# THE MACFARLANE TRUST

# Minutes of the Meeting held on Monday 17 October 2005 at the Novartis Foundation, 41 Portland Place, London W1 from 11.00am

PRESENT		Mr P Stevens Mrs E Boyd Dr M Winter Mr P Spellman Mr S Gregg Mr C Hodgson	(Chairman) (Vice Chairman & Chairman NSSC)		
APOLOGIES		Mr <u>G Clarke</u> Mr <u>GRO-A</u> Mr <u>GRO-A</u> Mr W Payne	(Treasurer)		
IN ATTENDANCE		Martin Harvey For specific busines Mrs Susan Daniels	(Chief Executive) ss on the agenda (IFA)		
176.05	Apologies for Absence The apologies were recorded.				
177.05	<b>Minutes of the Previous Meeting</b> The minutes of the meeting held on 18 July 2005 were signed as a correct record.				
178.05	Matters Arising from the Minutes. 159.05 – Noted. 146.05 – Noted. 163.05 – (131.05 – 124.04) – Noted. 166.05 – Noted. 167.05 (Summer Payments) – Noted. Mr Spellman asked that, in light of the presentation at Dunford House on the legal duties that fall upon trustees in respect of their responsibilities towards prudent governance of the Trust, the minutes should record that a number of trustees present at the meeting did have a financial interest in the summer payment and that this fact should be duly recognised. The board agreed to this amendment and it will be recorded. The Chief Executive advised the board that arrangements were in hand to "tidy up" the Trust Deed to avoid any further confusion in respect of the future financial support from the Trust to user Trustees and, where applicable, payments to non-user Trustees.				

Mr Hodgson advised the meeting that he would have to absent himself at 1.00pm. The Chairman proposed, and it was agreed, that agenda items 204.05, 205.05, 207.05 be taken as the first three items of business.

## 179.05 The Business Case

The Chairman introduced the second draft of the business case and appendices to date that had been circulated with the agenda. He thanked the Board for substantive comments he had received on the first draft. On the second he had received from the Treasurer some very constructive suggestions mainly of a presentational nature, especially recommending that the summary should be developed into an executive summary; this would be done. He also advised the board of the excellent work undertaken by Mr Nick Fish who had taken on the responsibility for preparing the appendices. He advised members of the board that a new "appendix 2" had been laid around the table.

The Chairman noted that the matter of "debt", as part of the business case for increased funding, had yet to be included. He went on to mention the recent product liability settlement that has seen a compensatory award of 750K for another bloodborne viral infection and that this settlement could be used to put a price on HIV infection by contaminated blood products. Mr Spellman felt this if this figure was used as a lever in the business case, it might prove counter-productive. The Chairman felt that the mention of the settlement should be retained but was open to the form of the actual language.

(The debate then, briefly, moved away from the form of the business case and covered matters such as the Trust's new line of operational and policy reporting and the current staffing arrangements within General Health and Strategy & Legislation Branches.)

The debate then returned to the business case. The Chairman advised the board that he was seeking a ministerial meeting before the Christmas break and asked Mr Hodgson if Lord Morris could add weight to the submission of the business case. Mr Hodgson felt this support would be forthcoming and would make the appropriate enquiries.

The Chairman contrasted the business case with the Long Term Review, the core resource on which the business case was based. He felt the main area of difficulty was that 50% of the respondents to the survey in that said that they were financially secure. Members noted that it was probable that those best able to respond did so and that many of those that comprised the Trust's community of care, who were more in need, were less than able to respond to lengthy questionnaires.

Mr Spellman felt that the Trust should have a business case "number" in mind.

The Chairman said that there were two elements to the business case "numbers" (1) a capital payment and (2) an uplift in the block grant for general support. The capital payment should start at £750K and the strength of representations in respect of the need for a capital payment should be firm. For the uplift in the

block grant the Chairman had a "ball-park" figure in mind at  $\pounds 5m$ , but this would have to be based on the completed appendices. This would embrace some form of assistance for widows in terms of an uplift in regular payments and would fund items such as house repairs and other requests for help arising out of longevity.

Mr Spellman felt that in his experience a capital payment of  $\pounds750k$ , in the business case, would not succeed and asked what the cost of  $\pounds250k$  per registrant might be (+/- 380 x 250k =  $\pounds95m$ ).

There followed a general discussion on the "politics" of making the business case and it was agreed that an informal discussion with General Health Branch would be useful.

Dr Winter asked if the capital payment would go to all living registrants and exclude the bereaved; he felt that the bereaved would be angry if excluded and that the business case should embrace all beneficiaries. The Chairman noted this view, and observed the difficulty the Department would have in settling with Trust bereaved while excluding the bereaved from He noted the intention that additional the hepatitis C scheme. support for the bereaved would be from the block grant. It was resolved that the business case should include bereaved families and any possible capital payment should be linked to a likely sum that they might have received under normal life insurance risk management. It was recognised that the average life insurance risk cover would be to the order of £100/150k; it was resolved that a capital payment of circa £150k for bereaved families should be included in the business case. There followed a discussion on the possibility that the Trust might have to consider its future as a benevolent Trust if the business case was to succeed. It was resolved that the

possibility that the Trust might cease should be included in a side-document to the main business case.

In closing, the Chairman agreed that:-

- he would re-draft the draft business case where necessary.

- that work on the appendices should continue.

- that actuarial advice from Mr GRO-A and Susan Daniels be sought in respect of that element of the business case for bereaved families.

With these re-drafting points and others of a specifically medical nature referred to by Dr Winter accepted, the business case to date was approved.

# 180.05 Capitalisation of Revenue Support – "Buy-Outs"

The Chairman introduced the paper circulated with the agenda. He accepted that the initial response from the board to a verbal presentation of the buy-out proposition had been discouraging, but had proceeded to work on the idea in the interests of the three registrants who had raised the idea with him. He noted that the Charity Commission had indicated that the matter was one for the board of trustees although this had not yet been confirmed in writing.

He went on to say that a personal view from General Health Branch had been that "buy-outs" were a matter that might not necessarily find favour.

He advised the board that paper had deliberately refrained from mentioning any sums but it was felt that, based on actuarial calculations, the capital sums would be no more than £100k and no less than £70k. It was important for the board to note that financial well being was not the key driver to this proposal; rather it was independence from the Trust in an emotional and psychological sense. The value of this was endorsed by the board.

Dr Winter asked how this proposal might inter-face with the business case for increased funding.

The Chairman felt that the three registrants who had expressed an interest in the proposal should be advised to wait on the progress of the business case and that if the proposal was to go ahead, it would have to be made available to all registrants.

# 181.05 The Honeycombe Legacy

The Chairman advised the board that the one payment to date had taken account of the interest that would have been generated over a year and asked if there should be a defined period when applications would be entertained.

The Board noted that it had been agreed that capital would be spent in certain circumstances. There was no agreement on a defined period when the board would entertain applications from the legacy fund.

The following applications were either ratified or considered:-

- 1494W ratified the earlier agreement.
- 1990W that the application be funded form the Trust's block grant. Prior to the distribution of funds, Mrs Daniels would undertake a review visit of the circumstances leading up to the application.
- 1410W that the application be funded from Trust's block grant.
- 1384W that the application be funded from Trust's block grant, also with prior investigation by Mrs Daniels. That element of the application for gym membership assistance should be declined.

## **182.05 1059 – An Appeal** The Chairman the Chairman of the NSSC gave a background report to the circumstances and financial constraints leading up to this final stage appeal and the report from the Mrs Susan Daniels circulated with the agenda.

After a broad discussion, it was resolved that the loan of £5560.00 be converted to a grant and that the back-payments comprising loan deductions already received should be refunded

but used to reduce towards any credit card debts remaining and that this debt reduction exercise should be managed through Mrs Susan Daniels.

#### 183.05 Chief Executive's Report

The recent dismissal of Jude Cohen (HSS) and the current situation in respect of Ms Claudette Allen was referred to and discussed in detail.

The fact that an apparent breach of the Trust's electronic and manual filing systems by an anonymous party who had furnished Ms Cohen with information that was either legally privileged and/or confidential had occurred was regarded as a serious breach of confidentiality and it was resolved that the matter should be referred to the authorities. (*Chief Executive's Note: Prior to referring the matter to the authorities, the Chief Executive has sought advice from David Downton & Co as such action would have an impact on current legal proceedings – the EAC have been consulted*).

The report was accepted.

## 184.05 Financial Reports

1) Second Quarter grants & regular payments summary The grants & regular payments summary was received. The board asked for clarification in respect of grants made under the 40HM code for office and trustee payments. They are attached with an explanatory note.

2) The Investment Report

The board noted that the yields stated in the report had not achieved benchmark parity and the reasons given.

3) Management Costs

These were noted.

4) Investment Policy Recommendation form the Treasurer The Chairman proposed that the recommendation from the Treasurer, that the equities proportion be shifted to a target of 70% (65-75% parameter) and that cash and fixed interest be shifted to 30% (25-35% parameter) with that element of the portfolio being equally split between PIM and COIF, be accepted. The board accepted the Treasurer's recommendation.

# 185.05 National Support Services Committee

The Chairman of the NSSC presented the minutes of the meetings held on 29 July 2005, 2/3 September 2005 and 5 October 2005 and these were received.

# 186.05 The HIV in the Family Project

The Chairman presented the papers circulated with the agenda. He referred to the presentation form Mrs Sian Edwards art the Trustee Development Weekend.

The board resolved that the project should receive support from the Trust and that counselling support should be made available when requested with applications for such support directed to the Trust; also that the project should feature on the website and that it should be an article of some prominence in the forthcoming newsletter.

# **187.05 The Employment Affairs Committee** The minutes of the meeting held on 2 August 2005 were received. The board resolved that the Chief Executive should have a separate computer divorced form the Trust network

**188.05** Haemophilia Society Issues The board of trustees noted that the new Chief Executive of the Society was now in place and that Mr <u>GRO-A</u> was now a trustee of the Society.

# 189.05 Department of Health

The board of trustees noted that the Trust's reporting lines had changed and that operational and policy matters were now separate in that policy was still under the aegis of General health Branch and operational matters were under Strategy & Legislation Branch.

The board noted that there had been a 2.5% uplift in funding of management costs.

# 190.05 Partnership Group Report

The chairman of the Partnership Group introduced the notes and made specific reference to the proposed mini PG. The notes were received.

## 191.05 Annual Plan Update

The board of trustees noted the draft annual plan for the 2005/6 financial year and the objectives contained therein. Mr Spellman felt that there should be an independent method of scrutiny to ensure that the trustees were fully appraised of the Trust's modus operandi and that their responsibilities in respect of governance and obligations arising from those responsibilities were appropriately monitored.

It was resolved that an "audit committee" of trustees be appointed in due course.

Mr Spellman felt that there should be a section in the annual plan that related to staff training and development. It was resolved that a section of this order would be included in the 2006 annual plan.

The report was accepted.

# 192.05 The Glasgow Event Report

The report, from Eileen Trust Caseworker, was circulated for the benefit of the full board of trustees. The board felt that the report was of significant and a quasi- bench-mark for the way the

Macfarlane Trust might seek to establish contact with the member beneficiary base. The report was noted.

#### 193.05 The Skipton Fund Report

The report prepared by the Company Secretary and Scheme Administrator was noted.

## 194.05 Any Other Business

The Chairman asked of members present if they had any further business not itemised on the agenda.

The Vice-Chairman brought to the attention of the board a difficulty a registrant was having in respect of an invitation that he should join the civil service pension scheme. It was resolved that the Chief Executive take the matter up, in the first instance, with General Health Branch at the Department to see if they could advise as to how such a delicate mater might best be handled.

Mr Spellman advised the board that the potential employer mentioned was subject to the most stringent rules in respect if an employee's rights to privacy.

The Chief Executive would explore this matter further as directed.

The diary for 2006 was agreed as follows:-23 January 2006 – 24 April 2006 – 21 August 2006 and 16 October 2006.

## The meeting terminated at 3.30pm

# 184.05(1) EXPLANATORY NOTE - AS REQUESTED.

#### Office Guidelines

	Onice Guiu	ennes				
	Trx Date	Registrant	Account Code	Description	Amount	
	15.4.05	1134	40HM-R	PPC	£93.20	
	8.6.05	2148	40HM-R	Assisted Con'	£1760.00	
	8.6.05	2148	40HM-R	Ancilliary Costs	£100.00	
	23.6.05	2070	40HM-R	Fertility Treatment		
	15.7.05	2001	40HM-R	Ancilliary Costs	£46.80	
	15.7.05	2001	40HM-R	ACU Saline Scan	£135.00	
	15.7.05	2001	40HM-R	Ancilliary Costs	£133.30	
	27.7.05	1023	40HM-R	PPC	£93.20	
	11.8.05	1029	40HM-R	PPC	£93.20	
	19.8.05	1512	40HM-R	3 Cycles of IVF	£1950.00	
					£5754.70	
Trustee Grants						
	Trx Date	Registrant	Account Code	Description	Amount	
	15.4.05	2051	43HM-R	M &PC	£28.00	
	15.4.05	1015	43HM-R	BA	£620.38	
	19.4.05	1845A	43HM-R	RS	£4285.00	

M&PC BA RS	= Medication & Prescription Costs = Bio-Alcamid Treatment = Reconstructive Surgery					
15.9.05	2001	401 101-1 (		£5249.28		
15.9.05	2051	43HM-R	M&PC	£28.00		
15.8.05	2051	43HM-R	M&PC	£28.00		
15.7.05	2051	43HM-R	M&PC	£28.00		
15.6.05	2051	43HM-R	M&PC	£28.00		
15.5.05	2051	43HM-R	M&PC	£28.00		
10.5.05	1173	43HM-R	Spectacles	£175.90		

#### 2051

This matter is the subject of review. The £28.00 payment is a regular pay supplement, agreed by trustees, for Chinese medicine and has been in place for several years. The individual is being written to say that the supplement will cease in three months; if he wishes to re-apply, then the matter will go to the NSSC.