PAYMENTS REVIEW GROUP - BRIEFING
December 1999.

THE COST OF LIVING WITH HAEMOPHILIA, HIV AND COMBINATION THERAPIES.

A group of registrants and Trust staff met together to re-assess the cost of living with haemophilia, HIV virus and combination therapies. The group accepted that over 95% of registrants would also be coping with hepatitis C co-infection, and that the treatment and/or effects of this virus compounded the health problems they experienced.

The Group considered their way of life, and ways in which the daily cost of living was increased by living with symptoms and treatment of haemophilia, HIV and hepatitis C related illnesses. The group compared expenditure in a range of areas, and attempted to determine how this differed and was greater than similar expenditure areas for the average family.

The Group used the original 1993 paper produced by the Trust at the time of the last major review of Regular Payments, adding to these where new issues were raised, and updating costs related to the areas originally identified.

The Group identified that major changes to the situation as experienced in 1993 included:

(i) The majority of those living today are unemployed, whereas in 1993, many of those who were well were still in employment. In most cases, where men had been in a permanent relationship, partners were also in employment. Today many relationships had broken down due to the burden of caring, and of living with a partner who was HIV positive. Many partners today were unemployed and engaged in caring for their partner, and sometimes their children.

(ii) In 1993 all registrants had received two tranches of capital payment from Government. They were able to afford to buy household goods, go on holiday and afford some luxuries. Today well over 70% of Trust registrants are largely dependent on State Benefits and Trust funding. This means that the majority of people registered with the Trust are living at or below the poverty line; this is more than twice the National average.

(iii) In 1993 there was no successful treatment for AIDS. People either got ill and died, or remained a-symptomatic and continued their daily life, watching many of their friends die, and living with a very short life expectancy and no hope. Today combination therapies mean that for many there is hope of a future, albeit uncertain. Many people will be sick for much of the time; living with chronic illness and periods of fluctuating health. Sometimes feeling well enough to consider part time work, and sometimes very seriously ill. This uncertainty of life expectancy and quality of life makes planning difficult and adds greatly to stress levels in the family.

Against this background, the group considered the following areas, and identified extra costs that could be attributed to 'living with HIV':

DETAILED BREAKDOWN - MONTHLY ADDITIONAL COSTS:

	£
DIET High Energy food and drinks to counter weight loss and nausea Vitamin Supplements, fresh foods, frequent meals, special foods.	100
ELECTRICITY/GAS/FUEL BILLS A warm dry atmosphere needed. Central heating and hot water on 24 hours a day, 7 days a week, all season. Frequent baths/showers and laundering of bedding and clothes.	58
CLOTHING Drugs and illness leading to large weight gain and/or loss, changes to body shape. Heavy and frequent laundering at high temperatures due to bleeds, sweats and diarrhoea leading to high levels of wear and tear on fabrics.	33
SKIN CARE AND TOILETRIES Special soaps and creams, very high use of toilet rolls/tissues and rubber gloves. More costly creams and soaps may be needed to prevent allergies.	12
CLEANING PRODUCTS AND WASHING POWDER Bleach, disinfectant, carpet shampoo, washing powders, salt for water Softeners. Large quantities needed to guard against contamination.	8
DOMESTIC MATERIALS Bedding and towel replacements. Washing Machine replacement.	37
TRAVEL - MULTIPLE HOSPITAL VISITS Many now seeing three specialists regularly: Haemophilia, HIV and liver. Health Budgets may mean that supplies of HIV,Hep C therapies and Factor VIII may have to be collected from hospital at frequent intervals.	12
COMPLEMENTARY THERAPIES Many people now use a range of alternative and complementary therapies To help them to cope with the effects of HIV and side effects of multiple Drug therapies.	80
HOLIDAYS Living with stresses arising from HIV, Hepatitis C and multiple drug therapies, as well as haemophilia, means that families badly need a break. Incomes are so low that for most families, saving up for a holiday is not an option at present.	60
COMMUNICATION Telephone communication with family and friends and with support Networks is very important for families housebound by illness. Whilst Internet communication may be more cost effective, this is only available to those with computers.	20
TOTAL ADDITIONAL MONTHLY COST	**£408**

The Group that worked on costing these additional needs recognised that Regular Payments were meant to contribute to but not necessarily cover the full cost of meeting the needs. However they felt that the costs identified were a fair and realistic representation of the additional expenditure incurred by the majority of families registered with the Trust today.

The Group recognised that if the Trust were to give all registrants and infected intimates a Regular monthly payment of £408, it would cost £2,374,560 a year at present rates. Payments to widows and dependant children, and Single Grants would be an additional charge on the fund.

The Group also recognised that circumstances varied according to health needs, size of family and current situation, and that the present criteria applied to payments was a reasonable approach to allowing for these variations. However participants felt that there were two areas which were not as fair as they might be at present. These were:

(i) qualifying levels for payment of the Trust's health supplement, which depended upon whether registrants were in receipt of High Rate DLA, a matter which in turn depended upon the interpretation of DSS rules by medical staff at Centres.

(ii) And the payment of a basic rate only to all registrants who were employed, and not in receipt of Income Support. Many families where one or both partners were able to work part time or for a very low income were penalised because they chose to work.

The Group recommended that the Care supplement be available to all on Medium or High Rate DLA.

The Group recommended that the Basic Rate be removed, and everyone paid a minimum 'Standard Rate' which recognised the cost of living with HIV, whether or not they or their partner were able to work some of the time.

The costs of making these two adjustments had already been estimated.

The Group recommended that an additional monthly payment be made to all those infected with HIV, whether registrants or 'infected intimates'. The increase would need to be large enough to eliminate all but strictly health-related applications for Single Grants. The monthly increase proposed would be in addition to the 11% increase agreed in October, and would be added to all existing payment levels, after the above adjustments had been made.

It would be necessary to advise Lord Hunt that the monthly increase would add to annual expenditure, and would mean that the Trust would need to seek 'capital top-up' earlier than had been indicated in the Strategic Review.

The attached schedules show the effect on cash flow of a monthly increase to regular payments to all those infected of £100, £125 and £150.