

**THE MACFARLANE TRUST**

**National Support Services Committee  
7 October 2009**

**ATTENDANCE SHEET**

**Mrs E Boyd**  
Name .....

Signature ..

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**Mr P Dolan**  
Name .....

Signature

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**Mr** GRO-A  
Name .....

Signature

**Apologies Received**

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**Mr R Mishcon**  
Name .....

Signature

**Mr P Spellman**  
Name .....

Signature

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**In Attendance**

**Mr C FitzGerald**  
Name .....

Signature

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**Chief Executive**  
Name .....

Signature ..

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**Support Services Manager**  
Name .....

Signature

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361.09

**Minutes of the meeting of the National Support Services Committee held at  
Alliance House, Caxton Street, London SW1H 0QS on the 7 October  
2009**

**Present:** Mrs Elizabeth Boyd (Chairman)  
Mr Philip Dolan  
Mr Russell Mishcon  
Mr Patrick Spellman

**In attendance** Mr C FitzGerald (up to 367.09)  
The Chief Executive (for part of 367.09)  
The Support Services Manager

**Apologies** Mr GRO-A

**363.09 Apologies for Absence**  
These were noted.

**364.09 Minutes of the Previous Meeting**  
The minutes of the meeting held on the 2 September 2009 were signed as a correct record. The schedule of disbursements arising from the meeting on the 2 September were also approved.

**365.09 Matters Arising**  
359.09 (353.09) (334.09) the "Activate" reports for September, previously circulated by e-mail on the 1 October were tabled and noted. It was agreed that further information be asked for and that it should be included in the monthly reports:  
- a breakdown of the beneficiary groups.  
- further information in respect of the activities.  
- specific information about pain management and the possible conflict with services provided by CCCs.  
The report as presented was accepted.  
359.09 (355.09) Case 12 Update. The Chief Executive reported that to date there had been no further developments. The Support Services Manager informed the Committee that a full benefits review remained ongoing but was proving problematic due to different regime that operated in the Irish Republic.

**366.09 Policy Matters**  
1) Mr FitzGerald and the Chief Executive reported on the likely disbursement arrangements arising for the infected and non-infected beneficiary communities in light of the Government's response to the Archer Inquiry report. Mr FitzGerald referred to the

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meeting (where the Chairman of the Board of the Eileen Trust was also present) held on the 9 September and that it followed the exchange of letters that he had written to the Minister and that the Chief Executive had written to the lead official which the Committee had seen at the last meeting of the Committee prior to their despatch. He went on to say that there had been no replies but the letters were a matter of record and will be used for any briefing material should they be required by interested parties in the future. Mr FitzGerald said that officials were made very aware of the strength of feeling that resulted from the Departmental response to the Archer Inquiry Report. He went on to say that officials had said that the representations made would be taken back for review and that a definitive response would be forthcoming by the end of the month (September). He went on to illustrate the following key points arising from the meeting and what had transpired subsequently

- the global settlement for both Trusts would be £7.6m:
- the flat-cash would remain at 12,8k per annum.
- that the discretionary fund available would be in the region of £2m.
- that, as a first preference, efforts had been made to try and get an uplift to the flat-cash payment of £12,800 within the global allocation of £7.6m.
- as a second preference to allow additional discretionary support to the infected community as well as the non-infected community.
- that the Chief Executive had had off the record conversations with officials that led him to believe that discretionary support to the infected community would be sanctioned.
- that funding would be reviewed each year.

He then went on to talk about the new framework in respect of disbursement arrangements post-Archer

- that non-discretionary payments cannot be made via a discretionary Trust but the Department of Health remained sure that this would be possible having inquired of the Charity Commission. The question put to the Charity Commission by officials was not known.

- that, in light of the advice from Wilsons, there should be a non-discretionary vehicle to manage the 12.8k flat-cash disbursement..
- that he saw difficulties with making additional discretionary support available to the infected community, in particular in respect of financial need when taking into account the value of the non-discretionary payment and when taken together with benefits and earnings may well place some if not all primary beneficiaries in a relatively high income bracket.

He went on to say that a paper with a number of disbursement options that could apply to the infected community would be available for the Board to consider on the 26 October. In that

respect when taking matters forward, it was vital to make clear what the Trust felt it needed to do, in particular when seeking Charity Commission approval which was deemed vital; he gave an illustration of discretionary support which might be meeting the additional costs of living with HIV which were not recognised in isolation by the benefits system and were not considered to be an additional salary cost to be taken into account by any employer. Mr FitzGerald concluded by saying that if the given illustration as well as others that a paper would be scheduled in the paper top be considered on the 26 October were not acceptable to the Charity Commission then it would be necessary to resort to meeting discretionary support by way of single grants.

The Chairman asked about the payment of legal fees and it was confirmed that the Department of Health would meet the reasonable legal costs incurred.

Mr Spellman was of the view that a main aim of the Department had been to secure the removal of a supported organisation (the Eileen Trust) and that the reality was that matters had now moved on. There followed a brief discussion about linkage between the new funding for the Haemophilia Society and the post Archer funding arrangement; this was thought unlikely if at all.

Mr FitzGerald concluded by saying that at all times the Trust had remained consistent in seeking the best arrangement for the community of care but that he was aware and officials had been advised that the campaign would continue.

2) The Committee were of the view that this item be deferred pending receipt of the letter from the Minister and consideration of the paper on disbursement arrangements and possible options post-Archer that would be considered by the Board on the 26 October.

3) The Chief Executive referred the Committee to the letter from Lord Penrose that had been circulated with the agenda. He had nothing further to add other than to say the Inquiry secretariat had been advised that the Trust would respond positively if called to give evidence or prepare a submission for consideration by the Inquiry.

4) The Chairman reported briefly on the recent Trust weekend for families. A copy of the report from the Holistic Health Team in respect of therapies undertaken at the weekend was tabled. When the report from the conference coordinator was available, it would be circulated.

**367.09**

**Applications for Support including any circulated by “round robin”, cases, reviews and first appeals.**

Declarations of interest were made known where appropriate. The schedule of applications and other matters were considered by the

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Committee and a record of those decisions appears on the attached schedule.

**368.09**

**Any Other Business**

The Committee noted that the next meeting will be held on the 4 November.

The December meeting of the Committee will be held on the 17 December at the New Cavendish Club, 44 Gt Cumberland Place, London W1H 7BS to coincide with the annual Christmas lunch for the Board as a whole – details will be circulated in due course).

The meeting terminated at 1.45pm.

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# NSSC Decisions - 7 October 2009

Ref. No.	Description	Requested	Agreed	Deferred	Declined	Comments
<b>Discretionary</b>						
1318	Living Expenses (FA)	£250.00	£250.00	£0.00	£0.00	
		<b>£250.00</b>	<b>£250.00</b>	<b>£0.00</b>	<b>£0.00</b>	
<b>Cases</b>						
1114	Replacement Carpet (LF)	£801.46	£0.00	£0.00	£801.46	
<b>1114</b>	<b>Facial Lipoatrophy (HM)</b>	<b>£1,080.00</b>	<b>£0.00</b>	<b>£1,080.00</b>	<b>£0.00</b>	<b>Letter of representation to PCT</b>
1174	Repairs to Pathway (AA)	£178.00	£178.00	£0.00	£0.00	
1231	Satellite Communication System (SP)	£2,191.85	£2,191.85	£0.00	£0.00	
1279	Hospital Fares (MF)	£133.40	£133.40	£0.00	£0.00	
1058	Washing Machine (LA)	£289.00	£289.00	£0.00	£0.00	
1707	Carpet (LF)	£796.00	£796.00	£0.00	£0.00	
1986	Computer (EC)	£514.76	£0.00	£0.00	£514.76	
1699	Financial Assistance (FA)	£1,000.00	£1,000.00	£0.00	£0.00	
1987F	Loan Repayments & Financial Assist (FA)	£600.00	£0.00	£0.00	£600.00	
2050	Balance of School Trip (ED)	£122.40	£122.40	£0.00	£0.00	
2055	Financial Assistance (FA)	£261.00	£261.00	£0.00	£0.00	
1512	Computer (EC)	£899.00	£899.00	£0.00	£0.00	
1902	Microwave (LA)	£399.99	£100.00	£0.00	£299.99	
<b>2002</b>	<b>Extension (AA)</b>	<b>£8,500.00</b>	<b>£0.00</b>	<b>£8,500.00</b>	<b>£0.00</b>	<b>Deferred subject to additional info.</b>
1074	Moving Home (AL)	£4,000.00	£4,000.00	£0.00	£0.00	Offset against loan
1074	Setting Up Home (AF)	£3,000.00	£3,000.00	£0.00	£0.00	Offset against loan
2128	Respite Break (SH)	£1,339.00	£0.00	£0.00	£1,339.00	
2018	Financial Assistance (FA)	£500.00	£500.00	£0.00	£0.00	
2101	Dishwasher (LA)	£334.71	£150.00	£0.00	£184.71	
		<b>£26,940.57</b>	<b>£13,620.65</b>	<b>£9,580.00</b>	<b>£3,739.92</b>	
<b>Tables Cases</b>						
1185A	Mortgage Assistance (AM)	£500.00	£500.00	£0.00	£0.00	
1702	Roof Repairs - Appeal (AA)	£5,000.00	£5,000.00	£0.00	£0.00	
1845	Scooter (SP)	£4,500.00	£1,000.00	£0.00	£3,500.00	
		<b>£10,000.00</b>	<b>£6,500.00</b>	<b>£0.00</b>	<b>£3,500.00</b>	

Signed: .....

Date: .....

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# NSSC Decisions - 7 October 2009

Ref. No.	Description	Requested	Agreed	Deferred	Declined	Comments
1987D	Extend Holiday Offer	£0.00	£0.00	£0.00	£0.00	Agreed to the end of the financial year
1755W	Legal Fees (AL)	£661.25	£0.00	£0.00	£661.25	
		£661.25	£0.00	£0.00	£661.25	

Types of Requests		Amount	Agreed	Deferred	Declined
6	Accommodation	£21,178.00	£12,678.00	£8,500.00	£0.00
3	Education	£1,536.16	£1,021.40	£0.00	£514.76
5	Financial	£2,611.00	£2,011.00	£0.00	£600.00
1	Health	£1,080.00	£0.00	£1,080.00	£0.00
1	Mobility	£133.40	£133.40	£0.00	£0.00
5	Living Conditions	£2,621.16	£1,335.00	£0.00	£1,286.16
3	Stress	£8,030.85	£3,191.85	£0.00	£4,839.00
0	Loans	£0.00	£0.00	£0.00	£0.00
0	Honeycombe	£0.00	£0.00	£0.00	£0.00
1	WDF	£661.25	£0.00	£0.00	£661.25
0	DDF	£0.00	£0.00	£0.00	£0.00
0	RP	£0.00	£0.00	£0.00	£0.00
25		£37,851.82	£20,370.65	£9,580.00	£7,901.17

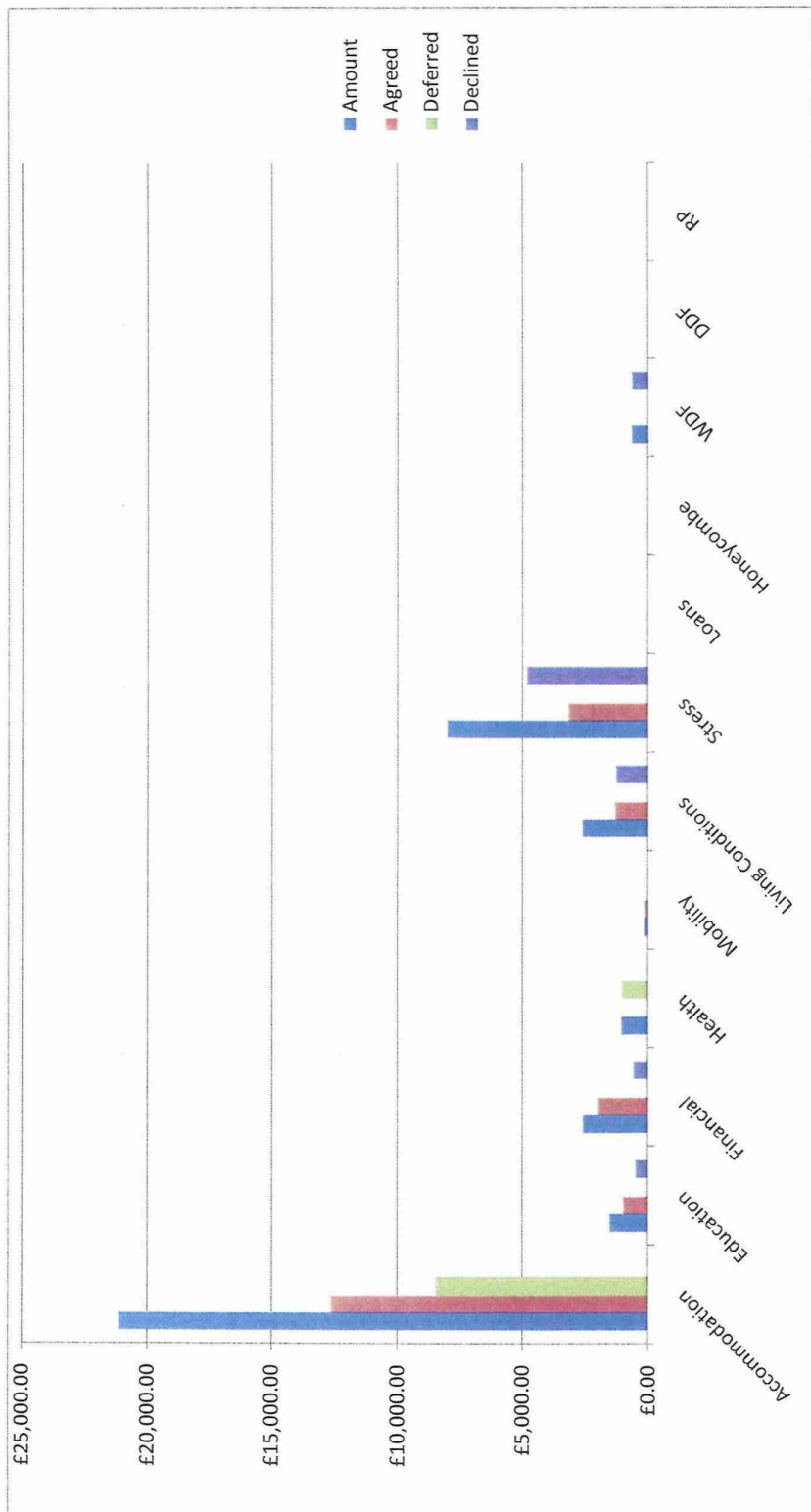
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# NSSC Decisions - 7 October 2009



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Date: .....

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