

## Minutes of TRUSTEE'S MEETING

held at 11am on 10<sup>th</sup> October 2003

at Munro and Forster, 89 Albert Embankment, London, SE1 7TP

### Present:

Roddy Morrison (Chair); **GRO-A** (Treasurer);

Rona Macdonald (Vice Chair); **GRO-A**

Ann Hithersay; Bill Payne [part of meeting]; **GRO-A**

**GRO-A** [part of meeting]; **GRO-A**

### In attendance:

Karin Pappenheim (CEO); Sue Rocks (PA to CEO)

T03.27

#### Apologies

Apology received from: **GRO-A**

T03.28

#### Minutes of the previous meeting held on 4<sup>th</sup>/5<sup>th</sup> July 2003

The minutes were agreed as a true and correct record.

T03.29

#### Matters arising

a) (T03.05 Local Groups)

*Yorkshire*: still awaiting confirmation that the group have separated the roles of chair/treasurer and appointed a second signatory.

*Northern Ireland*: the bank account has been unfrozen and the group are still endeavouring to provide information on the outstanding restricted funds.

Noted.

b) (T03.22) WFH Global Forum (Budapest): attended by chairman

The chair will provide information about the forum to be circulated later.

*International Society of Thrombosis and Haemostasis*: attended by Bill Payne

Noted.

*EPFA (Edinburgh)*: **GRO-A** attending in November.

c) (T03.23 Macfarlane Trust): discussions on cost sharing options are ongoing.

This is an agenda item.

T03.30

#### Finance and fundraising

##### a) Financial situation and action plan

The CEO reported that Gopa Shah had been appointed as finance officer on 1<sup>st</sup> September. She further reported that due to problems with entry of data into the accounts system (Sage) since the previous finance officer had left in March, it had not been possible to produce accurate management accounts. The problems had been discussed with the Society's auditors, Knox Cropper, who had agreed steps to be taken to generate full management accounts by the end of October.

Trustees noted that there would be a cost of some £2,000 for new Sage software and additional freelance finance assistance to remedy these difficulties. It was agreed that these should be included in the "change fund" of £35k previously agreed by trustees.

The treasurer reported his concern that lack of financial reports meant that trustees could not properly meet their responsibility to account for the charity's income and expenditure. The CEO reported that proper controls on spending were in place and that reporting via the Society's fundraising system, Raiser's Edge, was accurate.

It was proposed by the treasurer and seconded by **GRO-A** that the chair and the treasurer receive a summary of the Society's end bank balances every month. **AGREED**

It was agreed that specific supervisory controls needed to be placed on the finance officer as recommended by the auditors, and that the CEO would be responsible for overseeing these.

**b) Fundraising**

A report on fundraising activities was discussed and trustees noted that the Society had applied to the Department of Health for the core grant of £100k over three years and a decision would be received in February or March 2004.

It was also noted that BBC Children in Need had agreed to part fund children/families work for three years, including a part-time worker and that John Ellerman Foundation had committed funding for three years support of HIV and hepatitis work.

**c) Staff salaries cost of living increase**

- i) Trustees agreed to uplift the salary scale by 2.8%, backdated to 1 October 2003.
- ii) Trustees also agreed that the increase should apply to the person who had become redundant as of 31 October.
- iii) Trustees agreed that an exceptional payment of £200 would be paid to all staff (including those who had become redundant) in October 2003 as recognition of the achievement of the Society's two main campaign goals this year, and a further £200 as a Christmas payment in December. Funds would be taken from the 'change fund' and would be accompanied by a letter from the chair.
- iv) The CEO's salary would be discussed at a later date.

**T03.31**

**Recombinant for all implementation update**

The CEO reported that she had attended two meetings of the advisory group, together with the Society's other representatives, **GRO-A** and Chris Hodgson. The first priority for the group had been data collection to establish the location of patients not yet on recombinant by PCT and their current use of plasma products in order to calculate costs of switching them to recombinant; this data then was validated by PCTs in September. The second priority had been to organise a national tender exercise to purchase the extra product for the adults; and to decide which products to purchase on basis of prices received (noting quite a large variation in prices from different companies). Following this, it was expected to see first patients going on to recombinant in October.

It was suggested that profiles of people who had benefited from the switch to recombinant be included in HQ and perhaps publicity gained by highlighting people in the constituencies of members of the All Party Parliamentary Group on haemophilia.

**T03.32**

**Update on cost saving/restructure**

The CEO reported on implementation of the cost saving measures agreed by trustees in July. Two staff members had been made redundant. She noted that it would not be possible to achieve the full £73k staff savings previously agreed without seriously weakening the organisation. In particular any further staffing reductions could undermine both administration and information advice services.

It was noted that savings plans included converting the finance officer post to a 3 day week in 2004. trustees agreed that the end of the first quarter would an appropriate time – March 2004. Trustees agreed to discuss the possibility of the CEO changing to a four day week at a later date.

The CEO reported that with this and other changes likely staff costs savings could be at maximum £56,000. She also reported that redundancy and other cost of some £11,200 to date were within the £35k "change fund" agreed by trustees. It was noted that additional temporary finance support costs should be covered by this fund as well.

As regards 2003, CEO reported that the savings of £30k previously proposed would not be achieved because of extra spending on finance support and would be closer to £20k.

The chair expressed trustees' thanks to the CEO for the work undertaken and to staff for their responsible approach to the need to achieve savings.

**T03.33 CEO report July to September 2003**

The report was noted.

**T03.34 Sub committee reports**

- a) Health - noted
- b) Resources – noted. The sub committee had recommended to the board that the cheque signing limit for the CEO be raised. Following discussion it was **agreed** to refer this to the resources sub committee for discussion.

It was also agreed that the sub committee should prepare a capital spending authorisation procedure.

**T03.35 Any other business**

- a) A letter had been received from Dr Paul Giangrande requesting that the Society nominate him for a second year to the role of Vice President, Medical with the World Federation of Hemophilia.

**AGREED**

[Bill Payne 12.40 pm]

- b) The CEO reminded trustees that plans needed to be made for the Society's attendance at the WFH Congress in Thailand in 2004.

- c) **GRO-A** offered his apologies for the resources sub committee meeting to be held on 18 November 2003.

**T03.36 Hepatitis ex gratia payments update**

**GRO-A** arrived 1.05 pm]  
[Bill Payne, **GRO-A**, **GRO-A**, **GRO-A**, **GRO-A**, Ann  
Hithersay and **GRO-A** declared their interest in the following]

The minutes of the Extraordinary Trustees Meeting held on 25 September were discussed. At the meeting a series of key points had been agreed to set out the Society's position regarding a proposed scheme. These were reviewed and it was agreed that a further point should be added to specify that any scheme should not be means tested.

Following further discussion **GRO-A** proposed, and **GRO-A** seconded, that:

**"those infected with HIV/HCV should receive the same amount as those with HIV only."**  
**AGREED**

With these amendments the Society's position was agreed as follows:

- a) The scheme cannot exclude HIV/HCV co-infected.
- b) It must include provision for those who have died.
- c) There must be no exclusions from future action (i.e. no waivers).
- d) We are aiming for implementation of the Ross committee recommendations as a minimum and ideally our own think tank's proposals - and reject Malcolm Chisholm's reduced level proposals as unacceptable.
- e) We want one scheme for the whole UK rather than different ones for each 'jurisdiction'.
- f) We want meaningful consultation with the Society on the basis for the scheme.
- g) We want a scheme that allows for future need as proposed by our expert group and the Ross group i.e. not just a one shot payment. If a one-shot payment is the only way forward it must be sufficiently generous to take account of future declines in health etc as shown in the Society's future projections of the health of the affected group.
- h) We want a benefits/tax disregard as applies with the MFT payments (and extending to income from investments).
- i) We expect the scheme to include some provision for those who cleared the virus as proposed by our expert group.
- j) We will not accept a scheme based on means testing.

It was stressed that actual sums should not be mentioned in order not to raise expectations and that the Society should continue to follow its own think tank report.

Trustees then discussed the next steps proposed:

- a) **To invite support from the UKHCDO:** the chair of the UKHCDO, Dr Frank Hill, had agreed to take a letter asking for support from the Society to the next UKHCDO meeting in November.
- b) **Parliamentary:** the chair of the All Party Parliamentary Group on Haemophilia, Michael Connarty MP and Lord Morris had been written to. Lord Morris had agreed to undertake necessary actions once the Houses were back from recess.
- c) **Depart. Of Health consultation:** the Society's think tank experts were available for consultation to the Department of Health. The Department had asked the Society to nominate a representative to attend a meeting on 14 October and it was agreed that Phil Dolan should be nominated. Concern was expressed at the very short notice given for the meeting.
- d) **Macfarlane Trust (MFT) joint work:** Trustees were advised that the Society's chair and CEO had held a meeting with MFT in order to discuss a common position. It was noted that MFT had been asked by the Depart. Of Health to put forward proposals for operating the payments scheme as a new trust fund. The MFT had stressed to the Department that all people with HIV/HCV and families of the deceased must be included in the scheme.
- e) **Scotland:** **GRO-A** reported on a meeting held on 8 October with Malcolm Chisholm MSP. It was agreed that the UK Society would continue to offer support as needed to Scottish campaigners. In particular the CEO had written to Malcolm Chisholm to make clear that the Society supported the Lord Ross report and did not accept Malcolm Chisholm's solution.

- f) It was agreed if necessary the Society should walk away from the negotiations as an absolute last resort.
- g) **Public affairs/PR support:** the chair proposed that **the Society hire public relations support at a maximum cost of £5k plus expenses per month with a limit of £12k to be spent from unrestricted reserves.** **AGREED**
- h) It was agreed to form an action group with the CEO, chair **GRO-A** **GRO-A** **GRO-A** Ann Hithersay and **GRO-A** Bill Payne also offered his support.

There being no further business, the meeting closed at 2.20 pm.