

THE MACFARLANE TRUST

Minutes of a meeting of the Trustees held at Alliance House,
12 Caxton Street on Friday 9th December 1988 at 3.00 pm.

Present: The Revd Alan Tanner, Mrs Guy, Mr Grinsted, Dr Jones,
Mr Knight, Mrs Leitch, Mr Palmer and Mr Stevens.
In attendance: Wg Cdr Williams and Mr Williams.

AGENDA

- 88.81 Apologies for absence
- 88.82 Minutes of meeting held on 24th October 1988
- 88.83 Matters arising
- 88.84 Finance
- 88.85 Allocations Committee
- 88.86 Insurance/Mortgage Protection
- 88.87 Information and Public Relations
- 88.88 Administration
- 88.89 Any Other Business
- 88.90 Date and place of next meeting

The Chairman welcomed all present to the meeting and before formally opening the proceedings he commended the staff for the amount of work that they had covered in recent weeks in dealing with the rush of applications in the pre-Christmas period.

88.81 APOLOGIES FOR ABSENCE had been received from
Mr Simon Taylor.

88.82 MINUTES OF PREVIOUS MEETING held 24th November 1988.
The Chairman asked for comments. None were raised,
and it was proposed by Mr Grinsted and seconded by
by Mr Knight that the Minutes be accepted as a true
record. This was agreed unanimously and the Minutes
were signed by the Chairman.

88.83 MATTERS ARISING

It was agreed that there were no matters arising from
the previous Minutes that would not be covered by the
current Agenda.

88.84 FINANCE

The Administrator reported that because of the very
short time elapsed since the previous meeting a
further written summary had not been prepared. He
reported that the position remained unchanged with
regard to revenue and expenditure. It had however
been a bad month in terms of loss of capital on
investments and he reported that the Investments
Sub Committee would be reviewing the matter shortly.

The Administrator presented a new summary of Grants and Payments made and this is attached to the Minutes as Annex A.

88.85 ALLOCATIONS COMMITTEE

(a) Grants made prior to the meeting had been covered by Agenda Item 88.84.

(b) It was reported that at the morning meeting a further 16 cases had been dealt with and grants made totalling approximately £20,000. The increased mandate to the Administrator and Social Worker allowing them to make grants up to £1,000 as agreed in November had led to a marked reduction in the number of cases which had to be dealt with by the Committee and this had allowed the Committee to spend more time on each case and give greater attention to the more complicated ones.

(c) Two cases involving provision of assistance for self employment were put before the Trustees for consideration of the principles involved. There was no ready consensus on the amount of money which might be committed to projects of this nature or even on the principle of whether loans could be made at all for this purpose. There was general agreement that as the two cases under consideration had been outstanding for some months a practical solution to a positive decision should be pursued which might lead to the establishment of a principle for further cases. It was further agreed that there should be an upper limit to each project, based on which the Trust would be prepared to make a partial grant and that any further capital should be raised by loans from Banks and other institutions with the Trust possibly providing some security if necessary. During discussion a top limit for each project of £10,000 was selected with the Trust being prepared to make an initial grant of 25% of the total and if necessary to stand security for some part of the remainder. This proposal was put to the vote and was carried by five votes to two, the Chairman not voting. Mr Grinsted undertook to investigate the two cases in question and to negotiate as necessary with the Banks concerned in an attempt to assist the individuals and at the same time minimise the financial commitment of the Trust in each case.

88.86 INSURANCE/MORTGAGE PROTECTION

Discussion on this subject continued from the previous meeting. Mr Stevens reported that he had not been able to arrange a meeting between members of the Trust and representatives of insurance

companies and/or building societies but that he would continue his efforts to do so. It was reported that a considerable number of cases of arrears of mortgages were emerging and that this appeared to be a priority area where the Trust could possibly take effective action. In the ensuing general discussion no formal proposals were put to the vote and no policy decisions were taken. However there did appear to be a consensus on the following points.

(a) The Trust could not expect to provide mortgages as a form of compensation. In this as in other matters the aim of the Trust should be to preserve the life style of individuals from deterioration and to cater for the special needs arising from HIV.

(b) In following such a policy the protection of existing mortgages should be a priority. The Allocations Committee should therefore give sympathetic consideration to cases involving arrears of mortgage payments.

(c) Where difficulties occurred the Trust policy should normally be to seek to maintain the mortgage by means of regular payments rather than to settle mortgages by parting with large sums of capital.

88.87

INFORMATION AND PUBLIC RELATIONS

(a) Visits to Centres. Mrs Leitch reported on the visits which she and Mr Stevens had made to the Centres at Glasgow and Edinburgh. A copy of this report is attached as Annex B. Mr Williams had reported that he had made some visits to Centres for discussion with the professional staffs and that further visits were planned. It was also reported that a visit to Newcastle had been arranged and one to Cardiff was being negotiated. There was general agreement that further visits were desirable and that these should be pursued. However the Chairman stressed that it was essential that this programme should be co-ordinated and therefore ad hoc visits should not be arranged without reference to the office. It was agreed that a standard brief should be developed and updated as a result of feed back from the visits. The brief should include a list of the most common questions asked of visitors with our suggested standard line of answer.

(b) Sunday Times article. It was reported that the second article by Rosemary Collins in the Sunday Times had provoked no further action at all.

(c) TV interview. It was reported that the Link Programme which was broadcast by ITV on Sundays was preparing a programme dealing with people with haemophilia affected by HIV and this would include an interview with the Chairman. Broadcast date was not then known.

(d) Letter to MPs. Attention was drawn to a letter sent on 7th November 1988 by the Haemophilia Society to Members of Parliament giving them information of progress. Copies of this letter were distributed.

(e) In general discussion the subject of a further newsletter was raised, no timetable was set but it was generally agreed that it should probably be some time in February.

88.88 ANY OTHER BUSINESS None.

88.90 DATE AND PLACE OF NEXT MEETINGS

Further meetings were confirmed or agreed as follows:

Thursday 5th January Alliance House

11.00 am Allocations Sub-Committee

Tuesday 17th January Alliance House

11.00 am Allocations Committee

3.00 pm Trustees

Thursday 16th February venue to be notified

11.00 am Allocations Committee

3.00 pm Trustees

GRO-C: Alan Tanner

17th January 1989

Chairman

MACFARLANE TRUST

Summary of Grants Made

9th December 1988

A Single Payments

	No	Total	Amount	Overall
January to March	84		25,671	
April	25	109	8,812	34,483
May	21	130	11,611	46,094
June	59	189	23,627	69,721
July	37	226	19,733	89,454
August	43	269	25,533	112,987
September	23	292	14,835	127,822
October	68	360	39,663	167,485
November	108	468	65,498	232,983
December(to 8th)	60	528	32,791	265,774

B Regular Payments

156 payments

Backdating to Nov 87	144,330
Forward dating to Jan 13 89	32,450

Total **£176,780**

Overall total paid out **£442,554**

This overall total will certainly exceed £1/2 Million by the end of the year.

Notes on Regular Payments

Current maximum is £20 per week per person

As at 8 December

5	Payments are greater than £20 covering more than one person in a family
131	Payments are at maximum £20 per week
20	Payments vary from £5 to £15 per week

156	

There are already clear indications that the maximum per person should be raised when possible, and also that the thresholds should be lowered at least in some special cases. However, the commitment to regular payments is already £3,000 per week (£155,000 p a) and there is every indication that this will at least double (in the next 4-6 weeks) before the growth rate may begin to slow down.

Report to the Trustees.

SCOTTISH VISITS.

Christina Leitch and Peter Stevens had meetings in Glasgow and Edinburgh with a number of people, either HIV positive haemophiliacs or relatives, on November 7th and 8th respectively. Both meetings were organised at our request by the local Haemophilia Centre and in each case was represented by a Centre Director (respectively Drs. Gordon Low and Chris Ludlum) and by the Social Worker (respectively Miriam Guthrie and Geraldine Brown). The Edinburgh meeting was also attended by the psychiatrist and a nurse from the Centre. The purpose of the meetings was to explain what the Trust is doing and to answer questions. There were certain common characteristics at both meetings but also certain striking differences between the two; both are significant.

On both occasions the meeting was run by us without an "independent" Chairman, although this was less to the taste of the Edinburgh staff than in Glasgow. On both occasions the meeting started with the expression of considerable anger directed at us, although not necessarily entirely justifiably; at Glasgow this anger was moderated well within the first hour of the meeting which then became firstly neutral and then productive as a support group with little or no reference to the Trust at all; at Edinburgh the anger was barely assuaged at the end of two hours, at which point Dr. Ludlum brought the meeting to a close.

Glasgow.

The Glasgow meeting was held in a nurses rest room with people sitting informally in an approximate circle. The initial anger was directed at four points:

1. The inadequacy of the £10 million fund.
2. The decision by the Trustees not to pay all or most of the fund immediately on a lump sum basis to everybody.
3. "Means Testing".
4. A refusal by the Trustees to respond to one specific request.

It appeared that our explanations relating to the first three points were eventually accepted and understood; the claimant presenting the fourth was not satisfied but did at least stop pressing his claim throughout the meeting.

A significant part of the meeting in its later stages was taken up by a dispassionate survey by Dr. Lowe of the history of infection by and discovery of HIV in haemophiliacs, in response to questions about possible litigation.

The meeting was concluded after some two and a half hours, by when most discussion points appeared to have been settled, although informal discussions continued for some time thereafter.

No points were raised which required or suggested immediate action by the Trustees.

Edinburgh.

The only room available was a lecture theatre so the meeting was held with the two Trustees seated in front of people arranged cinema style. The anger was directed at similar issues as at Glasgow, although on this occasion there were several specific requests raised which it was felt had been inadequately handled. In addition a recently widowed lady was particularly distressed by what she regarded as delay and by the failure of the Trustees to substitute her name for that of her late husband on the address list; both of her points had, without anybody's knowledge, already been answered at the time of the meeting.

A considerable amount of time in addition was spent "discussing" the limits imposed upon us by the Trust Deed and anger was expressed at the fact the copies of the Trust Deed had not, as a matter of course, been sent to everybody.

Additionally anger was expressed related to haemophilia as much as to HIV: both those at the meeting and the social worker later, suggested that "people who have struggled all their lives with haemophilia ought to have special consideration now". In other words, the Trust's limitations to HIV-related problems only were a cause of dismay and it was thought that we should be more flexible, may be recognising that coping with haemophilia is made harder by the stress of being HIV positive.

The points raised came largely from a small number of people whose monopoly of the situation might have precluded other people from speaking; towards the end of the two hour duration of the meeting other people began raising points in the audience which suggested that they were still dissatisfied, and the meeting was closed most probably somewhat prematurely.

Several points raised required urgent attention.

Summary and Recommendations.

1. We are concerned that the difference in response to a large extent reflected the different types of help and support received by people from their Centre in the two locations.
2. The depth of anger expressed in both places suggest that the Trust must, as a first priority, hold similar meetings at all major centres before the year end.
3. The Society's assistance should be sought to assess which Centres are most likely to contain particularly embittered people; these Centres should be seen sooner rather than later (it is understood that Cardiff might be a prime candidate).
4. We should talk to the local professionals immediately before each meeting to get a good understanding of their attitude and how this could affect the meeting itself. (This was done briefly at both Scottish meetings, but the Edinburgh experience suggests that these pre-meeting discussions should be definite formal arrangements.)

5. We should insist that future meetings take place in an informal situation - e.g. like that of Glasgow rather than at Edinburgh - with the duration and conduct of the meeting determined solely by the Trustees.
6. Renewed consideration should be given to sending copies of the Deed, or at least of pertinent parts thereof, to everybody.
7. The next Newsletters must be brought out as soon as possible and should inter alia cover:
 - reports on these meetings;
 - money paid to date;
 - a repeat review of our allocation policy;
 - a repeated explanation of why we are not making immediate lump sum payments to "everybody";
 - some examples of "good" things we have been able to do.
 - review of housing finance and insurance.
 - discussion of self-employment and "interests"
 - indication of when, and on what, grounds we might return to the Government for further funds.
8. We should review our policy on needs arising from haemophilia which have been exacerbated by HIV but are not solely attributable to it.

PRS/e11/11.11.88.