

Minutes of the third meeting of the National Support Services Committee (NSSC) will be held at 11am on 1st December 2004 at Alliance House, 12 Caxton Street, London SW1H 0QS

Present:

Mrs Elizabeth Boyd, Chair of the NSSC
Mr Stuart Gregg
Mr Peter Stevens, Chair of the Macfarlane Trust
Mr Roger Tyrrell

In attendance:

Ms Jude Cohen, Head of Support Services (HSS)
Mr Martin Harvey, Chief Executive (CE)

Apologies:

Mr William Payne

22.04 Minutes of meeting 23rd September 2004

Tyrell should be spelt with two 'r's. With this amendment the minutes were **agreed** as a correct record.

23.04 Matters arising

a. (21.04) It was noted that, with other diary dates already booked, 25th January 2005 is too short notice for the Trustees' strategy day.

b. (13.04c.) The Head of Support Services approach to setting fees for the Independent Financial Advisor was approved.

c. (14.04) 1534W It was **agreed** that the status quo should remain until the question of a re-mortgage is resolved. If this is not successful the NSSC will reconsider granting a loan.

It was **agreed** that reg. pay. for disabled widows should only be awarded where they are disabled at the time of bereavement, not if they become disabled later.

It was noted that 1534W is now in receipt of reg. pay. as a result of disability, and it was **agreed** that the Head of Support Services should stop this as soon as practical, in light of the ongoing casework.

24.04 Financial report

The financial report was tabled.

a. There was a discussion on the costs of the Bereavement Group, in particular the high fees of counsellors attending the Bereavement Weekend and meetings.

b. It was **agreed** that the Bereavement Group will be asked to prepare a detailed budget for the next financial year. **Action: Chief Executive**

c. It was suggested that a weekend for carers be added to the list of possible events for 2005.

25.04 One-off grant policies

a. There was a discussion on the policy for respite breaks, and it was **agreed** the old policy of allowing respite breaks as well as convalescent breaks be reinstated. It was also **agreed** that the new maximum £1,000 a year remain, and that in future supporting letters be accepted from medical staff at haemophilia centres but not from GPs.

b. Additional policies were **agreed** for domestic appliances, gym membership, clothes due to weight loss or gain, and beds/bedding

c. With these amendments and additions, the office guidelines for one-off grants were approved for implementation and circulation to registrants.

26.04 Applications and ongoing cases

1059 Top-up to house alterations grant from local authority

A loan of £8,000 was **agreed**, to be repaid by deduction of £100 a month from reg. pay.

1292 Repairs to roof

A grant of £4,050 was **agreed**.

1694 Dyslexia assessment for son

It was **agreed** the application be refused, as the local education authority should fund this if it is necessary.

1888 Yearly gym membership

It was **agreed** a grant of £582 be awarded, to be sent with a recommendation that a less expensive gym is identified for next year as this level of award is unlikely to continue.

1902 Thermal clothing

It was **agreed** the application be refused, as it is a retrospective application, there is no medical support, and clothing should be funded from reg. pay.

1975 Request for travel expenses for assisted conception

It was **agreed** to apply the new policy agreed under 25.04. (ie NHS rates).

2000 Three applications for mattress, cooker and additional home care costs

It was **agreed** that £200 be awarded towards the mattress, £300 towards the cooker, and the application for additional home care costs be refused.

2001 Applications for washing machine

It was **agreed** to apply the new policy agreed under 25.04. (ie a grant of up to £250).

2032 Respite break

It was **agreed** a grant of £1,315.93 be awarded.

1173 Two applications for additional support towards a motability deposit and a contribution towards the cost of complementary therapy

It was **agreed** a grant of £750 be awarded towards the motability deposit and the application for funding of complementary therapy be refused.

1318 School music lessons for children

It was **agreed** the application be refused.

1406W Review of case

28.04 Events planning

The outline plans for events for 2005 were approved.

It was noted that, as the events are largely dependent upon one 'volunteer', it is essential that contingency plans are in place for each of the events, in case of illness.

29.04 Further discussion of policy on assisted conception

It was **agreed** that this item be deferred to the next meeting of the NSSC.

30.04 Initial discussion on principles of regular payments

It was **agreed** the review of reg. pay. held as part of the review before last should be circulated to help with identifying the appropriate levels of reg. pay.

It was **agreed** that the basis of reg. pay. should be to relieve poverty caused by registrants' HIV status and to help reduce the additional stress caused by financial uncertainty.

It was **agreed** that, under the terms of the Trust Deed, a flat rate of financial support offered to all is not allowed.

It was **agreed** that the Chair of the Macfarlane Trust should contact a number of registrants know to be in 'well-paid' employment, to seek their views on the principle of reducing reg. pay. for individuals in this group.

Action: Chair of the Macfarlane Trust

It was **agreed** that reg. pay. should be an agenda item for all meetings until the action to be taken is determined.

It was **agreed** that the Board, the staff team, and the Partnership Group should all be asked individually to brainstorm suggestions as to how, if it were being set up today, the Macfarlane Trust should support registrants.

Action: Chief Executive, Head of Support Services, Stuart Gregg

31.04 Initial discussion on assets policy

It was **agreed** that this item be deferred to the next meeting of the NSSC.

32.04 Widows' business case

It was **agreed** that The Chair of the Macfarlane Trust and the Chief Executive will produce a discussion document for the next meeting of the NSSC.

It was **agreed** that this item be deferred to the next meeting of the NSSC.

33.04 Dates of meetings 2005

It was **agreed** that the February meeting will be held on the 23rd.

34.04 Any other business

It was **agreed** that, if necessary due to shortage of funds, grants will be paid to cover the overnight expenses of registrants attending the Life History Project Away Day.

The meeting closed at 5.30.