

**Aide Memoire
TRUSTEE DEVELOPMENT DAY**

**Held on the 4 November 2006
at the Novartis Foundation, 41 Portland Place, London W1.**

Present:	Peter Stevens – Chairman	(MFT)
	Mrs Elizabeth Boyd – Vice Chairman	(DH)
	Mr Christopher FitzGerald – Chairman Elect	(MFT)
	Mr Russell Mishcon	(MFT)
	Mr Philip Dolan	(HS)
	Dr Simon Chapman	(DH)
	Mr GRO-A	(HS)
	Mr Patrick Spellman	(DH)
Apologies	Mr Christopher Hodgson	(HS)
	Mr Gordon Clarke – Hon. Treasurer	(MFT)
	Mr GRO-A	(HS)
	Dr Mark Winter – Medical Trustee	(DH)
Officers	Martin Harvey – Chief Executive	
	Ms R Riley – Support Services Manager	
	Ms L Haigh – Finance Manager	

The trustee development day took place on the 4 November 2007. The programme for the day embraced the following agenda:-

- A Governance Update led by Miss Gillian Fletcher of Berwin Leighton Paisner.
- A review of two papers, prepared by the Chairman, that sought to explain the need for a new policy framework that would enable the Trust to focus on where financial need could be properly identified to enable support, as defined in the Trust Deed, to be disbursed.
To agree a formal proposal that a supplementary “one off” payment, to each beneficiary household, should be made in January 2007 to help meet the rising energy costs, that had been announced during the year, and to assist with some of the more general increased costs of living that confronted the beneficiary community.
- To debate issues arising from the two papers to prepare a framework for the 2007/08 annual plan and objectives to be set out for the period.
- To review the current risk strategy policy adopted by the Trust.

This aide memoire seeks to include as many of the points raised by members as was possible.

Session 1

Governance Update

The key points arising from Miss Fletcher's address were as follows:-

- a) It was a key duty of trustees to establish and respond to need. Need was identified as "financial" funding the many and varied categories of support sought by the beneficiary community.
- b) The Trust clearly had primary and secondary beneficiary constituencies; the level of financial support was a matter for trustees to determine.
- c) To regularly review the levels of beneficiary household income to enable need to be quantified and equate to an appropriate level of support.
- d) To develop an evidential system of confirming beneficiary support made available that reflected need as defined rather a universal distribution of financial support.
- e) To review regular payments made to registrants and infected partners.
- f) To ensure that determination of need remains at the discretion of trustees and not as a formulaic process.
- g) To assess if a proportion (estimated at around 10%) of the registrant community that was thought to be relatively secure in financial terms should be receiving regular payment support; it was recognised that any system of "needs testing" should be sufficiently flexible to allow an individual registrant to access financial support as and when health conditions forced that circumstance.
- h) To undertake a method of confirming need against support received every 1 – 1 ½ years.

Other areas of governance

Resignation of trustees

In light of the reaction by trustees to the settlement made by the DH in response to the business case, the various options as to how the trustees might represent their dissatisfaction were considered.

Miss Fletcher confirmed that it might well be breach of trust if the trustees resigned en masse. It was likely that the Trust would be subject to a winding up process with available funds being distributed to a body empowered to make the disbursements to beneficiaries.

Quorum

It was noted that the trust deed did not contain a quorum provision

Declarations of Interest

All declarations of interest should be made known.

Information

All trustees were presented with a series of loose-leaf updates for their governance packs. Additional updates will be sent to those trustees unable to be present.

Trust Deed Amendment

An amendment to the trust deed that gives the board of the Macfarlane Trust the discretionary power to appoint up to two registrant trustees (the clause before this amendment stating that at least one registrant trustee will be appointed) was agreed and the amendment was signed.

A copy of the trust deed amendment and the new consolidated trust deed will be circulated to all members of the board.

Session 2

Policy Papers

The papers circulated with the programme were considered.

The purpose of the two papers was to review possible shortcomings in the Trust's approach, in policy terms, to financial support disbursement and, secondly, how the Trust might refine its approach to disbursing financial support taking into account need as defined by Miss Fletcher.

The Chairman's aspirations:-

- A clearer targeting of funds.
- The need to question automatic payments.
- The stage where non-infected widows are no longer deemed to qualify for support.
- The responses to various questions, where appropriate, are presented in brackets.

There was a vibrant and extended debate covering a wide variety of matters that were both relevant and peripheral to the debate. They were:-

- a) To establish the needs and wants of registrants (RM)

(This had been established as far as possible by the Long Term Review which was the genesis of the business case "Funding Long Term Survival".)

b) It was important that there were different needs that were driven by an *individual's* own circumstances GRO-A

(The business case sought to do this. An individual's availability for work could be reviewed in greater detail).

c) Home Ownership? (EB)

(It was thought that approximately 60% of the registrant community owned their own property. Life Insurance cover was not available).

d) The various need definitions were considered. The requirement to encourage people out of a psychologically destructive mind-set was important GRO-A

e) What if the Trust did not exist? (PS)

(SG responded that he would have to find employment but this might well have a severe impact on his health status. The Trust was a financial life-line only)

f) The establishment of self-supporting networks? (PS)

(PRS reported that when he had visited a number of CCCs, very few registrants attended any meetings and it was generally felt that all beneficiaries anted to simply to get on with the business of living).

g) The relevance of the Partnership Group was considered in terms of the network capability (PD)

h) SC asked, in terms of this debate, what was the end-state the Trust was seeking to achieve? He suggested that it could be a sense of well-being, a positive approach to life, a degree of financial security and the ability to undertake a degree of self-development. (PD considered that there was a need to get out and meet the registrant community. There followed a discussion on what had happened before and the proposed RSW network that had failed because of a lack of registrant support).

i) SC proposed that the LTR should be revisited, by a number of registrants, to see if it remained relevant.

(There followed a discussion about how this might be achieved, if the RSW proposal could be revisited and whether or not the THT network could be utilised. The cost of the outsourced THT arrangement was confirmed at £25.00 per hour exclusive of travel arrangements.)

j) The debate moved forward to debating need levels, whether or not individual empowerment and personal development were as important as financial support, the importance of regular payments (these did not contradict the trust deed as long as they could be in terms of defined need. It was accepted that only 5-10% of the registrant community would find it difficult to demonstrate need in terms of regular payments).

- To define need by the receipt of Income Support was reasonably simple as a benchmark. The most prominent area of difficulty was those beneficiaries on incapacity benefit.
- If the Trust was to seek to isolate those registrants who were high earning, it was setting a standard as to what was an acceptable standard of living.
- The debate on benefits qualification and the difficulties arising followed.
- The need to consider the given expectations of the registrant community against trying to establish from the registrant community what they actually require. It is probable that financial security with reasonable levels of assistance were paramount.

This session moved on to a group discussion on the second paper. Two teams were asked to consider the paper and make a presentation on the questions the paper asked.

The purpose of this team session was to try and establish a series of objectives that might form the 2007/08 annual plan. Trustees present noted the separate paper prepared by the medical trustee.

The second paper discussed the following key points:-

- That there had been no increase in regular payments (RP) since 2001. That the purchasing power of RP had declined and as a consequence grant requests for support that should be funded from RP had increased. Should the Trust attempt to meet these cost of living increases?
- That the lower rate of RP, £255.00, applies to all those not in receipt of income support (approximately 25% of the total). This 25% are in a number of disparate categories as shown in the first paper. Are we meeting the needs of these different categories?
- Are the discretionary powers available to trustees sufficient for the purpose? Is acute need or more basic need met?

The paper referred to the fact that the increase in the 06/07 settlement might well attract an expectation from the registrant community. Debate was needed on whether or not that need should be targeted to those on the higher level of RP (where need can be supported by the qualification of Income Support) with an explanatory letter to those on the lower level of RP (and therefore, in theory, not in equivalent "need" as defined) who could be given the opportunity to explain why their circumstances merited consideration.

The paper went on to discuss the unavoidable inequity in the provision of single grants, the need for a firmer approach by the Trust to access external funding public and agency

provision (social services, Warm Front etc) to balance the advocacy support by Haemophilia Centres when representing individual registrants.

The suggested adaptations to the business case were considered and noted.

Members and staff present, excluding the Chairman and Chief Executive, divided themselves into two teams. It was clear that each team adopted the challenge of seeking to ensure that the block grant for support for 2006/7 was fully disbursed.

There was common agreement as follows:-

- That there should be a supplementary payment to meet higher fuel costs.
- That this supplementary payment should avoid any expectation of a similar payment in the following year.
- That this supplementary payment should go to all beneficiary households.
- That there should be a clearer definition in terms of convalescence and respite as presented.

Arising from this, the Chairman put the proposal (explicit within the paper) that there should be a supplementary payment of (circa) £650.00; this would meet not only higher than anticipated fuel bills but also go some way towards meeting some increases in cost of living expenses. After debate, it was agreed that this should go to each beneficiary household. The text of the letter announcing the payment would be a matter for further debate.

The suggested text in respect of respite and convalescence was considered. Opinions varied from a prescribed qualification for support to no qualification whatsoever. It was agreed that the text as suggested would be a matter for the NSSC at their next meeting.

Session 3

The Annual Plan

A first draft of the proposed annual plan is attached. (*Chief Executive's Note: The Chief Executive is meeting with Dr Chapman to give further consideration to the objectives contained within the plan*).

Session 4

The Risk Management Strategy

The risk management strategy was noted.

Mr Spellman's suggestion that an independent audit committee be established was deferred for discussion at a regular Board meeting during 2007.

The draft health & safety policy was accepted.

Closing Remarks

The Chairman elect, Mr Christopher FitzGerald, at the invitation of the Chairman thanked members for their contribution, affirmed his determination to push forward the aims and objectives of the business case "Funding Long Term Survival" and looked forward to his term of office as Chairman of the board of trustees.

The development day terminated at 4.00pm.