## MACFARLANE TRUST

# A PROPOSAL TO FUND ANCILLARY COSTS OF FERTILITY TREATMENT

### Background

For a period of more than 7 years, the Macfarlane Trust provided limited grant funding to assist registrants with the cost of fertility treatment, normally through insemination by donor. The reason for funding such treatment was to reduce the risk of pregnancies resulting from unprotected sex. Many couples managed to gain funding for this treatment without applying to the Trust. Many babies have also been born through natural conception. A number of mothers became infected with HIV due to unprotected sex and a number of these women have since died. Sadly in all cases where the child was born HIV positive, the child has also died. Some Haemophilia Centres have assisted couples to have a child through 'Timed Ovulatory Intercourse' and there have been requests from Centres for the Trust to fund Sperm Washing and other safer methods of conception.

In 1998, Trustees were concerned that if the Trust continued to assist couples by funding treatment they would be taking on a funding responsibility that should rightly rest with the NHS. Trustees were further concerned that if a woman became infected with HIV through use of sperm from a registrant, as part of a 'sperm washing programme', the Trust could be liable to be sued because it had paid for the service. As a result of these concerns, in September 1998 Trustees decided to discontinue all grant funding related to safe conception.

In recent years treatment for HIV has meant that provided the viral load of the registrant is 'undetectable', it is less likely that mother or child will become infected with HIV when Timed Ovulatory Intercourse or unprotected sex is used to enable a couple to have a child. Nevertheless, there will always be a significant risk of HIV infection from unprotected sex. The Trust must therefore have regard to reducing this risk wherever possible and try to ensure that where an HIV discordant couple wants a family, the safest means of conception is used. Up until about 18 months ago, this meant that the prospective mother would apply to her Health Authority for fertility treatment using donated sperm.

#### **Fertility Treatment Today**

Since 2000 it has been possible for couples to undergo fertility treatment using the HIV positive registrants sperm which is 'washed' using a technique developed in Italy more than 10 years ago. This treatment is the only known way that enables the couple to have their own baby with minimal risk of infection. However it is expensive and the success rate is low. Some Health Authorities may fund treatment for up to three cycles, others are unable/unwilling to fund at all. Over the years, Macfarlane Trustees have been keenly aware of the desire on the part of many Trust registrants to start a family. The matter of funding to enable couples to take part in fertility treatment programmes has been reviewed at least every 18 months since grants for this purpose were discontinued in 1998.

In October 2001 the Trust's Solicitors advised:

"The relief of persons who are infertile either through the provision of information advice or support or to pay for treatment is an accepted charitable purpose. The objects of the Trust are sufficiently wide to cover funding for such treatment and it is open to the Trust to meet the cost of such treatment, notwithstanding that this may be available through the NHS (at least in some areas). However, whether or not the trustees choose to fund such treatment is entirely a matter for their discretion.

Under Article 12 of the Human Rights Act 1998 men and women of marriageable age have the right to marry and found a family according to national laws governing the exercise of this right. While artificial and assisted reproduction fall within this Article, commentators take the view that there seems to be no obligation on a State to provide for these procedures to take place. If there is no obligation on a State then there can be no obligation on a voluntary organisation."

The solicitor commented further regarding concern about liability:

"The position of the Trust is that it is merely making funds available to the beneficiary to undergo the treatment. If as a result of treatment, the beneficiary's partner or child became infected with HIV then liability would fall on those responsible for providing fertility treatment in a negligent manner'. The Trust should not contract with the NHS Trust to provide treatment. Grants should be made direct to an individual."

At their meeting in May 2002 Trustees considered the latest information about sperm washing available in the UK through a programme at the Chelsea and Westminster Hospital. Trustees confirmed that despite awareness of the strong desire of many registrants to start a family, they did not believe that the Macfarlane Trust should fund fertility treatment of any kind, since this was the responsibility of the National Health Service.

However, Trustees accepted that the ancillary costs of such treatment were high, even if all treatment costs were born by the NHS. It was therefore decided to prepare proposals to enable the Trust to contribute toward ancillary costs of fertility treatment, particularly costs related to travel and subsistence for a maximum of 3 cycles of treatment.

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### **Funding Proposal**

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Chelsea and Westminster Hospital have advised that dependent upon where patients live, they could need accommodation in London for between 1 to 3 weeks per cycle. Therefore accommodation would be needed for 3 to 9 weeks if the Trust were to fund ancillary costs for up to 3 cycles of fertility treatment. the a worke a

The Trust has an arrangement with the Copthorne Tara Hotel whereby registrants can use an adapted or standard twin room for £99 per person per night. This cost includes breakfast and VAT. Dinner at the hotel is £20 per person for a standard 3 course meal. Whilst it might be possible for the couple to find somewhere cheaper to stay, I have based estimates on these costs.

£240 per night per couple. Therefore a possible total cost for a 5 night stay of £1,200 with estimated costs for 15 nights of £3,600 and 45 nights of £10,800.

Chelsea & Westminster Hospital have said that it would not normally be expected that patients would remain in London for treatment unless travel distances were excessive and that it would be unusual for a couple to need to stay in the vicinity of the hospital for 3 weeks.

It is therefore proposed that Trustees agree to a Guideline grant towards ancillary costs of fertility treatment of up to £3,000 per couple, and that it is stated that the grant is intended to contribute towards costs for up to 3 cycles of fertility treatment in London. Any other exceptional costs would need to be put to the Trustees for their consideration.

It is proposed that this funding would be available under Guidelines for up to 10 couples a year. Any couples applying for help after the budgeted amount for the year had been spent would need to apply to Trustees to be considered for a special allocation.

Therefore Trustees are asked to approve an annual budget for ancillary costs related to fertility treatment made under Office Guidelines of up to £30,000 a year.

Ann Hithersay Chief Executive

23.07.02

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