16 Campaign**

**a) Progress report from Weber Shandwick (WSPA) – to note the January/March campaign report**

The report was well received and noted. It was explained that WSPA was focusing on a submission to the Chancellor in advance of the budget setting out the case for provision of recombinant for all. It was noted that Budget Day was also World Haemophilia Day (17 April). It was noted that a valuable meeting had been held with supporting MPs and health minister Yvette Cooper. The CEO reported that the minister had asked the Society whether recombinant or recompense for hepatitis was a greater priority for members, a question which possibly indicated that a limited amount of money might be available.

Trustees commended Lord Morris' debate in the House of Lords on 12 March and it was noted that the Government's representative, Lord Filkin, had said that a decision on the availability of recombinant for all regardless of age would be made this year. That statement offered the hope of an early decision on the matter.

It was also reported that the chair of the Treasury Select Committee, John McFall MP, had attended a meeting of the All-Party Parliamentary Group on Haemophilia and that this represented a step towards the achievement of one of the original campaign aims to involve treasury as well as health team MPs.

It was noted that the first meeting of the Expert Group in Scotland under the Chisholm Review chaired by Lord Ross would be taking place on Monday 25 March and that Philip Dolan would be representing the haemophilia community on the group.

It was reported that contact had been made with Professor Ian Kennedy, chairman of the Bristol heart inquiry who was a strong advocate of a no fault system of compensation for those harmed by the NHS such as the haemophilia patient group.

He had recommended making contact with the Chief Medical Officer, Professor Liam Donaldson in connection with the CMO'S review of compensation in the NHS. Contact had been made and Professor Kennedy's comments were used in the letter. A meeting has also been arranged with the chair of the health select committee David Hinchliffe.

**b) HCV think tank report – to consider final report and agree next steps**

The CEO gave a presentation on the final report by the think tank and outlined the next steps to be taken. Trustees discussed the report and the various issues raised. It was noted that the think tank's report simply set out the costs of translating the Canadian scheme to the UK with no modifications to reflect different circumstances in the two countries. Various possibilities for adapting the model were discussed including combining elements of the Canadian scheme with the existing UK based Macfarlane Trust. One of the merits of that approach would be to spread out payments as regular monthly sums (ie the Macfarlane Trust system) so as to give ongoing support. This would also have the effect of reducing the financial input from government in year one, and spreading the costs over future years. It was recognised that this might be an advantage in persuading government to adopt such proposals. Trustees also agreed that this position represented a "bottom line" for the Society and its members and that anything offered by government below this level would be seen as unacceptable.

The proposed next steps were;

- ❖ Seek meeting with Government to present proposals
- ❖ Consider joint approach with Macfarlane Trust
- ❖ Use Scottish version of proposals with Malcolm Chisholm's group.
- ❖ Discuss proposals with health/treasury teams of Conservative and Liberal Democrats

Trustees then discussed the question of at what stage should the Society inform/consult members. It was noted that there would be opportunities for feedback at the AGM conference and via the HQ newsletter in the summer and autumn. It was agreed to set up a management panel consisting of Karin Pappenheim, Simon Taylor, Rona Macdonald and Philip Dolan to take the matter forward as follows:

1. Present the proposals to the Chisholm Review
2. Discuss proposals with health and treasury teams
3. Write to Yvette Cooper to request another meeting for possibly May.
4. Organise a briefing on the Think Tank work for Scottish Members of Parliament in conjunction with Margaret Smith MSP.

It was also agreed that in the event that any settlement were offered by government, trustees would have to consult the membership before accepting such an offer.

**c) Options available for the future – presentation by CEO**

The CEO gave a presentation and outlined the options available for the future of the Society's campaigning work, assuming that the current campaign on the impact of contaminated blood products would be much scaled down or even ended in the next 12 months. It was agreed that the resourcing/staffing of campaigning/public affairs functions was dependent on the future direction of campaigning, and that the Society could not sustain further spending on campaigning at the current levels. The CEO's proposals therefore reflected the need to save substantial costs whilst ensuring the Society still had access to the necessary skills. Trustees considered the four options proposed by the CEO:

- A. Create an in-house post - press/information officer to handle occasional press work/produce HQ/other publications (*saves freelance costs on publications*)
- B. Create an in-house post - campaigns/parliamentary officer to handle parliamentary work, occasional campaigning, policy research, continue to use freelance editors for HQ/other publications (*but.... no funding for additional post; concern about adding to permanent staff*)
- C. Redistribute functions to other team members or reorganise the staff team to create a new post as a substitute for existing (*but....existing team members don't have the skills; would have to reduce service level*)
- D. **[preferred option]** Use single, lower cost freelancer for selected public affairs/campaign functions: handling APPG and other parliamentary work; occasional campaigning on specific topics; In-house fundraising/marketing team handle routine press work (*Advantage – much lower costs than WSPA; no long-term commitment; flexibility to make changes as Society's future directions become clear*)

Options A and B were dismissed because of the financial commitment involved, it being agreed that given the uncertainties about future funding it was not prudent to add another member to the staff team. Option C was dismissed as unfeasible; trustees endorsed Option D in the light of the timescale for change set out by the CEO between April and December 2002.

T02.17

#### Board/Governance

- a) **Trustees retiring – to note the retirement of Simon Taylor, Carolyn McGimpsey and GRO-A and George Levvy at the AGM.**

It was noted that GRO-A, Simon Taylor, Carolyn McGimpsey and George Levvy would be retiring following this year's AGM. It was agreed that as in previous years the CEO would write to haemophilia centre doctors and nurses to ask them to recommend anyone they think would be suitable as a trustee.

- b) **Macfarlane Trust appointments – to agree the re-appointment of Chris Hodgson and action to be taken regarding GRO-D**

Trustees reviewed the list of Society appointed trustees to the Macfarlane Trust. It was noted that GRO-D's term of office would end in 2002 and that his attendance at meetings had not been as regular as expected. It was agreed to write to him to advise him when his term of office will end and that he would not be asked to stand for a further term of office. It was agreed that the trustees of the Society would appoint Chris Hodgson for another year to 2003.

- c) **Elections process – to note the timetable and call for nominations**

The election process was noted. Trustees were advised that the letter calling for nominations would be sent out with HQ within the next week. They were also advised that on receipt of a request for a nomination form members would be sent a very comprehensive pack containing the



nomination form, trustee job description, trustee undertaking, conflicts of interest form and code of conduct for trustees.

**d) AGM and Conference – to note the plans**

Trustees were shown the proposed programme for the weekend. The CEO advised that although an international item had been planned for the programme unfortunately Brian O'Mahony, president of the World Federation of Haemophilia, had not been able to attend. Simon Taylor, who works extensively with WFH, offered to give a talk, possibly in conjunction with Gordon Clarke, chairman of the European Haemophilia Consortium.

Roddy Morrison also offered to give a talk on his experiences with treatment as compared to that of an older person with haemophilia.

**T02.18 Strategic planning: to discuss proposals for staff and trustees' away days as part of the planning process.**

The CEO gave a presentation on the proposals for staff and trustees' away days at which the Society's future direction and possible changes in strategy would be discussed. Following discussion, the board agreed with the proposals to undertake a full strategic review involving staff, trustees and members to consider possible changes in direction and strategy.

**T02.19 Fundraising: presentation by Juliet Harris**

The Fundraising and Marketing Officer gave a presentation on the fundraising opportunities of the Jeans for Genes appeal. She then went on to advise trustees of the fundraising and financial position to date and the difficulties experienced in raising funds from trusts and the risk that fundraising targets for the year would not be met. An analysis of the impact on reserves position of shortfalls in income from trusts was presented and discussed. It was agreed that the resources sub committee should keep the position under close review and that the board would consider fundraising progress and possible contingency plans from the CEO at its May meeting.

[Nigel Hamilton left the meeting at 4.15 pm]

**T02.20 Complaints procedure and policy: to note the new complaints procedure and leaflet for service users**

The complaints policy and leaflet for service users were commended by trustees.

**T02.21 Local Groups: report on local groups forum**

Trustees noted the report on the local groups forum.

**T02.22 Haemophilia Alliance: report on launch of national service specification**

Trustees noted the report and GL informed the board that inspired by the Haemophilia Alliance, the Neurological Consortium had been formed.

[Rona Macdonald left the meeting at 4.20 pm]

**T02.23 CEO Operational report for January/February 2002**

The report was noted.

**T02.24 Sub committee notes:**

□ **Resources sub committee meeting – 5 February 2002**

Trustees noted the minutes of the meeting. It was noted that the sale of the chalet is making progress but contracts have not yet been exchanged. It was noted that the risk assessment report would be brought to the next meeting as various aspects were still under investigation.

□ **Health sub committee meeting – 6 March 2002**

It was noted that the sub committee was continuing to discuss vCJD, viral inactivation of plasma derived products and the quality of source donated plasma.

**T02.25 Any other business**

**T02.25.1 Birchgrove**

The CEO advised trustees that a sum of £10k had been set aside for Birchgrove's use and was awaiting their request for funds. This had now been received and trustees therefore agreed that funds would be allocated accordingly.

**T02.25.2 Visit to Baxter, Switzerland**

Concern had been raised by Rona Macdonald that it was not appropriate for trustees to be subsidised by the pharmaceutical company Baxter Healthcare in order to visit their plant in Switzerland. It was noted that the Society's commercial sponsorship policy states that acceptance of sponsorship does not entail any endorsement of a particular company or product and it was agreed that the purpose of the visit was purely educational as it was important for the Society to be aware of all developments in product safety and supply. Trustees therefore felt comfortable that the visit had a valid purpose and should go ahead as planned.

**T02.25.3 Manor House march**

Trustees were informed that the Manor House group would be marching to Westminster again on 14 May. [GRO-A]'s memo on this subject was noted. It was further noted that the Society would advertise the march in *C Issues* and on the website to bring it to the attention of any members who might be interested, and that some individual members of the board and staff team would probably attend.

**T02.25.4 Correspondence with [GRO-D] and [GRO-D]**

Trustees were advised of recent correspondence from Mrs [GRO-D] and Mr [GRO-D] and were reminded of their previous decision that such correspondence would be dealt with by the CEO and chairman. Replies from both the CEO and Chairman were tabled. Some trustees expressed concern that the information being generated by Mrs [GRO-D] and Mr [GRO-D] was out of date and misleading. Trustees were informed that the health sub committee had considered the issues relating to safety and supply of plasma products; and its members were not aware of any modern evidence base for Ms [GRO-D]'s claims. It was agreed that if any of her claims could be substantiated with valid evidence they should be investigated.

Minutes of trustee meeting 20<sup>th</sup> March 2002

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The health sub committee would continue to keep safety and supply of products under close review.

**T02.26      Date of next meeting and board calendar:  
12 noon on Wednesday 1<sup>st</sup> May - venue to be confirmed.**

It was noted that there may be problems with holding the next meeting in London due to the possibility of various demonstrations in the central London area. It was therefore agreed to hold the meeting out of London to be combined with the proposed visit to BPL in Elstree rather than to change the date.

[Karin Pappenheim and Sue Rocks left the meeting at 5 pm]

**Closed meeting of trustees**

Chris Hodgson and Simon Taylor reported to trustees on the outcome of their recent annual appraisal meeting with the CEO.

There being no further business the meeting closed.

Signed

GRO-C

date

1 - 5 - 2002