

**Minutes of the meeting of the National Support Services Committee held at  
The New Cavendish Club, 44 Great Cumberland Place W1H 7BS on  
2 December 2009**

**Present:** Mrs Elizabeth Boyd - Chairman  
Mr Philip Dolan  
Mr [GRO-A]  
Mr R Mishcon  
Mr P Spellman

**In attendance** Mr C FitzGerald  
Chief Executive  
Support Services Manager  
Support Services Officer

**366.09 Apologies for Absence**  
There were no apologies.

**367.09 Minutes of the Previous Meeting**  
The minutes of the meeting held on the 4 November were signed as a correct record. The schedules relating to disbursements were noted.

**368.09 Matters Arising (other than those itemised separately)**  
It was agreed that any matters arising from the minutes of the meeting held on the 4 November will be deferred until the meeting of the Committee to be held on the 17 December.

**369.09 Policy Issues**  
1) Mr FitzGerald updated the committee on the various meetings that have taken place, namely on 6 November, 17 November and 1 December 2009. Mr FitzGerald talked in depth about the issues arising and opined as follows:-  
- that the MSPT2 non-discretionary Trust, with amendments and additions to the existing Trust Deed, will be the interim vehicle to enable the post Archer non-discretionary payments (which will be in the form of a capital payment) covering the period from 20 May to 31 March 2009 will be made and in each individual case, regular payments under the existing Trust's disbursement policy will be netted off. It is anticipated that this disbursement will be made on or about the 15 December 2009 but this could not be confirmed as there were significant but not insurmountable legal

issues to be overcome, in the main to do with the re-casting of the MSPT2 Trust Deed and the need to make sure the Trustees indemnity was sufficiently widely drawn to protect them from any liabilities arising from this process. He opined further that it may well be that the non-discretionary disbursement might be held over to January 2010 but every effort was being made to meet the December 15 mooted disbursement date. The Chairman thanked Mr FitzGerald for his overview report and made the following observations going forward:

- That as there will be no regular payments after the month the non-discretionary payment is made until April 2010 it was vital this should be communicated to the primary beneficiary community in a manner that was understood.
  - The Committee noted that an electronic consent has been created in the sharing data and that any data will only be accessed by the current MFT staff. All primary beneficiaries and next of kin where necessary will receive a letter explaining the current situation and there will be a consent form with the letter to enable those without access to the website to complete and return the consent form.
  - Mr Spellman advised the Committee that it can take up to 21 days for government departments to manage the non-primary legislative process. This would mean that the new vehicle, to replace MSPT2 and make the non-discretionary payments can be reasonably established by the start of the 2010/11 financial year.
  - MSPT2 as the interim vehicle will have as corporate trustees/directors Mr Peter Stevens, Mrs Sue Phipps and Dr Simon Chapman and that their terms of office will end at March 31 2010. There will be a consultation exercise to appoint directors to the new non-discretionary vehicle and the Trust will make such recommendations to the Department of Health to enable the appointments to be made.
  - The Committee noted that the two trusts will not, in the short-term, merge as previously thought. It was further noted that the DH will make a direction as to the disbursement of the non-discretionary payments and how the balance for charitable disbursements should be apportioned between the two Trusts.
  - The Department of Health will meet the reasonable costs of the legal fees incurred in this process.
- Mr Mishcon referring to the position where it had been reported that income arising from the directed non-discretionary allocation for disbursement could not be retained, for example, to defray administrative costs arising and that it should be possible to include in the deed for the new non-discretionary vehicle a clause to reflect that requirement. *(Note: It would seem that such a provision could*

*be included in the letter of direction from the Department of Health and would be reflected in the agency agreement arising between the MFT/ET and the non-discretionary vehicle. The NSSC will be asked to consider their preference for report at the Trustees briefing meeting that will follow the meeting of the Committee on the 17 December)*

The frequency of disbursing the non-discretionary payments was considered. The Committee agreed that until the way forward had been confirmed, there was little point in taking this matter further until clarification as to payment of the allocation by the DH to the new non-discretionary vehicle had been settled.

2) The NSSC considered the paper, circulated with the agenda, entitled "Post Archer Discretionary Disbursement Arrangements to the Infected Beneficiary Communities of the Macfarlane and Eileen Trust".

#### Loans

The NSSC were asked to determine whether short term loans should continue to be made available to primary beneficiaries under the proposed new discretionary "top up" arrangement and whether they could be repaid from that source. Prior to making any determination, the NSSC have asked for details of existing loans to be made available with the following information:

- the purpose of the loan
- amount of the original advance
- the balance owing
- the frequency of repayment

#### Supplementary Payments

The Committee considered the proposed threshold for supplementary payments and the suggestion from Mr FitzGerald that they might be made to those with a household income of less than £50k gross. There followed a lengthy debate taking into account the level of discretionary disbursement against the reported net household income. A series of monetary adjustments were made to option B as presented to ensure that those on lower incomes received a higher supplementary payment and that those with a household income of over £50k, it was eventually agreed, would not receive any supplementary discretionary payment. It was further agreed that due to the various levels of payments and direct expenditure savings (which could be counted as notional income) made to those on Income Support that this category should be re-cast and that a census be carried out to establish the individual values of income support and that the resulting data would enable the individual primary beneficiary to be included in a given net income range. In the interim, it was agreed that as part of the overall recommendation to the Board of Trustees in January and as part of the Trustee briefing on the 17 December that option B, as

amended, would be used and that the supplementary payments would be tapered as follows:

- < £7,001 supplement of £4,000
- £7,001-£14,000 supplement of £3,000
- £14,001-£21,000 supplement of £2,000
- £21,001-£24,000 supplement of £1,000
- £24,001-£28,000 supplement of £1,000
- £28,001-£35,000 £0
- £35,001-£42,000 £0
- £42,000+ £0

*(Note: A revised schedule with a further variation was circulated to the Committee on the 4 December 2009).*

In further debate, Mr Mishcon firmly believed that the Trust should be rethinking its disbursement policies in light of Archer by taking families affected by this disaster into account in a more pro-active manner. Mr Spellman felt that a dedicated fund could be set up, utilising part of the retained reserve fund, to effect a quasi-insurance arrangement where it was clear that debts arising from the non-availability of life insurance/mortgage protection cover were apparent and need for such relief was established.

3) The NSSC referred to the paper, circulated with the agenda, entitled "Post Archer Draft Discretionary Disbursement Policy for the Non-Infected Beneficiary Communities of the Macfarlane & Eileen Trusts". The Committee were advised that it would not be realistic to believe that this policy area and any firm recommendation embracing all the issues arising could be contemplated at this meeting of the Committee. As a result, the Committee addressed the following key questions:

#### Who Qualifies as a Beneficiary?

After careful consideration, it was decided that the recommendation to the Board of Trustees about beneficiary qualification should include people who have given up their lives and their economic or educational potential to care for the primary beneficiary. These would include::

- Widows (with and without dependents)
- Carers (both current and former)

The Committee further considered as part of their recommendation that a qualifying beneficiary would include

- Orphans
- Estranged couples with dependents where those dependents are living with the non-infected parent
- Dependent Children

It was agreed that widows, without dependents, who have remarried or are co-habiting will not qualify as a beneficiary and in the event that that relationship ended, beneficiary status would not be resumed.

### Census Form

The census form, circulated with the agenda, was considered. Modifications were made to the census form and it was agreed that it would be divided into two separate parts. The first part to be sent will establish the details of the Bereaved Partner and Carer and will comprise/exclude the following:

Part 1 - will exclude Next of kin.

Part 2 - remains the same;

Part 3 - will exclude the Income and Expenditure form

Part 4 - will be replaced by Part 5.

The second form would consist of the beneficiary's details, next of kin and an Income and Expenditure enquiry form.

### Payments

Qualifying beneficiaries will be able to apply for single grants and some may receive monthly payments. The Chief Executive suggested that a lump sum payment could be made to the newly bereaved where there is no life insurance. Mr Dolan agreed with this and said that the Trust should, for various reasons, should limit the payments to certain individuals and that a lump sum of money should not be paid as a matter of course to all newly bereaved or the next of kin. Mr Mishcon put forward the setting up of a designated fund but stipulated that financial need has to be established before a payment can be made and that next of kin cannot automatically be accepted as a Trust beneficiary. Mr FitzGerald added that the lump sum payments should not just be made to the newly bereaved and that we should be considering extending the offer to those who were bereaved in the past and that the any amount made available should be considered on a case-by-case basis depending on financial need.

### Recommendations

Under the section "Way Forward", recommendation one has been agreed as per item 3 above, further recommendations are as follows:

1. That we continue with our current policy arrangements in respect of the non-infected community.
2. That the Board be invited to empower the NSSC to refine and develop a range of disbursement policies to be integrated and/or refined where necessary to meet the specific needs of this community.
3. That the new range of policies be introduced 1 April 2010 and reports are made available to the Board of Trustees with a full review at the year-end.
4. Single grants to primary beneficiaries will end after 31 March 2010.
5. The structure and composition of the NSSC to be reviewed in light of the new disbursement policies arising and what might

take place in respect of any review of the current governance arrangements.

6. Advertise through the Haemophilia Society for those who have been bereaved so that their beneficiary status could be considered.
7. The Trust needs to be proactive with regards to advertising the various funds available to support the beneficiary community..
8. A follow-up on all primary beneficiaries who have applied for financial assistance to set-up a commercial enterprise.

**370.09**

**Any Other Business**

The Committee noted that the next meeting will be held on the 17 December 2009 commencing at 10.00am. The venue will be the New Cavendish Club, 44 Great Cumberland Place, London W1H 7BS.

The meeting terminated at 3.30pm.