

THE MACFARLANE TRUST

Minutes of the Meeting of the Board of Trustees held on Monday 14 July 2008 at the Novartis Foundation, 41 Portland Place, London W1 from 10.00am

PRESENT	Mr C FitzGerald	(Chairman)
	Mrs E Boyd	(Chairman NSSC)
	Mr P Dolan	
	Mr R Evans	
	Mr S Fuller	
	Mr C Hodgson	
	Mr GRO-A	
	Mr P Spellman	
	Dr M Winter	(Medical Trustee)
APOLOGIES	Dr S Chapman	(Chairman EAC)
	Mr G Clarke	(Hon. Treasurer)
	Mr R Mishcon	
IN ATTENDANCE	Mr M Harvey	(Chief Executive)
	Mr N Fish	(Assistant to Chief Executive)

361.08 Apologies for Absence
The apologies were noted.

362.08 Minutes of the Previous Meeting
The minutes of the meeting held on 21 April 2008, previously circulated, were approved and signed as a correct record.

363.08 Matters Arising
346.08 (339.08) (d) The Board of Trustees received the Chairman's memorandum and proposed policy statement on the reserves. The Chairman alluded to the reasons why he felt that the assurances from the Department of Health in respect of future funding were sufficient to enable the Trustees to consider a less conservative approach to the maintenance of the reserves: that would be to maintain them at a level which would meet a forward expenditure need of 6 months for disbursement and operating costs, plus a buffer of 10% in the first instance to make some allowance for market variations, in place of the current policy of 12 months cover. In the same context, the Chairman drew the attention of the Board to the proposed statement on future reserves policy that would be incorporated into the annual report and accounts for the period to 31 March 2008. He felt that it would be appropriate to calibrate the reduction in the level of the retained reserve and accordingly the proposal stated a target reserve figure of £3m at the end of 08/09 with a formal review prior to any further diminution of the

value of the portfolio. The Chairman added that the level of reserves to be utilised for enhancing the disbursement fund would be dependent on the policy recommendations currently being discussed within the National Support Services Committee but that it was appropriate for the reserves policy statement to be debated and included in the annual report and accounts for the period to 31 March 2008. The Chairman advised members of the Board that he had been in full consultation with the Hon. Treasurer about this matter. In response to a question from Mr Evans regarding how funds received from the Department were deployed pending disbursement, the Chairman assured the Board that these were not passed to the Investment Managers but held directly by the Trust in an interest bearing account until needed. In response to a further question from Mr Evans regarding the inclusion in the financial reports of a source and application of funds statement, the Chairman guided the Board to finance paper 374.08/1.3. He pointed out that the estimated income on the reserves should also be included as it was already Trust policy to utilise this income in support of beneficiaries. An additional £200,000 should then be recorded, demonstrating only a very small deficit for the 08/09 period. He also pointed out that, although there was an over-spend for the current quarter, this was largely due to the non-recurring disbursement item "Summer Payment" and the timing of that cash outflow.

In response to a question from Mr Fuller regarding secured loans and whether they were properly treated in the accounts as assets which were fully recoverable even though they were not repayable until the secured property was sold following the death of the primary beneficiary and his/her partner, the Chairman acknowledged that any risk of non-payment could have an impact on the reserves and that this should be looked into.

Mr Spellman suggested that there was a need for a clear statement as to why an element of the reserves was being utilised and why this was being done now. The Chairman reminded the Board that this was largely due to the commitment now expressed, with all the usual caveats, by the Department of Health.

Following the wide ranging debate, the Board approved the proposed policy changes and further approved the statement to be included in the annual report and accounts for the period to 31 March 2008. It was also agreed that the investment policy would have to be addressed in the light of this new reserves policy and any changes in welfare support policy when those were agreed.

346.08 (e) The Chairman invited members of the Board to review the accounts and to report any comments they might have. He advised the Board that the Chairman's Statement and the Trustees' Report would be circulated in due course and

members would be invited to approve that text. Messrs Dolan and GRO-A pointed out that their geographical representation was incorrect; Mr Dolan asked that Lanarkshire be replaced by Scotland or Glasgow and Mr GRO-A asked that Worcestershire be replaced by Warwickshire.

349.08 The revised Trustee Information paper was noted and approved. It would now form part of the Trust's "Trustee Induction Information Pack".

350.08 (2) The Board of Trustees were advised that there had been no further correspondence in respect of the appeal for support with dietary supplements from 1902. The arrangements in respect of financial support for the supplements had been discontinued.

The Chairman reminded the Board that there were several Trustees whose terms of office were due to end in March 2009. They were Dr Winter, Mr Spellman and Mrs Boyd (DH) Mr Hodgson, Mr GRO-A and Mr Dolan (HS) and Mr Clarke (MFT). He alluded to the lengthy recruitment process that was involved, in particular where the member of the Board was nominated by a body with the right of appointment and asked those concerned should give some thought as to what they wished to do. He also reminded the Board that the re-appointment of members to the National Support Services Committee had been deferred until the composition of the new Board of Trustees was known. He confirmed that Dr Winter had written to him confirming he would not be seeking re-appointment by the Department of Health and that steps were in hand to find a successor which may or may not be a Haemophilia Centre Director. Mr Hodgson advised that he would not be seeking re-appointment as a Trustee by the Haemophilia Society.

352.08 – Mr Evans (Chairman of the Long Term Funding Working Party) reported to the Board on the activities of the Working Party and drew attention to the draft report prepared by First Actuarial which had been tabled. He apprised members of the report and the options therein and said that the actuaries would be prepared to speak either at the meeting of the Board on October 27 or at the preceding Strategy and Development day. He alluded to the presentation given by the Chief Executive and Mr GRO-A at the recent Men Only event and spoke about the difficulties that had arisen in terms of communicating the work of the Working Party to the wider beneficiary constituency, in particular the representations arising from members of the bereaved community. He reported that the aim of the Working Party was to report in October to the Board with the opportunity to discuss the report at the preceding Strategy and Development day. If the report was accepted, his aim was to organise a formal consultation exercise with the primary beneficiary community, having full regard at the same time to the position of other beneficiaries, and thereby to take forward the options for debate. Mr Evans asked members of the Board to report to him any

observations they might have on the report from First Actuarial. Mr Fuller opined that, although the full meaning of the aims and objectives of the Long Term Funding Working Party may not have been fully absorbed at the Men Only weekend due to the range of other business that was under discussion, the presentation was nonetheless well received. Mr Evans was congratulated on the work of the Working Party to date.

364.08

Chief Executive's Report

The Chief Executive went through his report page by page and invited comments. Matters raised included the following:-

- The Chief Executive cited the office staffing arrangements in respect of Miss Baker Benjamin's maternity leave and said that Mr Baker would be acting in Miss Baker Benjamin's stead and that a temporary employee would be recruited to undertake general office duties. –
- The Assistant to the Chief Executive spoke about the continuing discussions in respect of trying to achieve supported conservative dental treatment and the ongoing representations surrounding this matter. He informed the Board that he had written to Janet Clarke (Chair of the Committee for Community and Public Health Dentistry), as suggested by the Chief Dental Officer, and that he was awaiting a formal response from her. He had also emailed Selina Master (Clinical Director of Dental Services for the Surrey PCT) and Chris James (the Chief Executive of the Haemophilia Society) both of whom provided positive email responses confirming their support for the proposal. In the coming week he would be writing to Margie Taylor, the Scottish Chief Dental Officer, to apprise her of the proposal. Dr Winter suggested that the Trust would stand a better chance of achieving its objective by approaching those that lose out financially through having to fund factor treatment for intrusive dental surgery. He would provide the Assistant to the Chief Executive with a contact name at the Haemophilia Consortium.
- The Board accepted the view of the Chief Executive that in order to achieve value from the WFH Congress there should be additional representation from the community of care and possibly staff and Trustees. The Chief Executive was asked to prepare a likely budget scenario for the 2010 Congress in Argentina.
- The Board noted the Conference Coordinator's Report and the IT report prepared by the Office Administrator.
- At the request of the Chairman, the Chief Executive stated that a briefing note on the operational arrangements that existed in the office in respect of the inter-face between the Macfarlane Trust and the Skipton Fund would be attached to these minutes.
- In respect of the outsourcing arrangement with the THT, the Chief Executive was asked to ensure that a proper feedback and case reporting process was established.

- The Chief Executive confirmed the revised arrangements for the annual remembrance service which in 2008 would be held in the Chapel at St Thomas's Hospital, Vauxhall.
The remainder of the report was noted.

365.08

National Support Services Committee

Mrs Boyd, Chairman of the Committee, presented the minutes and schedules of support payments from the meetings held on 7 May and 12 June. The minutes and schedules were noted. In response to a question raised, the Board was advised that when dealing with requests for respite and/or convalescence, these matters were considered on a case by case basis and that the restriction to designated centres for respite/convalescence had been removed. Mr Fuller felt that this change of policy was understood by the community of care and that there was no need to issue new guidance now but it was agreed the Office Guidelines would be re-considered at the time they were next due to be re-issued.

The Chairman of the Committee drew the Board's attention to the papers, circulated with the agenda, that had been considered by the Committee on 12 June. She invited the Board to consider each paper and the NSSC's recommendations. After a detailed discussion, it was resolved that representations should be made to the Department of Health on the category (g) claimant situation and the equalisation of treatment in respect of female infected adults but that the texts of the letters should be agreed by the National Support Services Committee in each case. Mr Spellman suggested approaching the Department of Health on the basis of asking them to explain why there were these differences in the capital payments rather than simply asking the Department for additional funding. It was agreed that a Trustee of the MSPT2 and the Chief Executive should jointly sign any letter in that respect.

The Chairman alluded to the suggestion by the Department of Health that there should be a merger between the Macfarlane and Eileen Trusts but suggested that this was not presently feasible, particularly in light of historical differences in capital payments between the two Trusts and their respective disbursement policies. The Board noted these sentiments.

366.08

Paper from Mr Mishcon

The paper circulated with the agenda was received. The advice from Berwin Leighton Paisner (BLP) was also received. The Chairman advised that the paper was a summary of Mr Mishcon's conclusions and recommendations and he felt it raised important issues that should be debated at the forthcoming Strategy and Development day in October. The Chairman noted that, in his view, the advice from BLP was fully supportive of the strategic direction taken by the Board in relation to welfare policy and beneficiary support over the 18 months since the last

Trustees' Strategy and Development Day in November 2006, while acknowledging that this was a continuing process with more to be done in developing greater differentiation among beneficiaries in terms of financial need. The next stage in this direction was already being developed within the NSSC and was to be the subject of further discussion at the Trustees' Strategy and Development day in October. The Chairman went on to say that informal advice had been taken from the Charity Commission and that the person contacted had no difficulty with the Trust's current approach to disbursement of funds to relieve financial and health related needs.

The Chairman advised the Board that he and the Chief Executive had met with the Immediate Past Chairman of the Trust and his predecessor and each of them had confirmed that from the inception of the Trust it had been the considered view of the Trustees that it was both right and proper to take into account health as well as financial need. They had said that this was on the basis that in consequence of their conditions the Trust's primary beneficiaries all had needs which were self-evidently exceptional and which the Trust had been designed to relieve. Both had also said that there was neither the time nor the resources to carry out individual means testing which it had been agreed by all the then Trustees would be unduly intrusive. The Rev. Preb. Alan Tanner had added that at the inception of the Trust civil servants from the Department of Health had been present at all meetings when welfare and disbursement policies were considered and these had been fully endorsed by them. Members of the Board expressed various degrees of concern and disappointment regarding the contents of the summary paper and the way in which the author's views had been expressed. After several significant observations, the Chairman was mandated to bring the views of the Board to the attention of Mr Mishcon.

Regarding the question of publication, the Board was unanimously of the view that this was not in the interests of either the Trust itself or its beneficiaries. It was felt that there appeared to be a number of statements and assertions which should be challenged as unfairly impugning the governance of the Trust, both past and present. It was agreed that the Assistant to the Chief Executive would review the document to see whether there might be sections in the dissertation that could be adapted so as to make it possible for the Board of Trustees to agree to publication of the dissertation in an expurgated form and that the Chairman should meet with Mr Mishcon to explore whether there might be some common ground in that regard.

The Board received the papers circulated with the agenda and noted the progress to date in respect of the terms and conditions of employment of the Chief Executive. It was agreed that the Employment Affairs Committee would review their proposals and conclude their discussions with the Chief Executive and that their recommendations be brought back to the October meeting of the Board.

369.08 The Annual Plan Update 2007

The plan with the current update and previous update positions was noted.

370.08 Trustee Strategy and Development Day 2008

The arrangements for the Strategy and Development day to be held on the 26 October were noted.

371.08 Risk Strategy & Assessment 08/09

The Chairman asked that the paper be deferred again to the October Strategy and Development day and this was agreed. The Chief Executive asked members of the Board to review the paper in its current form and to advise of any material that should be added or excised.

372.08 Partnership Group

There was no business conducted during the quarter (*Note The revised date for the next meeting is 18 August*).

373.08 Financial Reports

The reports circulated with the agenda were noted.

- 1) The schedule of grants and regular payments for the first quarter of the 08/09 financial year was noted as being within budget parameters. The schedule of disbursements for the first quarter of the 08/09 financial year was also noted. It was agreed that a revised statement of the indicative costs and income which would include estimated income on the reserves should be distributed with the minutes.
- 2) The investment report for the first quarter of the 08/09 financial year was noted.
- 3) The first quarter management accounts for the 08/09 financial year were noted.
- 4) It was agreed that the indicative disbursement reports and budget for the full year would also include estimated income on the reserves.
- 5) The proposal from the Hon. Treasurer in respect of the procedure for drawing down from the retained reserve fund was noted and approved in the following terms:-
 1. The limit for any one withdrawal of funds from the capital of the reserves be set at £300,000.
 2. The instruction for any withdrawal up to this limit be signed by the Chief Executive and either the Chairman or Hon. Treasurer.

3. To support that instruction, there should be a copy of the relevant minute from a meeting of the Board of Trustees confirming the authority and stating the reason for the drawdown.
4. In the event that authority from a duly convened meeting of the Board of Trustees is not practicable, the Investment Managers are to be furnished with a note of the "round robin" procedure giving the authority for the drawdown and the reason for the transfer of funds.
5. In the unlikely event that a drawdown of more than £300,000 is needed, this would require a comprehensive statement of case from the Chairman of the Board of Trustees and the Hon. Treasurer which would be considered at the next duly convened meeting of the Board of Trustees.
6. For the disposal of any significant (£100-300,000) segment of the Trust's investment portfolio, as with the day to day management, of the portfolio, the Trust will require its Investment Managers to be mindful of the Trust's investment policy so as to ensure that the balance of assets retained matches the investment policy guidelines.

374.08

Any Other Business

Mr Dolan reminded the Board of Trustees that the recent ruling by Lord MacKay of Clashfern in terms of the forthcoming judicial inquiry in Scotland was UK wide and not just pertinent to Scotland. He mentioned the recently published article by Mr Frank McGuire and it was agreed that this should be attached to these minutes.

The next Trustees' Strategy and Development Day will be held on 26 October 2008.

The next meeting of the Board of Trustees will be held on 27 October 2008.

The first meeting of the Board of Trustees in 2009 will be held on 26 January at Alliance House.

The meeting terminated at 1.20 pm.

Minute 364.08 refers

Skipton Fund/Macfarlane Trust Inter-Face

Skipton Fund Ltd (SFL) is an agent company, wholly funded by the Department of Health, to administer the ex gratia payment scheme to those that were infected with Hepatitis C condition by way of contaminated blood products through their treatment by the National Health Service.

The Macfarlane Trust, because of its experience and history as a disbursement organisation, was invited by the Department of Health to assist in the establishment of SFL.

In order to ensure that SFL and the Macfarlane Trust (MFT) are kept entirely separate the following procedures are strictly adhered to. The Chief Executive, although a Director of SFL, does not approve SFL applications for payment which are processed by the Scheme Administrator. He does, however, sign off the schedules of payments and carries out spot-checks on all forms that have been signed off.

He also supports the "traceline" process with the NHS to verify patient records.

SFL is independently covered by its own insurance policies. All costs incurred by SFL (rent, utility charges, post and telephone) are apportioned between the two bodies. SFL has its own bank accounts. The MFT Finance Manager makes the apportionments.

The salary of SFL's Company Secretary is paid fully by SFL and a re-charge is made to the MFT for his services as Assistant to the Chief Executive. The Company Secretary of SFL is also the Scheme Administrator.

SFL pays the MFT Finance Manager an hourly rate according to the number of hours spent. There is an agreement to pay the Directors of SFL a rate of £25.00 per hour. No other Trust staff carry out work for SFL.

**Medical Matters: Time is
of the essence for a local GP**

Time to stop playing NHS politics with HIV and Hep C infection

I HAVE just returned from an "inquiry" in London into hepatitis C and HIV infection in the NHS. It is particularly concerned with the situation in England and Wales. I add the parenthesis not as any sign of disrespect for the inquiry but more to qualify what it is – or rather, what it is not.

It is not an inquiry set up by the Westminster government, nor is it a Westminster parliamentary committee inquiry and, above all, it is not a judicial inquiry. It cannot compel witnesses to attend or give evidence, compel the production of documents (a contentious issue in the history of hepatitis C infection) or test the evidence of witnesses and experts by others represented at the inquiry.

In particular, its powers are limited regarding those to whom it would look for evidence and explanations on the question of hepatitis C and HIV infection, including the NHS, relevant ministers at the time, the Department of Health, civil servants, the blood transfusion services and others.

In the complete absence of such a judicial inquiry, the victims have been left to set up their own private inquiry, at their cost and the goodwill of its chairman, Lord Archer.

Of course, when such an inquiry reaches its conclusions, the Westminster government and others could dismiss its findings, voice concerns about its limited nature and no doubt damn with faint praise where it pointed up some relevant matters.

The situation, by stark contrast, is entirely different in Scotland. Here we have a judicial inquiry under Lady Cosgrove, instigated by the Scottish Government, complying with the call of the Health Committee of the Scottish Parliament to hold an inquiry and above all, as a response to Lord Mackay's judgment in the Court of Session.

Lord Mackay's judgment set aside the Lord Advocate's decision not to hold an inquiry into two hepatitis C deaths (one transfusion and one haemophilia, the issues for the families being germane to all of the other cases) and also gave a clear signal that if the Scottish Minister also refused, that decision would be set aside as well.

Notwithstanding the Scottish inquiry, there is little doubt that Westminster will continue to stonewall the question of any judicial inquiry in England and Wales. As for the Scottish inquiry, their mistaken belief might be that



**Frank
Maguire**

it is a Scottish inquiry involved only with Scottish matters which will not affect them.

However, those in Westminster will have to realise that Lord Mackay found that it was the state's obligation (and that does not just mean the Scottish Government or the Lord Advocate) to hold an inquiry into the deaths in question.

It is inevitable that the trail of evidence will also lead to Westminster, ministers at the time and the relevant departments. The infections occurred well before devolution.

Lord Mackay's judgment specifically identified systemic failures of bodies that may have been responsible as relevant to such an inquiry.

The state includes Westminster. If the Scottish Government and the Lord Advocate cannot fulfil the state requirements, the obligation to do so rests at the door of Westminster. It would not be a matter of political option or policy for Westminster but a legal obligation.

One way in which Westminster could readily fulfil its obligation would be for its minister to agree to a joint inquiry with the Scottish Minister under the Inquiries Act 2005 and that way we would be reassured at a stroke of covering all the facts and circumstances pertaining to Hepatitis C deaths in Scotland and a fulfilment of the State's obligation. The Stockline Inquiry is an example of a joint inquiry.

One has to wonder whether Westminster is going to be big enough to set aside its politics fuelled by an anathema to an SNP Scottish government and instead put the rights of its citizens and its own legal duties at the forefront.

However, the fear is Westminster will continue with its stonewalling resistance, passive or otherwise, to the detriment of those affected by hepatitis C and HIV through the NHS and notwithstanding that, ultimately, it can be compelled to co-operate.

● Frank Maguire is a solicitor advocate and senior partner with Thompsons Solicitors.