

**THE MACFARLANE TRUST  
THE PARTNERSHIP GROUP**

**Notes of a Meeting held on the 1 October 2004  
At the Novatis Foundation, 41 Portland Place, London W1**

**Present**

GRO-A

P Stevens (until 3.00pm)

GRO-A

**In Attendance**

M Harvey	Chief Executive
J Cohen	Head of Support Services

**Apologies**

GRO-A

**1. Introduction & Welcome**

The Chairman welcomed GRO-A the new Head of Support Services, to the meeting. The Chairman welcomed GRO-A from the Haemophilia Society to the meeting. The Chairman advised members present that he had notification from GRO-A that he would be resigning from the Group. Expressions of regret were Made; it was resolved that the Chairman and Chief Executive would write to GRO-A thanking him for his unstinting service and work over a number of years.

**2. Mr P Stevens**

The Chairman of the Macfarlane Trust sought leave to make an announcement in respect of concerns he had felt from exchanges with members of the Group. He felt there was a need to clear the air in respect of concerns emanating from the Trust's community of care that were concerned with the future direction of the Trust and that some perceptions of a number of individuals were either incorrect or wholly misinterpreted.

**Incorrect Perceptions**

The Chairman cited the clear sense of anger over the recent announcement, by the DoH, in respect of V-CJD. It was clear that the way this matter had been handled had left registrants worried, angry and unclear as to the future. This, in itself, had exacerbated worries about the Trusts strategy for the future and caused misunderstandings.

Members of the Group were invited to comment.

**GRO-A** said that V-CJD was a clear issue of concern; of additional concern was the perceived decline in service delivery and the situation in respect of the Trust n-not being able to meet its counselling and other services. It was accepted that the Trust has undergone a difficult situation in respect of staffing with unforeseen long-term sickness, the impact of the Skipton Fund, the office move and other salient matters.

P Stevens, in his capacity as Chairman of the Trust, spoke at length on the following:-

- a) Regular Payments. That they will continue and will be targeted to meet need and try to bring about a “full life not just an existence” (Long Term Review 2003) through inter alia deficit free (domestic) situation.
- b) To make a business case for additional capital funding. This element of the business case had been sidelined but with the V-CJD announcement, there was an opportunity to resurrect this to meet the demands arising from longevity.
- c) It was a fact that civil servants (and therefore ministers) would not readily accept such a business case because of the perception of the level of cash values already applied to this specific constituency.

**GRO-A** gave a succinct exposition of the communication sent to haemophilia centres which was the source of the current anger emanating from the trust’s registrant community. The letter had dire implications for ongoing medical treatment of registrants.

## **Governance**

The Chairman invited P Stevens to talk about the proposals for future governance of the Macfarlane Trust. An exposition followed:-

- The governance of the Trust as it was.
- What the governance might be if the Trust had commenced operations now.
- The debate that took place at the December 2003 Away day in respect of the Macfarlane Trust as a charity, the Skipton Fund as a limited company and how those relationships were to evolve within an acceptable legal framework.
- The Skipton Fund would also be the corporate trustee.
- That the Chairman of the Haemophilia Society would be invited to become a trustee ex officio and as part of the existing cadre.

Mr Stevens went on to say that there had been an earlier meeting with the Trust auditors where it was suggested that the Trust and the Fund could and should remain separate functions.

Members, collectively, asked what the current position was. Mr Stevens responded that prior to the meeting with the auditor, the option to introduce a corporate trustee would be proposed. The exact preferment remained unclear although it was still recognised that a change in the way the Trust was governed was required.

There was a need to resolve matters with the Charity Commission at an early stage and a need to communicate the agreed decision at an early stage.

### **Bulletin Board**

The Group collectively expressed the amount of mis-information that was appearing on the MFT website bulletin board. There were complaints about delays in the overall "response time" and that the ability of registrants to communicate their feelings on the bulletin board was (as a form of relief) was, either directly or indirectly, as a result of GRO-A not being available to fulfil her function.

It was resolved to introduce an electronic mechanism to enable registrants and beneficiaries to express concerns anonymously to either the Chief Executive or Head of Support Services

It was of concern to the Chief Executive and Head of Support Services that there was a climate of fear within the registrant community when seeking to approach the Chief Executive or the office in general.

It was resolved to ask the Trust Webmaster to facilitate the electronic interface with registrants.

### **Conclusion**

It was felt that this exchange had been thoroughly constructive and that lessons on each side had been learned.

The agenda as published was resumed.

### **3. Notes of the Previous Meeting held on the 18 June 2004**

The Chairman referred to a communication from GRO-A That note 7, regarding parity, should embrace all registrants, those bereaved and widows.

### **4. Matters Arising from the Notes**

(3) The policy on hospital fares was now clear in that the Trust would reimburse to the same level available from the NHS. It was resolved to publish this in the Winter Newsletter.

2(3) GRO-A gave a full report, that would soon be published, on the recent SFTW(2) conference. It was proposed that the Trust should make available resources to hold an SFTW(3) in 2006. The Group noted that the costs of the event were well within budget and GRO-A was congratulated on this and other aspects of the overall performance of the event. He went on to thank a number of people who had contributed to the success of the event, they included GRO-A (HS) Roz Riley

(MFT) [GRO-A] (MFT) and the volunteer planning group that comprised members from the Partnership Group and others.

It was resolved to place [GRO-A] recent article in the MFT the Summer Newsletter on the website.

(6) The Chairman reported that he had not been able to complete his report. It was noted that only one member of the Group [GRO-A] had achieved a contribution in this respect. His contribution would be available shortly. He hoped that others would find the time to make a contribution.

It was agreed to commence the PG LTR review as soon as possible and then to take matters forward that might include a meeting with the LTR author, Hilary Barnard.

(7) The Chief Executive reported that Jude Cohen has now joined the Trust as Head of Support Services and that this was her first day. He also reported that Carol Clisby, the Benefits Adviser, had resigned from the Trust and would be relinquishing her position as of today.

The Chairman invited Jude Cohen to speak briefly on her vision of the post of Head of Support Services. Members of the Group listened intently. There was a further discussion on the role and function of the National Support Services Committee (NSSC) and Regional Support Workers (RSW's). It was resolved that when the office guidelines in respect of single grants had been reviewed and agreed, they would feature on the website.

## **5. Assisted Conception**

The Chairman introduced the paper circulated with the agenda.

The Chief Executive reported that this matter was now a policy matter for the NSSC and that the views of the Partnership Group were sought. After a balanced and considered discussion, it was resolved that the NSSC be invited to consider Assisted Conception and related issues was of sufficient importance to make a business case, to the DoH, for funding as a stand-alone item.

It was further resolved to seek views on this matter through the medium of the website.

## **6. Reports.**

### **Department of Health**

There was no report from the Department of Health. In response to a question form [GRO-A] [GRO-A] the Chief Executive reported that there had been an approach to the DoH for a meeting to review matters of concern. The Chief Executive would keep [GRO-A] informed of dates to enable forward diary planning.

## **Haemophilia Society**

**GRO-A** from the Haemophilia Society gave a verbal report. Following the report, it was resolved that all further reports from the Society should be in written form.

### **7. Bereavement – Type and Level of Support**

It was agreed that “parity” was the key issue and that this would be remitted pending development of the business case. It was further agreed that the bereavement newsletter would be made available to the Partnership Group.

### **8. The Archive**

The Chairman presented his report and recommendations. It was resolved to accept the recommendations in full.

### **9. The Future of the Partnership Group, in particular, as Consultative Body.**

The Chairman invited the Chief Executive to expand on his proposals for a formal consultative arrangement that he thought was necessary to ensure that registrants and beneficiaries views were properly reported to the Trust. This embraced:-

**GRO-A**, in presenting his submission, said that what he required was a definitive statement on how the Group was perceived. The Chief Executive advised him and other members of the Group that they were, in essence, a discussion group rather than a consultative body.

a) A number of mini-partnership groups, from each of the proposed regions, comprised of registrants and beneficiaries that would meet collectively to discuss matters.

b) Part of their remit would be to elect a given number of individuals to a national Partnership Group. This national body could then demonstrate it had a legitimacy to be considered as a formal consultative body.

c) The RSW cadre would facilitate and enable the mini groups to function.

It was resolved the Partnership Group would consider its attitude in terms of taking matters further and would debate as to whether or not an electronic consultation exercise, via the website, should take place.

The Group concluded that there were sensible and constructive arguments for the formal process embracing elections from the regions and for treating the Group as a consultative body in either its current form or with a degree of fine-tuning.

### **10. Any Other Business**

It was resolved that the guidance notes for the second Skipton Fund payment be put on the MFT website.

That **GRO-A** should be informed of any changes in arrangements in respect of the meeting with the Department of Health.

The Chief Executive explained why he left the Bereavement Weekend on the first evening rather than stay for the three days.

The next meeting will be held at the Novatis Foundation on the 13 December 2004 commencing mid-day.

**The meeting terminated at 5.15pm.**