

MACFARLANE TRUST

DRAFT

Minutes of a Meeting held on 20th January 2003 at The Girls Day School Trust, 100 Rochester Row, SW1

PRESENT:	Mr Peter Stevens	Chairman
	Mr Gordon Clarke	Hon. Treasurer
	Mrs [GRO-A]	Trustee
	Mr [GRO-A]	Trustee
	Mr Chris Hodgson	Trustee
	M/s Tracey Morgan	Trustee
	Mr Patrick Spellman	Trustee
	Roger Tyrrell	Trustee
In Attendance:	Mrs Ann Hithersay	Chief Executive
	Mr Rodney Shepherd	Finance Officer
	M/s Zubeda Seedat	Department of Health
APOLOGIES:	Dr Mark Winter	Trustee
	Mr Anthony Yeaman	Trustee
	M/s Claudette Allen	Social Worker
	M/s Carol Clisby	Benefits Adviser

Introductions and welcome.

The Chairman introduced two new Trustees who had recently been appointed by The Haemophilia Society: He said that both new Trustees had been appointed because of their direct experience of haemophilia and HIV. [GRO-A] [GRO-A] was a registrant of the Trust and would replace [GRO-A] as 'user trustee'; Tracey Morgan was the partner of a registrant and would fill the vacancy left by the retirement of Pat Latimer at the end of December 2002. He welcomed them both on behalf of the Trustee Board and looked forward to working with them.

Tracey Morgan spoke briefly about her reason for wanting to become a Trustee of the Macfarlane Trust. As a partner of a registrant of the Trust she felt she should become more involved with the work of the Trust. She worked for the Office for National Statistics in Cardiff and hoped that her skills would be of use to the Trust in its forthcoming Review.

[GRO-A] said that he had been receiving HAART [Highly Active Anti Retroviral Therapy] for the past 6 years. As a result of successful treatment he now felt he had a new lease of life. He had recently completed a post graduate course and had been awarded a Masters Degree. He was continuing his research and spending time keeping fit. [GRO-A] said that he had felt it was time to become more actively involved in the work of the Macfarlane Trust and hoped that his knowledge and experience would be of value.

The Chairman also reported that The Haemophilia Society had re-appointed **GRO-A** to serve as Trustee for a further two years.

The Chairman reported that Chris Hodgson had been re-appointed last April to serve as Trustee for a further year. The Chairman had agreed with Chris and The Haemophilia Society that his term as Trustee should be extended to the end of July 2003 so that his term would end at the same time as his retirement as Chairman of The Haemophilia Society.

01.03 Minutes of the Meeting held on 29th October 2002

The Minutes of the meeting held on 29th October 2002 were agreed as a true record.

02.03 Matters Arising from the Minutes

There were no matters arising from the Minutes.

03.03 Chief Executive's Report and Statistics

The Report was noted. The Chief Executive said there was concern amongst registrants about proposed litigation against US drug companies through a joint action being taken by US lawyers acting through a British firm: Anderson Eden of Preston. Many Trust registrants had been approached to join in the action. To do this they had to register with the UK solicitors and get copies of all their medical records, so that these could be forwarded to the US lawyers. Registrants were calling the Macfarlane Trust for advice on whether or not they should join themselves in the action. Some had been worried by somewhat ambiguous wording about fees and costs.

After discussion it was agreed that the Chairman would ask Tony Yeaman to draft an 'advice note' that could be sent out to all registrants as soon as possible. The Note could be a joint action by The Trust and The Haemophilia Society.

04.03 Financial Reports

(i) Monthly Grant Summaries to 31.12.02

The Finance Officer said that single grant totals were running slightly behind those for the 9 months to December 2001 but considerably more than originally forecast.

Figures for the Bereavement Project would be revised for the final quarter of the financial year. The cost of the Partnership Group Review would be included in the final quarter's figures which would consequently be higher than for the same period in 2001/2002.

(II) Management Costs to 31.12.02

The Finance Officer confirmed that the Section 64 Core grant from Government had yet to be confirmed. To date the Trust had received a number of 'interim payments' which amounted to less than had been applied for for the financial year 2002/2003.

Staff costs were running below budget because the Finance Assistant had originally been included in the budget for the full year but the post had not been filled until September 2002. Any surplus Section 64 payments that might arise in the year would be offset against the deficit that had been carried forward from previous years.

Zubeda Seedat, speaking for The Department of Health, said that the Grants Unit had been very understaffed for a long time. Grants in excess of £100,000 were subject to special checking and at present the Department did not have staff to do this work. Zubeda confirmed that a further interim payment would be made shortly. Provision had been made for the budgeted amounts of funding to be available in the next 2 financial years, however this could not be confirmed yet. She felt that the Long Term Review would help.

(III) Investment Report

Unfortunately the value of the Trust's investments had fallen significantly over the financial year. No withdrawals had been made by the Trust since July 2002 but continuing falls in the stock market meant that there was little the Trust could do at present. It was confirmed that withdrawals should continue to be made from cash held on deposit. It was likely that funds would last until a further top grant was received from The Department of Health early in the new financial year.

Trustees agreed that there should be a review of Investment Managers' performance at the end of the financial year.

(iv) Draft Final Budget

The Finance Officer introduced the final budget for the year 2003/2004. He said that staff costs for the year had been increased to make provision for the appointment of a new Chief Executive should Ann Hithersay retire during the year. Bank charges had been reduced because it was proposed to move towards a form of direct payment into registrants' bank accounts for single grants as well as monthly payments. This should reduce the cost of banking and also reduce postage costs as it would no longer be necessary for registrants to return

acknowledgement slips to the Trust as proof of receipt of cheques. Postage costs in the current year had been revised to allow for the additional cost of distributing the new Handbook.

The Chief Executive said that whilst she did not feel ready for retirement at present, replacement of the post could be a costly business and it was important that adequate budgetary provision was made for it.

(v) Data Storage & Retrieval

The Chief Executive reported that staff had been exploring ways to store and retrieve data more effectively than the present method of keeping files of deceased registrants in many boxes and files of those still alive in a growing collection of filing cabinets. Apart from the risk of loss due to terrorist attack or fire, it was felt that there must be more efficient options available for storage of data today.

One system based on Sharpfind Data storage and Retrieval had been proposed. The cost of this would be in the region of £25,000 and would involve purchase of a new file server that would be used exclusively by the storage and retrieval system. After discussion in which the need to explore more efficient ways to store and retrieve data was accepted, it was agreed that the Chief Executive should seek and cost alternative options for electronic document storage and report back to Trustees. It would also be necessary to investigate the likely scale of the operation.

05.03 Risk Assessment Report 2003

Trustees reviewed the Report and pointed out that loss of political support at present showed a low risk, If this were to increase it could represent a serious problem for the Trust.

It was also noted that 'Legal Risks' had been omitted from the Report. The Chief Executive apologised for this and confirmed that these would be included in the next Report to Trustees. It was agreed that Risk Assessment was a topic that should be included on the Agenda for each Trustee Board meeting, particularly now due to increased risk of terrorist activity. It was agreed that a minimum level of records to be stored should be assessed and the Trust should then establish the most efficient method of ensuring safety of these records. It was agreed that the back-up disk from the file server should be taken out of the office for safe-keeping each night.

06.03 Department of Health Report

The Chairman reported that he had had a further meeting with civil servants in December 2002. Charles Lister had reported problems within the Legal Department of the Department of Health which had prevented a number of issues from being resolved. The issue of homosexual partners needed further work before a recommendation could be made to the Trust. In particular advice on 'recognition of legal partners' must be sought by The Department.

The Chairman confirmed that he and the Chief Executive were due to meet Hazel Blears, Minister with responsibility for Blood Policy, on 27th February. A 'Position Paper' had been sent to her Office towards the end of 2002. The Chairman would report the proposed US Litigation and explain that whilst the Trust had a responsibility to let registrants know that they should seek independent legal advice, the Trust could not advise people on whether or not to be joined in the Action.

Trustees agreed that the Position paper be amended as follows:

1.5

Add: ..share problems with relatives and friends 'and to approach statutory agencies'

1.7

Trustees wanted the aim of the meeting to be acknowledged as being 'the acceptance and agreement of points listed in 1.7 of the paper'.

07.03 Long Term Review

The Chairman reported that the Long Term Review had arisen from a meeting with The Department of Health at which Charles Lister had said that it was time for Government to make a new 'political commitment to the Trust'. It had been agreed that in order for this to happen the Trust should carry out a further Review to mark the 15th anniversary of the establishment of the Macfarlane Trust in 1988. At the previous Trustee Board Meeting it had been agreed that an external consultant be appointed to manage the Review process. The Chief Executive had prepared a brief that was sent out to 4 Consultants in November. Two had responded and both proposals met the terms of the brief and fell within the costs submitted to The Department in September. It was hoped that after a rigorous analysis of both proposals, the Chairman and Chief Executive would be able to select a consultant to manage the Review.

The Chairman saw the Review as being a means to establish new priorities for the Trust and look at different ways to use limited funds rather than seek to increase funds made available by The Department.

The Chairman had invited [GRO-A], Tracey Morgan, Pat Spellman and Mark Winter to join him in forming a Monitoring Group to oversee the work of the Review. A first meeting of the Group would take place soon after Peter Stevens returned from India.

08.03 Annual Plan

The Chief Executive said that the Annual Plan for 2003 was seen as being complementary to the Long-Term Review. It would be an opportunity for Trustees to take a close look at the Trust Deed and create a new vision for the Trust that would take into account the very significant changes that had taken place in the 15 years since the Trusts was set up. The Plan would review what the Trust does for registrants now, and measure its impact. The Plan would include possible new ways to achieve impact and also look at the wider beneficiary group and in particular what the Trust does for widows and dependents and what might be done to better meet their needs.

The Chairman had invited Gordon Clarke to lead a Group to monitor development of the Annual Plan. Gordon would be joined by [GRO-A] [GRO-A], Roger Tyrrell, Ann Hithersay and Zubeda Seedat. It was agreed that the Group would initially meet together 'face to face'. After a first meeting it might be possible to continue the work through use of Conference Call facilities. Gordon Clarke was very familiar with BT Conference Call facility and recommended this process.

09.03 Partnership Group Review

The Chairman reported that two meetings of the Review Group had taken place; both facilitated by Hilary Barnard. The Chairman had been very impressed and felt that at the second meeting he was able to see the emergence of an effective 'user group' which would be a really positive outcome to the Review. The Partnership Group had expressed a willingness to become involved in the drafting of the Questionnaire and planning Focus Groups. These activities would form an integral part of the Long Term Review process.

Charles Lister at The Department of Health had indicated at the last meeting that he would be happy for a delegate chosen by the Partnership Group to participate in future quarterly meetings with The Department. The Partnership Group had been asked to decide how a representative would be chosen from amongst their number.

The Partnership Group had also identified that greater involvement in the Group by Trustees would be useful. They had suggested that an informal Day might be held to build a strong foundation for an effective relationship between Trustees and the Partnership Group. The Chairman said he would welcome more Trustees being involved with the Partnership Group in future.

10.03 The Bereavement Project

It was noted that a full Report on the Project, together with a budget for continuing work in 2003, would be prepared for the May meeting of the Trustee Board . Trustees noted the Summary Report of responses from those who had attended the residential weekend meeting in October and looked forward to hearing more about plans for development of the Project.

It was possible that a further Bereavement Support Group would be established in Northern Ireland soon. Gordon Clarke was planning to meet Dr Elizabeth Mayne, one time Trustee of the Macfarlane Trust and for many years Centre Director of the Haemophilia Centre in Belfast, to discuss how such a group could be established.

Trustees agreed that the work of the Bereavement Project and similar initiatives to provide structured support to groups of beneficiaries was effective use of Trust funds. It was hoped that as a result of the Long Term Review, proposals would be put forward for a programme of such initiatives to provide practical support for specific groups.

The Chairman said that since Chris Hodgson would be retiring from the Trustee Board in July, he had asked GRO-A to take on chairing the Bereavement Project. Chris Hodgson had been invited to remain part of the Project Team in recognition of his experience and commitment to the Project.

11.03 Applications and Cases

Case 1982D – Acceptance of new ‘dependent child’

Trustees agreed that on balance of probabilities the child was the son of deceased registrant 1982. he had been accepted as the grandchild of parents of the registrant who had died before the child was born.

It was agreed that monthly payments should be made to the child’s main carer and that an ex-gratia payment of £8,000 be made in lieu of support not provided over the years.

Case 1416

No decision was made. The CEO agreed to check accuracy of monthly payments to the family and current Benefits status.

Case 1859

It was agreed that this particular case be approved but in future the Trust should ask for a full structural survey to be carried out properties on to be bought by registrants. The Trust would meet the additional cost of such surveys.

Case 1891D

A grant of £1,500 was approved to assist the dependent of a deceased registrant to learn to drive and purchase a car.

Case 2177

It was agreed to approve a grant of £675 to cover redecoration costs for this registrant who was unable to do the work himself due to poor health and mobility.

12.03 Social Worker's Report

The Social Worker's Report was noted. Trustees felt that visits to registrants were a particularly helpful use of staff time and welcomed the development of this aspect of the Social Worker's role.

13.03 Benefits Adviser's Report

Trustees noted the Report and welcomed reports that the Benefits Adviser was also making more Home Visits, often accompanied by the Independent Financial Adviser or the Social Worker. Reports based on these visits were particularly helpful to Trustees when making difficult decisions.

14.03 Any Other Business

(i) Policy on Gifts

The Chairman reported that at Christmas he had been given 2 bottles of wine by a registrant who had had a particularly difficult and time consuming insurance problem that he had been helping to sort out. The Chairman said this had highlighted the need for a Gifts Policy to be adopted by the Trust. He had discussed this with Roger Tyrrell and Pat Spellman. Pat had drawn his attention to a paragraph in the Nolan Report on Standards in Public Life. This had indicated that whilst Ministers were able to accept gifts up to the value of £125, as long as these were recorded, in his time at the Department of Health, the limit had been much lower: around £35.

After discussion it was agreed that the Chief Executive would draft a policy to be ratified by the Board at a later date.

(ii) Forthcoming NCVO Conference – Meeting the Mission

Details of this conference for Trustees, due to be held on 12th March at the Regent's college Conference Centre, had been distributed to all Trustees. Anyone wishing to attend should

email Ann Hithersay in good time for a group booking to be made.

(iii) Date and Place of next Meeting

The next meeting of the Trustee Board would take place on Monday 12th May at Alliance House, 12 Caxton Street, SW1.

There being no further business, the meeting ended at 2.25pm.