

THE MACFARLANE TRUST

CASE SUMMARIES

MAIN ALLOC MEETING

Time: 11.00 am

Date: 15th September

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**BENEFIT OVERPAYMENT**

3.0 15 Sep 98

1089

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**SUMMARY**

Age: 31 Marital status: M c/l Children under 18: 0

Family Circumstances: Lives with partner

Health/Disability: Haem <1%; Reg Disabled; No Hiv Effects  
Reported CDC= Karnofsky= Treatment=

Car: Motability

Housing type: House  
Housing Ownership: MortgageEmployment status: Unemployed  
Present/previous job:Means tested benefits: Income Support  
Other benefits: Severe Disablement Allowance  
DLA mobility component: Higher rate  
DLA care component: Higher rate

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**PAYMENTS**

Reg pay monthly rate: £265.00

Single payments: £1,550.00 6% (4)

Regular payments: £21,928.00 79%

Winter payments: £4,325.00 16%

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Total: £27,803.00

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Overall total (MSPT1/2+MFT): £71,303.00

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**REQUEST**

This couple are being required to repay £5129.35 overpaid by the Benefits Agency. The situation is not their fault and it must be stressed that there is absolutely no suggestion of fraud on their part. However the regulations operate in such a way that recovery can be required even in these circumstances. The overpayment arose because they were getting Income Support and one partner then claimed Severe Disablement Allowance which the DSS failed to deduct from their Income Support. Recovery is being pursued under two different sections of the regulations. Of the total amount £3119.83 may not have to be repaid if it is judged that the member acted reasonably in the circumstances. This decision can be appealed to an independent tribunal and we are doing this. The other £2010 however is absolutely recoverable with no mitigation in any circumstances and it is this amount I am asking the Trustees to cover by means of a grant. I am aware that this would represent a new departure for the Trust and can be seen as creating a precedent. I however ask the Trustees to take the following facts into account in reaching a decision:

- the couple thought they had given all the necessary information to the DSS and that it had been acted on
- this will mean a drastic reduction in benefit for people on a limited income and will last for a long period. The DSS will be wanting to collect this back at £7.34 per week. To repay the whole amount would take thirteen and a half years and even to repay the £3119.83 will take over eight years. This will clearly limit the income available for other (health-related) expenditure.
- recovery under this section is unusual. It is the first time I have personally come across it and I do not think this is a situation which will happen frequently. I shall be including an item in my next Benefits column to alert members to this danger.

**Amount Requested:** £2010

**Recommendation:**

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CLOTHES

3.0 15 Sep 98

1155

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SUMMARY

Age: 27 Marital status: S Children under 18: 1

Family Circumstances: Lives in portacabin in mother's garden.

Health/Disability: AIDS; Chronic sinusitis, has bronchiactais, severe disability due to haemophilia related athropathy; abnormal liver function. Health has been up and dwn over the past year due to protease inhibitors. CDC=C3 Karnofsky=70 Treatment=On regular intra veinous amphotericin as a day case for flucanazole resistant candida

Car: Motability

Housing type: House

Housing Ownership: Rented private

Employment status: Long term sick  
Present/previous job:

Means tested benefits: Income Support

Other benefits: Incapacity Benefit

DLA mobility component: Higher rate

DLA care component: Higher rate

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PAYMENTS

Reg pay monthly rate: £300.00

Single payments: £10,615.90 27% (34)

Regular payments: £24,376.00 62%

Winter payments: £4,325.00 11%

Total: £39,316.90

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Overall total (MSPT1/2+MFT): £91,316.9.00

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REQUEST

Mr ☐ GROA is requesting a grant to purchase a wardrobe of new clothes as, due to his new treatments, his health has improved but he has also gained an enormous amount of weight.

Mr ☐ GROA is also asking for an advance of Regpay of £900, repayable at £50 per month, to allow him to replace front and back doors with burglar resistant ones and to refurbish a second-hand burglar alarm system following a recent attempted break-in at his home.

Amount Requested: £350/£900

Recommendation: Approval recommended



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EXCESS MILEAGE/COOKER/~~Bridge Freezer~~ 3.0 15 Sep 98 1174

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SUMMARY

mattress

Age: 40 Marital status: Married Children under 18: 3

Family Circumstances: Wife and 3 children (80,82,86)

Health/Disability: Mild haemophilia; Recurrent staphylococcal skin infection; Depression - on anti-depressant drugs; Reasons for admission to hospital - depression, psychiatric hospital admission; Exact dates of admission not known. Last hospital admission: 4.97 - dates not known. Reason: depression. CDC=B2 and C2 Karnofsky=70 Date of test: 3.4.98. Type of test: HIV RNA Treatment=Didanosine; Stavudine; Nelfinavir; Inhaled Pentamidine; Anti-Staphylococcal antibiotics PRN.

Car: Owned outright

Housing type: House

Housing Ownership: Mortgage

Employment status: Long term sick

Present/previous job:

Means tested benefits: Income Support

Other benefits: Incapacity Benefit

DLA mobility component: Higher rate

DLA care component: Higher rate

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PAYMENTS

Reg pay monthly rate: £300.00

Single payments: £17,669.00 36% (31)

Regular payments: £27,773.00 56%

Winter payments: £4,325.00 9%

Total: £49,767.00

Overall total (MSPT1/2+MFT): £132,267.00

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REQUEST

Since last April Mr [GROA] has been ambulance driving people one day a week. Before this he had suffered a nervous breakdown and spent some time in a psychiatric unit recovering. He has found the driving has given him a sense of purpose and keeps him 'sane'. As he is unable to work otherwise because of his health, he and his wife spend a lot of time together. His being out of the house one day a week takes the pressure off both of them. The problem is with a Motability car his 100 miles per week excess mileage (all ambulance driving) pushes the amount he has to pay Motability up to £500 over a period of 3 years. He requests a grant to cover this.

2nd and 3rd request

Mr [GRO-A] moved into a new house earlier this year. Through this he inherited a cooker that hardly works at all and a fridge/freezer that even after replacing the thermostat does not work as it should. Obviously both are essential to his health. The fridge has to work correctly because he needs to store his factor VIII as well as his HIV medications.

4th request

Finally, Mr [GRO-A]'s mattress is in a dreadful state due to the night sweats he experiences. It is unhygienic and has to be replaced. With all his other expenses due to the move this is just one more thing he is having difficulty in finding the money for.

This request has been referred from the last mini alloc. Trustee also requested a list of members single grants.

Additional information is Mr [GRO-A] receives 19p per mile from the hospital for petrol.

**Amount Requested:** £500/£300/£400/£200

**Recommendation:** To make a grant for the excess mileage as the voluntary job is an essential part of his life at present.

To make a contribution towards a cooker and fridge/freezer if he is unable to secure funding for these through a community care grant (Jenny Jackson is currently applying for one).

To make a grant for the mattress due to issues of hygiene.

Breakdown of Single Payments for 1174.

G = grant

D = date

P = Payment (not all incl)

C = Cant (ie amount of  
payments makin  
up 'G')

G1: £3000.00

D1: 97.05

P1: holidays; convalescence (£500)

C1: 4

G2: £2670.00

D2: 97.08

P2: house move; replacement window

C2: 3

G3: £1135.00

D3: 89.05

P3: WM/TD & Fridge, bed & bedding

C3: 2

G4: £1000.00

D4: 95.11

P4: motability

C4: 1

G5: £770.00

D5: 97.09

P5: workshop & fares, survey fees; travel costs; water softener

C5: 4

G6: £3661.00

D6: 98.07

P6: gas boiler, school uniform (3 grants); central heating system;

C6: 5

G7: £995.00

D7: 90.08

P7: 3pc suite; chairs

C7: 2

G8: £1088.00

D8: 98.07

P8: Birchgrove w/e (2x); therapy, driving lessons; women's weekend, therapy  
partner

C8: 6

G9: £850.00

D9: 91.03

P9: video recorder; computer

C9: 2

G10: £2500.00

D10: 90.01

P10: redecorating; central heating £1500

C10: 2

GrTot: £17,669.00

Count: 31

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DOORS

3.0 15 Sep 98

1372

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**SUMMARY**

Age: 48 Marital status: Married Children under 18: 0

Family Circumstances: 2 Sons (b.72 & 75)

Health/Disability: Severe haemophilia. A chronic haemophiliac - arthropathy affecting joints in both upper and lower limbs. He has undergone several surgical procedures, most recently the removal of a total hip replacement. Mobility limited to short distances with crutches - unable to do stairs. CDC= Karnofsky= Treatment=

Car:

Housing type: House

Housing Ownership: Owned outright

Employment status: Employed @ work

Present/previous job: Self employed chauffeur

Means tested benefits: Income Support

Other benefits: Invalidity Benefit

DLA mobility component: Higher rate

DLA care component: Higher rate

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**PAYMENTS**

Reg pay monthly rate: £130.00

Single payments: £4,543.00 16% (7)

Regular payments: £20,120.00 69%

Winter payments: £4,325.00 15%

Total: £28,988.00

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Overall total (MSPT1/2+MFT): £109,488.00

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**REQUEST**

Having recently spent thousands on replacement windows (no MFT grant requested for this) Mr and Mrs [ ] find their lounge still extremely draughty as a result of the doors not fitting properly. They request a grant to purchase two doors, total being £1772. Please see enclosed letter.

Amount Requested: £1772

Recommendation:

1372

11/08/98

*Dear Trustees.*

*We should like to ask the trustees for help regarding the following.*

*We understand the trust can offer help with installation of replacement windows.*

*Well this is not strictly the area that we would like to ask for help with but it has a bearing. First of all we would like to put a bit of background to you this will help you to understand why we are asking you for help.*

*1372 has had some 20 odd major operations over the years and has very limited mobility. Coupled with the obvious problems that he has hence him being a member of the trust. February of this year he had to have major surgery to his right hip resulting in him having to have the hip joint removed and now live his life with no right hip joint at all, this as you can imagine makes it very difficult for him to get around and the hospital say that because of various reasons there can be no replacement hip fitted. He has to spend the rest of his life without a hip joint. He has various other joint difficulties which add to the mobility problems. He has to take various treatments regarding the HIV .*

*Although this is not accelerating you can imagine that his body has had such a bashing that any other problems become a lot greater because of the HIV weakness.*

*Well the point of this request is that 2 years ago we had replacement windows fitted to the house and bore the total cost ourselves. At that time we did not have the funds to replace the front and rear doors. We have since realised that replacing the windows did not make the house draft proof. It still is cold in winter and drafty. The reason that we are making this request is that we would like to replace these doors and are looking at the fact that because of the surgery that 1372 had this year he is going to feel the cold a lot more and the fact that he cannot move around much will have a bearing on this. This may weaken him to other infections and other problems.*

*and is of great concern to us as we need to make things as comfortable as possible for him. We feel that there is a real need for this work to be done now.*

*We felt that pointing out the fact that we paid to have the windows replaced ourselves and did not ask the trust for help then perhaps the trustees would consider helping us now. Please find estimates enclosed. -  
1372 would really benefit from this work being carried out and obviously we are looking for this to be done before the winter.*

*Obviously keeping some form of control over the enviroment that he lives in is the only way that we can help the HIV situation. As you well know we as people are helpless to do anything else.*

*Many Thanks*

*1372 and partner.*

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MOBILE PHONE

3.0 15 Sep 98

1617

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**SUMMARY**

**Age:** 17 **Marital status:** Child **Children under 18:** 1

**Family Circumstances:** Father emp, mother p/t; bro (b.78) haem. also

**Health/Disability:** Mild haemophilia.

Last hospital admission: 29.3.98 to 3.4.98. Very high temperature; unknown origin. This admission followed treatment with Sandoglobulin.

viral load >50,000 (copies m/l) 24 April 98 CDC=C1 Karnofsky= Treatment=d4T; 3TC; paramomycin; dapsone. On salvage therapy.

**Car:**

**Housing type:** House

**Housing Ownership:**

**Employment status:**

**Present/previous job:** School

**Means tested benefits:** Income Support

**Other benefits:**

**DLA mobility component:** Higher rate

**DLA care component:** Higher rate

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**PAYMENTS**

**Reg pay monthly rate:** £295.00

**Single payments:** £13,728.40 35% (26)

**Regular payments:** £20,703.00 53%

**Winter payments:** £4,325.00 11%

**Total:** £38,756.40

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**Overall total (MSPT1/2+MFT):** £80,256.4.00

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**REQUEST**

Request is made for funding to purchase mobile phone. Please see enclosed letter.

**Amount Requested:** £140

**Recommendation:** This letter was written in April. [GRO-A] is very unwell and on salvage treatment. The family are extremely concerned about his life expectancy. A mobile phone is considered essential.

M.F.T.  
P O Box 627  
London  
WS1 0QG  
9th April 1998

Dear Jenny

Further to my recent telephone conversation with Fumie I write to officially request help from the trust for the purchase of my mobile phone.

Since the pager was withdrawn last year we have reverted to using a mobile phone and were paying £20 per month with the inclusion of 15minutes call time per month.

Unfortunately it developed a fault and as its battery life had just about finished it was not economical to repair.

The best deal I could obtain this time was to change to the Orange tariff but they required a 12month payment in advanced which amounted to £140 which included 15minutes of call time per month. At present this charge is on my Barclaycard as the last few months have not been to good with [GRO-A] health and we have just been asked for the ICA books to be returned. I earn a meagre income of just over £50 per week mainly to try to reduce the stress and it would appear that they are not prepared to allow my expenses. ( Enclosed is a copy of our letter to them for your information )

You my feel that a mobile phone is a luxury and we should of purchased a pager. In our case [GRO-A] health is very complicated, he has numerous serious conditions and the underlying recent test\$ show that he is not responding to the new drugs. The last viral result was very disappointing increasing by over 400% on the previous and we are awaiting the latest test results any day now. Also due to the drugs n his Factor Viii, iX, X & Xi percentages are very erratic and it has been decided to put him profalectic care. I need to be able to speak to people should there be a problem.

Although these result are very poor and his general health is not very good [GRO-A] is managing to do a part time job. Virgin records in Salisbury have given him this chance and I have assured them that I will always remain local on the days he works and carry the mobile phone so that they can be confident of speaking to me direct with any problems.

I am also quite often contacted urgently by GOSH to return ASAP, the local Hospital and the GP.




Unless I have the mobile phone, the stress I am under would mean the end of my job and to be terrified of going out should there be a problem. It is all very well having a pager but you have to find a phone box, have the correct money then get hold of the GP or Hospital. The phone just makes life a little easier but has put a bit of a strain on finances at the moment.

Finally although GRO-A is now nearly twenty, he is not covered by the trust but is also haemophiliac with Hep C. He is managing to work at Nationwide and they also need to contact me should there be a problem.

It would be very much appreciated if under these circumstances you could authorise this help and I enclose a copy of the receipt for your records. I will also endeavour to put aside enough to replace this phone in the future.

Yours Sincerely



# Motaphone (Salisbury)

St Pauls Roundabout  
167 Fisherton Street  
Salisbury

Wiltshire SP2 7RP

Tel No: (01722) 415234 Fax No: (01722) 410415

VAT No: 542 0052 95

Invoice

Page 1

Motorola MR30  
connected to Talkahead  
Mobile No GRO-C

Invoice No.

15049

Invoice/Tax Date

31/03/98

Order No.

Account No.

KETLL01

Quantity	Product Description	Unit Price	Net Amount	Vat Amount
1.00	To supply Motorola MR30 connected to Talkahead Mobile No GRO-C Orange MR30	110.63	110.63	19.36
1.00	Motorola Flair Leather Case	8.51	8.51	1.49

Paid V.R.A

GRO-C

Total

119.14

Total Vat

20.65

Invoice Total

139.99

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TRANSPORT

3.0 15 Sep 98

1689

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SUMMARY

Age: 29 Marital status: Single Children under 18: 0

Family Circumstances: mother is disabled

Health/Disability: Severe haemophilic arthropathy that makes climbing stairs and general mobility difficult. CDC=A3  
Karnofsky=80 Treatment=Recently commenced on triple therapy

Car:

Housing type:

Housing Ownership:

Employment status: Employed @ work

Present/previous job: Research Assistant

Means tested benefits: Income Support ?

Other benefits:

DLA mobility component: Higher rate

DLA care component: Higher rate

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PAYMENTS

Reg pay monthly rate: £135.00

Single payments: £2,850.00 10% (3)

Regular payments: £21,425.00 75%

Winter payments: £4,325.00 15%

Total:	£28,600.00
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Overall total (MSPT1/2+MFT): £72,100.00

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REQUEST

Please see enclosed letter from Social Worker.

Amount Requested:

Recommendation:

Please Note:  
This Department closes  
at 4.40 pm on Friday

24 JUL 1998

My ref  
Your ref  
Direct Line  
Direct Fax  
Date

21 July 1998



CYNGOR SIR CAERDYDD  
CARDIFF COUNTY COUNCIL

Social Work Department,  
University Hospital of Wales,  
Heath Park,  
Cardiff CF4 4XW  
Tel: 01222 747747

Ms Fran Dix  
The Macfarlane Trust  
Alliance House  
12 Caxton Street  
London  
SW1 OQG

Dear Fran

Re

1689

I am writing regarding [GRO-A] who works at the University of Bath. I visited him recently and his work requires him to travel quite a lot within the city environment. He calculates that he spends at least £2.00 per day on bus fares. [GRO-A] does not have a car and is not interested in getting one. He travels to the Haemophilia Unit at Cardiff for his treatment and care and does so by train. He has been going this frequently and ever more so recently due to his deteriorating condition.

Given the fact that [GRO-A] does not receive, like others, a mobility grant towards the cost of a car would it be possible for the Trust to consider the amount of transport costs that he incurs both in his daily life and also travel to the Unit. I would be grateful for your thoughts on this.

Thank you for your attention.

Yours sincerely

Senior Social Worker

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SUMMARY

Age: 32 Marital status: married c Children under 18: 2

Family Circumstances: Lives with partner and her two children

Health/Disability: Severe haemophilia. Severe haemophilia arthropathy, particularly of right knee. This causes considerable problems with mobility. Previously had inhibitor. CDC=A2 Karnofsky=70 Treatment=PCP prophylaxis; patient is reluctant to to have anti-retroviral medication  
6.7.98: Currently taking zideviedine, lamviedine and indinavir. Good response to treatment but side effects are problematic.

Car:

Housing type: House

Housing Ownership: Mortgage

Employment status: Long term sick

Present/previous job:

Means tested benefits: Income Support

Other benefits: Severe Disablement Allowance

DLA mobility component: Higher rate

DLA care component: Higher rate

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PAYMENTS

Reg pay monthly rate: £295.00

Single payments: £8,160.00 23% (15)

Regular payments: £22,571.00 64%

Winter payments: £4,325.00 12%

Total: £35,056.00

Overall total (MSPT1/2+MFT): £78,556.00

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REQUEST

Interest in amateur radio has given a new lease of life to Mr <sup>GRO-A</sup> he no longer spends his time "stuck in the house for very long periods" (as the social worker puts it). He has recently spent 4 weeks in hospital with a number of different problems to do with his haemophilia and nasty effects of his combination therapy. Mr <sup>GRO-A</sup> requests a grant toward a course he would like to commence in early September. It is in amateur radio leading to a licence through exams in May. Listed below are the costs involved: the course itself is free to him as a disabled student  
travel - 24 mile round trip = £144 (at 10p per mile for 30 weeks, 2 days a week)  
books - £80

aerial - £50

H F receiver - £700

Above course fees agreed at mini alloc. Equipment refused on grounds that this is a policy issue which needs discussion at a full trustees meeting.

Mr [ ] is unable to proceed with the course.

2nd request

see letter from social worker

The caravan is an extremely important part of Mr [ ]'s life, as the letter suggests. He asks for a part loan part grant to enable them to keep it. Payment is due this month. They have paid off £3000 but are struggling with a further £3670. Upgrading is essential due to Mr [ ]'s health needs.

**Amount Requested:** £750/£3500

**Recommendation:** Another request supported by hospital staff because it keeps our registrants therapeutically occupied and free from dropping into recurring depressive states. Recommendation is we keep this man meaningfully occupied in order to prevent the above and thus a rise in viral load.

Please Note:  
This Department closes  
at 4.40 pm on Friday

1712



CYNGOR SIR CAERDYDD  
CARDIFF COUNTY COUNCIL

My ref Fy nghyfeirnod

TH/SP

Your ref Eich cyfeirnod

Direct Line Lein Uniongyrchol 01222 74

GRO-C

Direct Fax Ffacs Uniongyrchol 01222

Date Dyddiad

24 August 1998

Social Work Department,  
University Hospital of Wales,  
Heath Park,  
Cardiff CF4 4XW  
Tel: 01222 747747

Ms Fran Dix  
The Macfarlane Trust  
Alliance House  
12 Caxton Street  
London  
SW1 OQG

27 AUG 1998

Dear Fran

Re GRO-A GRO-A and GRO-A

I am writing regarding the above. Firstly may I thank you for the assistance given to GRO-A regarding the course that he wishes to take up in radio communications. GRO-A and GRO-A have recently looked into upgrading their caravan that they stay at on a regular basis at a local resort near Cardiff. This caravan provides them both with some respite and is somewhere for them to go when GRO-A's health allows for either a weekend or a longer break. However due to the difficulties both in terms of his mobility and coping with a strict regime of combination therapy they have found that the caravan they have no longer suits their needs. It does not have a flush toilet or electricity and they have decided to upgrade at a cost of £2,000 to £3,000.

Therefore I am writing to ask if the Trust would agree to help with some money towards this cost. If you need any more details please contact me.

Thank you for your attention.

Yours sincerely

Senior Social Worker





# AR7030 *high dynamic range general coverage receiver*

AR7030 is a combined project between AOR and internationally acclaimed designer "John Thorpe". This new design provides exceptional strong signal performance coupled with enhanced microprocessor features and facilities. Frequency coverage is from 0 - 32 MHz all mode: AM, Synchronous AM, USB, LSB, CW, DATA & NFM. Four 455 kHz IF filters are provided as standard with provision for a further two (including Collins mechanical filters), all of which are 'self aligned' by the receiver for optimum performance and passband symmetry; this plus the standard fitted TCXO makes the AR7030 ideal for ECSS applications. The self tuning variable bandwidth synchronous detector is a pleasure to use and 'hangs on' to the weakest of signals, audio quality is superb.



Where good strong signal handling, high performance and transportability are of great importance, the AR7030 is the solution offering an IP<sub>3</sub> greater than +30dBm (typical +35dBm reduced by 10dB with the preamp on). Intermodulation free dynamic range with the 2.2kHz filter is typically 105dB @ 100/200kHz spacing, 104dB @ 20/40kHz and still better than 90dB @ 5kHz. This fantastic strong signal handling is aided by the innovative configuration of a lateral DMOS F QUAD first mixer running at 15V, relay switching in the front end (not diodes) and the use of shielded inductors throughout the signal path. All this and GREAT SENSITIVITY better than 0.5uV for 10dB S/N in AM mode and better than 0.3uV for 10dB S/N in SSB. Selectivity too is razor sharp typically offering greater than 90dB @ 5kHz SSB, almost 100dB @ 10kHz and greater than 100dB @ 20kHz, these excellent figures are achieved by the implementation of a remarkably low phase noise local oscillator <-158dBc/Hz @ 100kHz.

The receiver is built around a TCXO frequency standard which provides the reference for all circuitry ensuring the ultimate in stability and optimum alignment. Single loop DDS provides the clean local oscillator reference essential for low reciprocal mixing levels and seamless tuning in 2.655Hz steps (10.62Hz in AM & NFM modes) with no tuning "plops" at regular intervals. The receiver is a double conversion superheterodyne with intermediate frequencies of 45MHz and 455kHz.

Enhanced features include pass band tuning  $\pm 4.2$ kHz, variable audio pitch tune on CW & data modes and a new "variable bandwidth synchronous detector" for AM listening to eliminate the effects of transmitter / receiver drift as well as reducing distortion from selective fading. The pass band tuning may be used in synchronous AM mode to select synchronous USB, LSB, DSB or anything in between. A specially developed AGC release characteristic has been developed to provide very smooth SSB. Noise spike compression has also been included to reduce the effects of noise pulses. A built-in six level attenuator provides levels of sensitivity from +10dB to -40dB.

*Despite the deceptively simple front panel layout, the AR7030 really packs a punch with enhanced facilities including an extensive computer command set ideally placing the receiver for semi-commercial applications... volume commercial purchasers are invited to discuss specific requirements such as rack mounting etc.*



**SUMMARY**

**Age:** 33 **Marital status:** Married **Children under 18:** 2

**Family Circumstances:** 2 children (b.90,96); brother HIV+

**Health/Disability:** Severe haemophilia. Hep c. Arthritic ankles causes difficulty in mobility. Experiences night sweats, diarrhoea, insomnia. CDC=A2 Karnofsky=100 Treatment=Admitted to Procom trial MRC 8/1/98  
DDI, Saquinavir, Nalfinavir, D4T

**Car:** Motability

**Housing type:** House

**Housing Ownership:** Mortgage

**Employment status:** Long term sick

**Present/previous job:** Post Office

**Means tested benefits:** Family Credit

**Other benefits:** Invalidity Benefit

**DLA mobility component:** Higher rate

**DLA care component:** Higher rate

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**PAYMENTS**

**Reg pay monthly rate:** £195.00

**Single payments:** £10,082.48 25% (20)

**Regular payments:** £25,641.00 64%

**Winter payments:** £4,325.00 11%

**Total:** £40,048.48

**Overall total (MSPT1/2+MFT):** £120,548.48.00

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**REQUEST**

PLEASE SEE LETTER. Request is made for washing machine and to reconsider decision of April 98 meeting which agreed loan of £4000, but no part of it as grant. Master loan was paid off by the loan but this has in fact made them only £70 per month better off. They ask that part of the grant is made into a loan.

**Amount Requested:** £300/?

**Recommendation:**

1763

3 September 1998

Dear Macfarlane Trust

I need to ask you if you can help me with the cost of replacing my washing machine which broke down recently - approximately two months ago. It was a Zanussi washer/dryer and has lasted me since 1991. It has been repaired twice already and is now beyond repair. I could probably get a decent washer/dryer for just under £300. I have exhausted the DHS social fund department so there is no point trying there. I have no funds or savings on which to draw from and am currently overdrawn by about £300 at my bank.

It is costing me roughly £12-£15 a week to do the laundry at the laundrette and this is very difficult for me. I cannot get it on credit card as they are all full and we are paying them off slowly. My credit reference of rating is bad so I cannot get it on hire purchase. I need the washing machine urgently as I do sweat at night and I also suffer from severe diarrhoea due to drugs that I have to take to control my condition.

I would also ask at this stage if I can get any more help to pay off my debts as they are making me more ill due to stress and worry. We have been paying off our debts slowly with advice and help from Susan Daniels but I just wanted to know if you can review the situation as it seems to be going on forever. Put it to the Trustees again please. Ask Fran to reconsider. It is difficult with your deducting £100 every month from my regular payment. We could really use the money. Thank you for trying on my behalf.

The Situation the alloc meeting  
Considered in April 98.

1763

# DEBTS

## Offers

John Lewis	£ 417.00	£20 p.m.	Accepted
Midland Mastercard	£1001.07	£20 p.m.	Accepted
Unity First Mastercard	£1326.25	£20 p.m.	Accepted
Preference Account	£1077.43	£20 p.m.	accepted £50
Mastercard	£ 563.07	£20 p.m.	Accepted
Visa	£1436.74	£30 p.m.	Accepted
Barclaycard Masterloan	£4101.58	£170 p.m.	Accepted
Overdraft approx.	£ 800.00		
	total 10,723.14	total	340.00

Various other smaller cards Adams, say £200, Principals £100, Catalogue £200.

## MONTHLY EXPENDITURE (NOT INCLUDING PAYMENTS ON ABOVE)

Mortgage	£ 75.00	
Insurance	£ 29.00	
Gas	£ 30.00	
Electric	£ 30.00	
Petrol	£ 40.00	
Food	£280.00	
Telephone	£ 20.00	
Concept 5	£ 12.17	
Concept 4	£ 33.10	(loan for cooker)
Life Insurance	£ 85.00	
	total 634.27	

## INCOME

Disability Living Allowance	£197
MFT	£195
Carers Allowance	£220
Income Support	£256
Disability Pension	£ 62
Child Benefit	£ 80
	total 1,010

---

**FOOD SUPPLIMENTS****3.0 15 Sep 98****1885**

---

**SUMMARY****Age: 17 Marital status: child Children under 18: 0****Family Circumstances: Only child**

**Health/Disability: AIDS HIV viral load (copies/ml) 20,000 - 50,000 Date of test: 23.6.98**  
**Type of test: CHIRON QUANTIPLEX,**  
**Hospital admission: 15.7.98 to 18.7.98 due to weight loss, lethargy. CDC=B3 Karnofsky=60 Treatment=Septrin; Zidovudine; Nevirapine; Lamivudine**

**Car: Owned outright**

**Housing type: House**  
**Housing Ownership: Mortgage**

**Employment status:**  
**Present/previous job: School**

**Means tested benefits:**  
**Other benefits:**  
**DLA mobility component: Higher rate**  
**DLA care component: Higher rate**

---

**PAYMENTS**

<b>Reg pay monthly rate:</b>	<b>£135.00</b>	
<b>Single payments:</b>	<b>£500.00</b>	<b>4% (1)</b>
<b>Regular payments:</b>	<b>£7,880.00</b>	<b>62%</b>
<b>Winter payments:</b>	<b>£4,325.00</b>	<b>34%</b>
<b>Total:</b>	<b>£12,705.00</b>	

**Overall total (MSPT1/2+MFT): £54,205.00**

---

**REQUEST**

**GROA** ill with ongoing infections and severe weight loss, and has recently been in hospital. Nutrition Consultant has suggested supplements for malabsorption, vitamins, minerals and protein shakes. None of which are available on the NHS (only Vit C). Father has recently lost job. Family financially struggling. cost = £40 per week

**Amount Requested: £40 PER WEEK**  
**Recommendation: Approval recommended**

---

**BABY EQUIPMENT****3.0 15 Sep 98****1886**

---

**SUMMARY**

**Age:** 24 **Marital status:** Married c **Children under 18:** 0

**Family Circumstances:** Has lived with partner since 95

**Health/Disability:** Severe haemophilia, HCV. CDC=B3  
Karnofsky=100 Treatment=DDI; Zidovudine ; Cotrimoxazole;  
Fluconazole

**Car:** Motability

**Housing type:** House

**Housing Ownership:**

**Employment status:**

**Present/previous job:**

**Means tested benefits:** Income Support

**Other benefits:**

**DLA mobility component:** Higher rate

**DLA care component:** Higher rate

---

**PAYMENTS**

**Reg pay monthly rate:** £265.00

**Single payments:** £9,227.00 30% (12)

**Regular payments:** £16,963.00 56%

**Winter payments:** £4,325.00 14%

**Total:** £30,515.00

**Overall total (MSPT1/2+MFT):** £72,015.00

---

**REQUEST**

Because of Mr [GROA]'s health he is unable to work and therefore will struggle with costs around a new baby. As having a new baby is an extremely stressful time anyway, and it is obviously beneficial to avoid stress where possible in his situation, any kind of financial support would benefit him.

This case went to mini alloc in August. It has been referred to the main trustees meeting because it was felt that with the increase in life expectancy and sperm-washing, it seemed likely that more beneficiaries would have children. The payment of such a grant would set a precedent and would, therefore, require reference to the full trustee body.

**Amount Requested:** £1500

**Recommendation:**

---

SUMMARY

Age: 48 Marital status: Married Children under 18: 2

Family Circumstances: Wife, son (76), two daughters (78,81).

Health/Disability: Symptomatic; severe haemophilia, incapacitated because of chronic joint/back pain and generalised muscle weakness & wasting - a combination of Haemophilia & HIV. CDC=B2 Karnofsky=60 Treatment=fluconazole,dapson,refuses anti-viral therapy.Despite low CD4 count remains reasonably well. Intermittent lymphadenopathy - has been biopsied. Antibiotics for oral thrash

Car: Motability

Housing type: House

Housing Ownership: Mortgage

Employment status: Long term sick

Present/previous job: teacher

Means tested benefits: Council Tax Benefit

Other benefits: Incapacity Benefit

DLA mobility component: Higher rate

DLA care component: Higher rate

---

PAYMENTS

Reg pay monthly rate: £245.00

Single payments: £13,672.00 32% (25)

Regular payments: £24,122.00 57%

Winter payments: £4,325.00 10%

Total: £42,119.00

---

Overall total (MSPT1/2+MFT): £122,619.00

---

REQUEST

Mr GROA's daughter has secured a place at Oxford University to take a teachers degree. This is a wonderful opportunity which they very much wish to support as a family. Due to their financial situation and the recent government policy on student's fees this will prove very difficult. Mr GROA requests the Trust help with the maintenance fees as they fall short by about £1343 per year, their £79 tuition contribution and a grant of £200 to cover the cost of necessary books and equipment. Please see attached details of expences and grants etc. This case has been referred to the main Trustees meeting by mini alloc in order that a policy decision can be made. It is thought that due to recent Government policy there will be a flood of similar cases.

**Amount Requested:** £1622 per year

**Recommendation:** Recommendation is that we support this request as we have with other similar cases.

18 AUG 1998

1990

Dear Fran Dix

August 1998

I am writing with further information that has arrived from the County Council with reference to my claim for a grant towards EDUCATION COSTS for my daughter **GRO-A**

Due to our circumstances we only have to pay ,this year, £79 towards the tuition fees of £1000. Unfortunately the maintenance grant allocated falls far short of the universities accommodation and living costs.

We need to apply for a grant from the trust of £1343 plus £79 tuition to be able to facilitate **GRO-A**s further education at Oxford. We do not have this sort of money from our own resources.

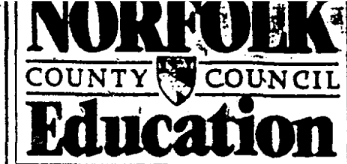
I can send further document details if this is needed.

Yours Faithfully

**GRO-A**

(1990)





Bryan Slater

Student Grants Unit

County Hall  
Martineau Lane  
Norwich  
NR1 2DL

Tel: (01603) 222146

Direct Dialling

GRO-C

1990

Ref No : 03/76093/1998

13 Aug 1998

Dear

## ASSESSMENT OF FINANCIAL SUPPORT 1998/1999 NEW RULES

Name :  
Course : BA/BTS Teaching  
College: Oxford Brookes University

Duration: from Sep 1998  
to Jul 2001

This letter gives details of your means tested entitlements for the academic year 1998/1999. They are subject to the conditions sent to you previously. This information supersedes any previous assessment letter for the same year.

## CONTRIBUTION ASSESSED ON FAMILY INCOME

Rental contribution: £ 79.00

## TUITION FEES

The standard tuition fee for the year is: £ 1000.00  
The amount you have to pay for tuition is: £ 79.00  
The amount payable by the County Council is: £ 921.00

## MAINTENANCE GRANT

Standard grant 810.06  
Extra weeks supplement (4 wks) 246.40

TOTAL £ 1056.40

Less: assessed contribution 0.00

GRANT PAYABLE £ 1056.40

£ 2600  
for accommodation

The grant will be paid in three termly instalments: Autumn £369.74  
Spring £369.74 and Summer £316.93).

A cheque will be sent to you via the University/College at the start of each term. Any balance due following a reassessment will also be sent to the University/College.

This is a provisional assessment which will be reviewed and if necessary adjusted when documentary evidence has been provided to confirm.

1. Mortgage interest payments made and allowed for tax relief in the year ended 5 April 1998 (eg MIPAS 5 certificate).

Please keep this letter for future reference. Your University/College will want to see it for fees and loan purposes and it is in your own interests to be able to produce it immediately on request.

D. S. NM

Yours sincerely

GRO-C: Paul Barber

## Arthur Sanctuary Hall (ASH)

### FACT-FILE

**Location:** Sandfield Road, Headington, Oxford, OX3 7RG - situated in the grounds of the John Radcliffe Hospital approximately half a mile from the Gipsy Lane Campus. Leased to the University by the Oxford Radcliffe Hospital Trust, ASH also houses nursing staff for the Hospital in a separate wing of the building. Therefore, consideration and courtesy towards the different living/working style of nursing staff on night duty will be required of you.

**Type:** Self-catering.

**Accommodation:** 106 student single study bedrooms with shared bathroom and kitchen facilities.

**Facilities:** Large common room with TV, separate study room and laundry room.

**Estimated cost 1998/99:** £50 to £55 per week (inclusive of all bills).

**Other:** A Hospital Residence Officer is available between 9.00am and 1.30pm, Monday to Friday, and the Hall is regularly patrolled by security staff overnight.

You will need to bring your own bedding and a small amount of personal cutlery, crockery and saucepans.

**Note:** THERE ARE NO CAR PARKING FACILITIES ON SITE.

## Mary MacDonald Hall

### FACT-FILE

**Location:** 50 London Road, Headington, Oxford OX3 7LP - situated in the grounds of Dorset House within walking distance of the Gipsy Lane Campus

**Type:** Self-catering.

**Accommodation:** 19 single study bedrooms, sharing kitchens and bathrooms.

**Facilities:** Common room and laundrette.

**Estimated cost 1998/99:** £50 to £55 per week (inclusive of all bills).

**Other:** A Resident Duty Warden is available to offer help and support where necessary. The communal areas are cleaned Monday - Friday by Domestic Assistants.

You will need to bring bedding and kitchen equipment.

**Note:** THERE ARE NO CAR PARKING FACILITIES ON SITE.

1990

**UCAS**PO Box 28, Cheltenham  
Gloucestershire, GL50 3SA

Tel. 01242 227788 (UK) 44 1242 227788 (International)

**AS12****Confirmation**

72534

Application No. 98-176057-3		Date 19/05/98	
Institution code	name	Course code	Entry date
6 066	OXFD	X500	SEP98

UCAS is a registered company (No. 2839815) and a registered charity.

Dear Applicant

This letter confirms your place at the institution named in the red box above for the course and year of entry indicated. If this was your insurance choice, it means that the offer which you accepted firmly has not been confirmed, i.e. your preferred institution has not offered you a place.

This place, whether or not you take it up, represents your final position in this year's UCAS scheme. You will not receive any other offers and you may not negotiate with any other institution in the scheme. You will not be eligible for Clearing, even if you choose not to take up the place.

If the place is for deferred entry and you inform the institution that you intend to take it up, you are not permitted to make a further application in next year's scheme. If however you do not wish to take up the deferred entry place, you should withdraw immediately from this year's UCAS scheme and may if you wish re-apply in next year's scheme.

Please note that the place is being reserved for you on the assumption that you have satisfied all general and course requirements for entry but it is in your interests to make certain this is so. If you have any queries about these requirements you should write to the university/college concerned. In some cases the institution may have asked you to comply with non academic requirements, e.g. financial guarantee. You must be in a position to meet in full any non academic requirements before you will be permitted to join the course.

You must now return the reply slip below immediately to the institution, to inform it of your intentions. If you decide later that you do not wish to accept the place, please write to the institution, to enable the place to be made available to another applicant.

May I take this opportunity to wish you every success in your studies.

Yours sincerely

GRO-C

M A Higgins  
Chief Executive

REPLY SLIP - AS12

PLEASE SEND TO INSTITUTION ADDRESS BELOW

MACF0000005\_036\_0031

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COMPUTER

3.0 15 Sep 98

2166

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SUMMARY

Age: 34 Marital status: M c/l Children under 18: 3

Family Circumstances: Now lives with partner and her two sons

Health/Disability: Mild haemophilia

Patient has been asthmatic since having PCP in 1992.

Awaiting operation for excision of osteoma left ear CDC=C3  
Karnofsky=80 Treatment=Septrin , DDC 075mg b.d., Itraconazole  
200mg b.d

Ventrolin Beclofone (inhaler)

Car:

Housing type: Ground Floor Flat

Housing Ownership: Rented private

Employment status:

Present/previous job: agency nurse

Means tested benefits: Income Support

Other benefits: Incapacity Benefit

DLA mobility component: Higher rate

DLA care component: Higher rate

---

PAYMENTS

Reg pay monthly rate: £295.00

Single payments: £1,750.00 10% (2)

Regular payments: £12,069.00 68%

Winter payments: £3,925.00 22%

Total: £17,744.00

Overall total (MSPT1/2+MFT): £69,744.00

---

REQUEST

Please see letter attached.

Amount Requested: £690

Recommendation:

2166  
29 JUL 1998

27 July 1998

Dear sir

**Reference no. 2166**

I realise that this is probably not a request that you would normally even consider, but it has become such an important part of my life that I feel that I must make it anyway.

I have been unemployed now for approximately 3 years and every attempt that I have made to return to work has failed dismally, usually for one of two reasons.

- The moment that I am placed under any pressure or stress I become ill and either have to resign or have it put to me by my employer that maybe I would be better off doing something else.
- Secondly, by about 1.00pm I am usually feeling very tired and lethargic and have to go and rest for a couple of hours. Needless to say most employers find this to be an unacceptable practice.

I was just about at the end of my tether when my brother-in-law knowing that I had a Diploma in Information Technology gave me what turned out to be my saviour, his old computer. Now, instead of sitting at home feeling sorry for myself and biting the head off of everyone in sight, I was able to regain some of my self respect and to feel useful again by helping others to write letters and type documents. I also started to teach people how to use computers and different software packages. Finally I found myself able to help my own and my friends children with school projects and homework.

Unfortunately my system is now rather old and keeps going wrong in ways that are well above my capabilities. I asked a specialist to give it an M.O.T, and in his opinion I am just throwing good money after bad in an attempt to keep it running and would be far better off getting a new system.

2166

Under normal circumstances I would either approach the bank for a loan, attempt to purchase one on credit or as I am the secretary of the GRO-A see if they would help. However I do not feel that any of the above solutions are viable for the following reasons.

- In our present financial situation we could not afford a bank loan or the credit repayments.
- If the Haemophilia Society supplied one and I then had to give up my position as secretary of the group I assume that they would require the system to be returned to them, leaving me in a worse situation than at present.

**Please is there any way that the trust can help me to get a new system that functions properly.**

I have approached a friend who builds systems for people and we have discussed my needs. He has kindly given me two quotes on the best deal that he is able to offer bearing in mind what I want the system to do.

Please find enclosed a summary of his quotes, a complete copy is available if required.

Thanking you in advance for your consideration

Yours sincerely

enc: costings for computer system

### COSTING 1

28dp 14" Monitor	£75.00
Midi Tower Case	£49.00
AMD K6 200 MMX	£60.00
H/S and Fan	£ 3.00
Motherboard Gig.ATX	£70.00
2 x 16mb edo ram	£20.00
2.1 gig hd HD	£75.00
1.44 fd	£12.00
2mb graphics card	£19.00
Sound Blaster awe32	£35.00
Speakers	£ 8.00
12 x CD rom	£28.00
Win95 keyboard	£ 7.00
Mouse	£ 2.00
Win95 and MS Office installed	£00.00
Labour	£70.00
Subtotal	£533.00
Vat @ 17.5%	£ 93.28
Total	£626.28

### COSTING 2

As for costing 1 except for:

- 28dp 14" Monitor would now read 28dp 15" Monitor Cost £102.00
- 2mb graphics card would now read 4mb 3D Matrox graphic card Cost £ 45.00

These changes would now give:

■	subtotal	£586.00
■	vat	£102.55
■	total	£688.55

---

**CAREER ENHANCEMENT**

3.0 15 Sep 98

2220

---

**SUMMARY**

Age: 26 Marital status: Married Children under 18: 1

Family Circumstances: Lives with wife and her child from a previous relationship.

Health/Disability: Severe haemophilia  
Prior to starting antiretrovirals was very "run down" low energy, chronic skin problems, now considerably improved.  
CDC=C3 Karnofsky=60 Treatment=Combination antiretrovirals with zidovudine and didanosine

**Car:**

Housing type: House  
Housing Ownership: Rented LA

Employment status:  
Present/previous job: u/e

Means tested benefits: Income Support  
Other benefits:  
DLA mobility component: Higher rate  
DLA care component: Higher rate

---

**PAYMENTS**

Reg pay monthly rate: £370.00

Single payments:	£6,650.00	20% (8)
Regular payments:	£22,844.00	67%
Winter payments:	£4,535.00	13%

Total:	<u>£34,029.00</u>
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Overall total (MSPT1/2+MFT): £77,529.00

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**REQUEST**

Mr [GRO-A] has been approached by Channel 4 and Chrysallis records to produce music for Channel 4. Mr [GRO-A] is obviously very eager to grasp this opportunity. He has been given a secondhand PC and modum but needs to find £500 to achieve his goal.

Above information went to mini alloc which requested further info on what £500 is for.

Please see letter which explains costs for recording needs plus a request for a colour printer to be used on the OU course he has been accepted on.

4 track tape unit £325 ✓ - employment  
has paid out £350 on second hand equipment  
colour printer £230 ✓ - Education



**Amount Requested:** £500/£230

**Recommendation:** This could open doors for him and make him less dependant on the Trust as well as boost his moral immensely.



2220

Yorkshire Region  
The Open University  
2 Trevelyan Square  
Boar Lane  
Leeds  
LS1 6ED

Telephone (0113) 244 4131

Your personal id R7154146

Region 07

Reservation No S0653982

Document reference RFS2B

19 August 1998

Mr **GRO-A**

**GRO-A**

Dear Mr **GRO-A**

I am pleased to invite you to register for the course(s) you have chosen:

Course	Award codes	Title	Offer open until
S103 99	BD	Discovering Science	29 Sep 98

We will hold this place open for you until the date shown above. If we do not hear from you by then we will assume that you are unable or do not wish to study with us on this occasion and will cancel your reservation. If you need more time to get your registration agreement and payment to us please let us know and we may be able to extend your reservation.

**What this registration pack contains:**

- Registration agreement
- Detailed course description(s), except for some courses that count towards taught higher degrees
- *Advice before you register for 1998/99 study*
- *Completing Your Registration Agreement 1998/99*
- *Personal Computing for Open University Study 1998/99*
- Sponsorship form
- Addressed return envelope

If any of these items are missing please contact us at the address given above.

**If you have questions or need help**

Before you complete your registration agreement please read the booklet *Advice before you register for 1998/99 study*. This, together with the course description, outlines the issues you should consider before committing yourself to OU study.

*Personal Computing for OU Study* contains information about the computing specifications for all courses that have a computing element. If your course requires regular access to a computer please read the booklet carefully and make sure that you will have access to equipment of the correct specification. If your course has an optional computing element the specification required is also explained in the booklet.

If the booklets do not answer all your queries we will be happy to discuss any questions you want to

PLEASE TURN OVER

## Recommended minimum computer specifications

### Multimedia

This kind of computer will probably have been acquired since early 1996. If you have one that meets this specification, you can be sure that you can do any current course that includes computing and you need read no further. You will probably also be able to do all the new courses that the OU will be presenting over the next couple of years. The software for many of the courses we have put in this category will run with a slower processor or less memory but the performance may be very poor. If you have to use a slower processor then it should be at least a 486DX2 66MHz with at least 16Mb memory.

- ✓ Pentium 100MHz processor
- ✓ Windows operating system (probably Windows 95 though for most courses Windows 3.1 or 3.11 will do)
- ✓ 16Mb memory (RAM)
- ✓ Hard disk drive, with at least 100Mb free for course software (probably a 1Gb disk or larger)
- ✓ 2Mb graphics card with colour monitor displaying to a resolution of 800x600, High Color (14" will usually be sufficient but 15" is better for higher-specification graphics)

Printer (probably colour but black and white will do for most courses)

- ✓ CD-ROM drive (probably at least 8 speed but double speed will do for a few courses)
- ✓ Sound card with speakers or headphones

A modem (probably 28.8kbps) is usually included in a computer with this specification, though you may not need it for your OU course. If you do need one we mention it separately in the lists on pages 6-7.

*This specification is less than the commonly available 'entry-level' computer at the time of writing (February 1998) and if you are thinking of buying a computer you should read our advice on page 4.*

### MS-DOS

If you have an old computer there are one or two courses that have older software and the following specification will be sufficient. This kind of computer may be up to ten years old and may not even have a hard disk drive.

- 8086 processor (or in some cases 80286)
- MS-DOS 3.3 operating system (version 3.2 on Amstrad 1512)
- 640Kb memory (RAM)
- CGA graphics with suitable monochrome monitor (or in some cases colour)
- Hard disk drive, with at least 5Mb free for course software (you may need only one or two floppy disk drives – 1F or 2F in the lists)
- Printer (black and white will do)

If you intend to use optional electronic communications, this class of machine is not suitable. You will need the higher specification described under *Windows* above.

### Windows

A computer like this will be suitable for all but our most recent courses, which need the Multimedia computer described opposite. It is likely to have been bought between 1992 and 1995, when Windows 3.1 (and the later version 3.11) was the usual operating system. Built-in CD-ROM drives and modems were less common but might have been bought separately. The processor types range from the 386SX to the 486DX4. Only the 486DX types include as standard a maths co-processor, which you might need for your course. The minimum you will need is:

- 386 processor
- Windows 3.1 or 3.11 operating system
- 4Mb memory (RAM)
- 1Mb graphics card, with 14" colour monitor displaying to a standard VGA resolution
- Hard disk drive, with at least 20Mb free for course software (probably a 200Mb disk or larger)
- Printer (black and white will do)

If your course needs a CD-ROM drive, sound card with speakers or headphones or modem we mention it separately in the lists on pages 6-7.

Performance will be improved with any increase in processor speed, hard disk space or memory. If you have Windows 95 and recent versions of Works, Word or Excel, you need a higher-powered machine than this minimum – at least 8Mb memory and a 486DX processor – otherwise the performance may be so poor as to be unusable.

*If your course uses electronic communication, optional or compulsory, anything less than a 486DX processor, 8Mb memory and 28.8kbps modem may lead to higher telephone bills.*

I HAVE  
MANAGED  
TO GET  
THESE  
MYSELF →

I FEEL THAT  
I WILL  
NEED THE  
OPTION OF

COLOR  
PRINTING  
FOR THE

ASTRONOMY  
PROJECTS

OF THE  
PHYSICS

ALSO FOR

MAGNETIC +  
ELECTROMETER

PRINTS ETC

Hewlett Packard

## DESKJET 720C

Holding two cartridges at a time, the 720C negates the need to switch between colour and black ink which speeds things up greatly. Indeed, we printed five pages of text in a minute in almost complete silence.

It looks great, too, and a built-in slot means that there is no need to remove your paper when you need to address your envelopes. A small door in the back will even let you get your fingers inside the printer to free up any jammed paper.

What really bowled us over, however, was the quality of the graphics it produced.

Any faded areas on the printed image were extremely smooth and there were no sudden jumps or steps between different shades. The colours were vibrant and a series of black blocks which we gave the printer as a test were output as a deep regular colour. This showed that the ink was being distributed across the printed page evenly.

Setting the printer up was no trouble at all using the intuitive

software drivers.

These do a lot of the set-up work for you, by going on to check that the computer and the printer

were communicating with each other without any problems.

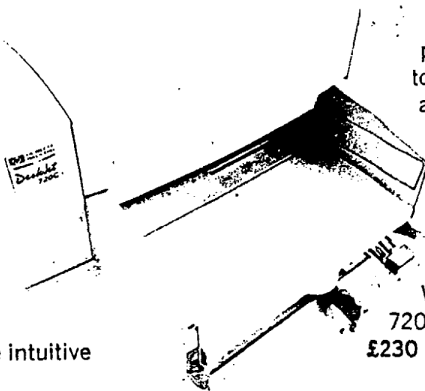
As we said before, whether you use generic papers or those supplied by the printer manufacturer, your decision has to be based on how much you want to spend and

the results you want. On Hewlett Packard's own Premium Inkjet Paper it had no trouble at all completing our thin-line-through-black-ink test, which stumped most of the others rounded up here.

We have no hesitation in awarding the 720C the Computeractive seal of approval.

£230

**BUY IT!**  
Computeractive



## VISITS AND LIAISON

## 1. Benefits Adviser

29 July	1845	Home Visit	GRO-A
5 August	1144	Appeal	Coventry
6 August	1318	Home Visit	GRO-A
17 August	2128	Home Visit	London
27 August	1379	Hospital Visit	London

## 2. Social Worker

12 June	Conference W/P	Haemophilia Society
22 July	Visit to Registrant	GRO-A
24-26 July	Birchgrove Conference	Bath
30 July	Conference W/P	Haemophilia Society
3 August	Visit of Registrant to:	Macfarlane Trust

## DRAFT TERMS OF REFERENCE - FINANCIAL ADVISER

BACKGROUND

The Macfarlane Trust has been using a Financial Adviser to assist Registrants with financial planning and mortgage arrangement since early in 1991.

Susan Daniels was originally approached by Tudur Williams because Trust Registrants were finding it very difficult to obtain mortgages due to their HIV status and dependance on Benefits. Susan managed to negotiate a 'Benefits only' mortgage package for Registrants with Nationwide Building Society, and in the first 5 or 6 years of her involvement with Macfarlane Trust she arranged approximately 40 mortgages for Registrants and at the same time advised many on their personal finances.

As time went on Tudur Williams asked Susan Daniels to become involved with financial planning more and more frequently due to the number of Registrants who had spent their original MFT payments and were left in poor circumstances.

Following a period of 'negative equity' and a flat housing market, things have improved considerably in the past two years, and many Registrants have been able to move to more appropriate housing with help from Susan Daniels.

More recently, Susan has been called upon to provide debt counselling and in a number of cases to negotiate with creditors and reschedule debt in a way that is acceptable to them and manageable by the Registrant.

Susan Daniels also gives advice to families following bereavement, and has become very much part of the support network offered to Registrants by the Trust.

Susan Daniels is professionally qualified with a Financial Planning Certificate awarded by the Institute of Chartered Insurers and carries her own Professional Indemnity Insurance. Her work for the Trust falls into two main groups:

1. General Financial Advice, for which Susan charges fees of up to £100 per client on the basis that advice given is 'guaranteed to be totally disinterested' and for which her only financial return is the fee paid by Macfarlane Trust;

and

2. Mortgage Assistance for which the Trust pays a fee of £275 for each arrangement which in most cases is deducted from the 'Moving Home Grant'. Susan also receives a small fee from Nationwide as a mortgage broker.

The Trust also pays Susan Daniels her Travel Expenses when on Macfarlane Trust business.

Susan has set up her own business: JTA Financial Services, and her role as Financial Adviser to Trust Registrants has 'grown like Topsy' over the years.

It is now felt necessary to establish a professional and formal Agreement between JTA Financial Services and Macfarlane Trust that will cover the following areas:

- (i) Initiation of specific business - how SD knows that work is authorised by MFT and will be paid for.
- (ii) Range of advice covered by Agreement: Financial Planning; Mortgage Advice/Arrangement; Debt Counselling and Rescheduling; other areas to be considered.
- (iii) Fee negotiation and review; payment of expenses.
- (iv) Professional Indemnity Cover and updating of Qualifications.
- (v) Review and Renegotiation of Agreement: frequency and who should be involved.
- (vi) Any other relevant points

This issue is raised to give Trustees the opportunity for further discussion on a suitable Agreement.

Ann Hithersay  
Administrator




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KENT AND CANTERBURY HOSPITALS NHS TRUST

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Kent Haemophilia Centre  
Comprehensive Care Centre  
01227 783157

2 September 1998

Ann Hithersay  
MacFarlane Trust

Dear Anne

### **HIV and Infertility**

I would like to suggest that it would be an appropriate time for the Trustees to reconsider the issue of HIV and infertility. From my own experience - and talking to a number of colleagues around the country - it is apparent that one of the major issues that has evolved over the past two years following on from the development of more effective therapy is a deeply felt wish by many patients to start a family. This obviously presents significant problems in view of the well defined risks of HIV transmission to the partner through unprotected sexual intercourse.

You will recall that around six months ago the Trustees discussed this issue and, having taken specialist medical advice, decided that at that time it would not be appropriate for them to fund this treatment. Since then, a number of Centres in the UK have started to offer the service on a formal basis and one must conclude from this that they are themselves satisfied - and have managed to satisfy their local ethical committees - that the treatment is as safe as can reasonably be expected.

You will be aware that the Trust has already received submissions from registrants asking for fertility treatment for HIV. The funding for such treatment is not widely available on the NHS as this is a new treatment, the cost of which would have to be met from existing funds.

My own view is that this is an especially sensitive and important issue for a number of families and that the Trust should reconsider its position in terms of being able to fund these families. There would appear to be a number of absolutely critical issues:

- As a matter of principle, do Trustees believe that we should be funding any form of treatment for patients?
- In the event of HIV transmission occurring to the female, would the Trust in any way be held responsible?
- Would it be a reasonable course of action to ask the families to sign some form of legal disclaimer?
- Given that only 20 - 30% of treatments are effective at this time, how many treatments -



and to what level of funding - could we support these families, if appropriate?

It might be appropriate for us to take a legal opinion on these issues so as to enable us to have a clearer view of what is a difficult situation.

Finally, the UK Haemophilia Centre Directors Organisation have asked me to prepare a paper on the current status of sperm washing for HIV discordant couples and I would be pleased to make this available to the Trustees once it is completed.

Best wishes.

GRO-C

Yours sincerely

**M WINTER**

Haemophilia Centre Director

There has been a great deal of Strategic Review activity since Trustees met in June.

**The Census Form**

The Census Form was circulated to all Registrants towards the end of June; so far over 350 forms have been returned, but a reminder will go out in the September Newsletter highlighting the importance of a 100% return so that up to date Census data can be fed into our computer records.

**The Questionnaire**

The Questionnaire was circulated to all Registrants at the beginning of July, together with a letter offering three levels of involvement in the Review:

- (i) completion of the Questionnaire;
- (ii) joining a Focus Group;
- (iii) participating in a 'One-to-One' Interview

To date more than 160 Questionnaires have been returned; around 50 people have asked to join Focus Groups and more than 20 people have offered to participate in a 'One-to-One' Interview.

Focus Groups and One-to-One Interviews will be held during September and October. We are grateful to The Haemophilia Society for allowing **GRO-A** HIV Worker, to devote so much time to this work over the coming weeks.

**The Interim Report**

The Interim Report was submitted to Baroness Hayman, Junior Minister in The Department of Health, who became responsible for blood safety issues after Baroness Jay was promoted to Leader of the House of Lords in the Reshuffle, at the end of July. The Chairman has received a brief acknowledgement from Baroness Hayman. Our accompanying letter also asked for financial help to enable us to complete the Strategic Review. We have had no response to this request as yet.

**Questionnaire Analysis**

At the last meeting of the Strategic Review Group in July, it was suggested that the Questionnaire analysis be offered to 'Public Attitude Surveys' (PAS) who carried out the Trust Review in 1996. However, the sum they quoted for the work was so high that we referred the problem back to the Consultant who had helped to draft the Questionnaire; she agreed to analyse the results for a significantly lower sum. The work of analysis is taking place at present, and has already identified a number of significant themes which will be highlighted in the main Report.

### **Literature Search**

We explored the possibility of a Literature Search with Professor Sarah Darby at Oxford University, Department of Epidemiology, Radcliffe Infirmary, who was of the opinion that as yet there was insufficient published material to make such a search worthwhile. As we have no funds available anyway, we have decided to abandon this part of our Review.

### **Financial Matters**

The lack of additional funds to complete our Review is a source of considerable concern. We have had no response from the Department of Health, and as yet have postponed applying to Trusts for support because all potential donors will first ask why we have not received further funding for the Review from the Department. However, the National Aids Trust has supplied a list of potential Trusts to apply to, and has also suggested that we contact the Department of Contagious Diseases within the DOH to see if they would provide some funds towards our Research.

Meanwhile, work on the Review must go on: we are on track to complete all research by mid-October, and plan to prepare a first draft of the Final Report by early November. There remains much administrative work to be done, and we will need extra help to complete this on schedule. I hope we shall soon have a positive response from the NHS Executive.

Focus Groups, One-to-One Interviews and Analysis of the Questionnaire, together with additional costs of printing our Final Report and ensuring that there is sufficient administrative support to complete the Review work without prejudicing other Trust activities, means we are looking for an additional grant of £15,000 from Government and other sources.

### **Psycho-Social Needs Sub-Group**

The attached note from the Psycho-Social Needs Sub-Group summarises main issues being considered by the Group at present.

Ann Hithersay  
Administrator

Number 40

SEPTEMBER

## MFT

## Newsletter

## Ann's Column

## Strategic Review Update

Although it is some time since our last MFT Newsletter, we have been communicating with you in other ways. . . First it was the revised Personal Information Form, sent out in May so that we could up-date the database here in the Office, then at the end of June we sent you the huge yellow Questionnaire to help us identify needs for the Strategic Review. So far you have returned 350 Personal Information forms and 159 Questionnaires to the Office. This is excellent progress, but we do need 100% return on the Personal Information Forms, Please. It is very important for us to know that the information we hold on our database is accurate, and that you have agreed it with us. So please, if you are still waiting for 'the right moment' to complete the PIF, do it now and post it back to us! If you have lost your copy, please call us and we will send you a new one!

Work on analysing the Questionnaire is almost complete, and interesting themes and issues are becoming clear. These will be helpful for those who will be facilitating the Focus Group that are to be held in September and October. We have tried to include everyone who indicated they would like to take part in a Focus Group or One to One interview, and hope that those involved will find it a valuable opportunity to contribute their own thoughts and feelings to the Review.

As you know, the Questionnaire was intended to be anonymous, though many of you have sent us letters and notes, and these will be answered. However, one or two of you have completed the Questionnaire in such a way that Fran and I feel you may need to talk to someone about your problems. We will respect confidentiality, but we are here to listen if you feel it would be helpful to talk. So do please call or write to us, no matter how angry and fed up you may feel with the world.

We have realised from replies that have reached us that, despite its size, the Questionnaire failed to cover a number of important areas. I will mention just two of these, and ask for your help, please.

**Hepatitis C:** we did not include a specific question on whether or not you had hepatitis C infection on either the PIF or the Questionnaire. The issue of co-infection is so important that I am enclosing a 'Reply Slip' and envelope so that everyone can let us know their Hepatitis C status as an addition to the Personal Information form, please.

**Mental Health Problems:** A number of you have mentioned depression and other mental health problems

when responding to the Questionnaire. Sometimes there have been episodes of disturbance following introduction to new treatments, and again we would find it useful to know whether or not such experiences are common. Therefore, if you have experienced depression or other types of disturbed feelings in recent years, and would be prepared to share information about this for the Review, please contact us. You can write anonymously if you wish, but remember that all information that we receive about an individual remains confidential to the Trust, and will not be shared with any third party without your expressed permission.

Thank you again for your help.  
Ann Hithersay

Fran's  
column

## Carers Centres

I have recently been sent information from The Prince of Wales Royal Trust for Carers advising of its 70 Carers' Centres throughout the UK.

The Carers' Centres provide information, support and practical help to those caring for relatives, friends or neighbours who otherwise may be unable to manage at home because of sickness, age or disability.

Services include a 'listening ear', information on benefits and services, personal counselling and support, access to respite care or practical help in the home, advocacy on behalf of carers with social services and other service providers and arranging training, social and recreational events for carers.

If you would like to find out where your nearest Centre is, telephone Peter Tahanyi on **GRO-C** or for London Centres, Gerry Mahaffey on **GRO-C**.

## My View of The Birchgrove Conference on Treatments &amp; Alternatives, Bath: July 24th - 26th.

I attended my first conference recently for Macfarlane Trust registrants. Returning home on Sunday I felt emotionally and physically exhausted. It was incredible, not because of the many people who expressed the support they felt in being in a situation with people "in the same boat" - no secrecy or having to pretend or being 'the only one' in that position. It was a chance for people to share what was going on in their lives and listen to how others handle their situation. For those whose first time it was watched as over and over again emotional support was offered by 'regulars' who seemed to say 'yes, I felt like this too'.

*Continued on page 2*

Continued from page 1

The conference workshops were only a small part of the weekend, most of the 'work' (I'm in danger of saying support for the third or fourth time, even though it's the best way of describing what was going on) happened over dinner and in the bar into the early hours of the morning or over card games - played with lumps of sugar and after dinner mints as winnings.

The talks on Hepatitis C/HIV co infection and HIV treatments and therapies were interesting as was the alternative therapies discussion.

As the presenter of the latter discussion did not turn up, one of the organisers, an MFT registrant and Birchgrove member, relayed his experiences of Chinese herbs and acupuncture. It was well received and provoked lots of questions - the thought of sitting with a row of needles sticking out of and around both ears in order to relax you while you wait for your 'proper' treatment, quite appealed to me. I wouldn't mind a row or two at work sometimes.

All in all, I felt privileged to be made to feel so welcome by a group of people going through such difficult, and sometimes unbearable, lives.

Thanks, Birchgrove, for arranging it.

## **Motability**

### **Motability Adaptions**

Many registrants ask about car adaptions. A request for a grant towards adaptions would go to a Trustees' Meeting for their consideration but in the first instance the Trustees have asked me to point out the help Motability may be able to provide.

- If you have an existing Motability vehicle needing adaptations you should write to Motability giving note of the necessary required. Dependent on the type of adaptation applied for it may take up to 3 months for an application for grant assistance to be considered.
- If the car is privately owned, you should write to motability with an estimate of the adaptations. The car must be under 5 years old and have done under 60,000 miles. Again, it may take up to 3 months for an application to be considered.
- If applying for a Motability car, a question on the application form should be ticked when requiring adaptations. It is a "Yes" tick for "advanced payments and adaptations options".
- On renewal of a Motability car, around 5 months before renewal a notification letter is sent to you with a pink page which is to be returned should you seek financial assistance.

• In all cases, where financial help is sought, Grants Department will send out a more comprehensive grant form. On receiving this back they at a person's physical requirements and their financial circumstances on an individual basis prior to deciding on an offer of a grant.

If you require more information and details, please call the Motability Customer Services Helpline 01279 635

### **Viramune also known as Nevirapir**

I have been asked by an MFT registrant (let us call him Iv) to make a request to those of you who have experienced Viramune to please contact the Trust by letter sharing experiences in order that I can anonymise the letters and them on to Mr X.

If he wishes to contact the writer of the letters I will contact first before giving any names out.

Fran



## Benefits Column

### **Housing adaptations for disability - related needs**

This is really a reminder rather than new information. You all probably know you can get help from the local authority towards the cost of adapting accommodation for the use of disabled people by means of a Disabled Facilities Grant. It takes time however before a scheme can be assessed and carried out. The waiting period can already be upwards of a year and looks set to increase following a recent legal judgment that local authorities should not take into account financial resources. Up until now there has been a means - test which has acted to some extent as a "rationing" system, but the judgment seems to mean that anyone who meets the criteria for help on disability grounds will be accepted for help whatever their financial circumstances. This will lengthen the waiting time even more.

**It is therefore essential to make an application at the earliest possible stage** so that you are not in a position of desperately needing work to be done and having a long wait.

The other point is that work of this kind can lead to a reduction in your Council Tax bill. You can get a reduction if anyone in the household is "substantially and permanently disabled" and you meet one of the three following conditions:

- You have a second bathroom or kitchen needed by that person
- You have a room (other than bathroom, kitchen or toilet) needed by and predominantly used by that person

You have enough space in your dwelling for that person to use a wheelchair

If any of these apply you move down to the next lower band for Council Tax. Unfortunately it does not help anyone in band A which is already the lowest band and there is no equivalent alternative type of reduction in its place.

### **Benefits Integrity Project**

This is the review which is currently being carried out of Disability Living Allowance paid to anyone getting high mobility and high or middle rate care component.

Several members have been reviewed under the project and the results to date are encouraging. Of the eight cases I have been involved with four people had their current rates left the same; two were reduced but re - instated on review; one is awaiting appeal and one has not yet had a decision. This is less worrying than we had feared

and I hope you will find this reassuring. There have been reports that the project is to be abandoned, but unfortunately this does not seem to be happening.

### **Changes to Disability Benefits**

I recently attended a meeting of the Disability Benefits Consortium to put forward ideas for a response to Frank Field's Green Paper but this is still general rather than specific and the recent changes of personnel at the top of the DSS causes further uncertainty so there is still nothing to report.

### **Fridgesavers**

I have recently come across this scheme whereby certain groups of people can have a faulty fridge replaced with a new one for a payment of £25. It is funded by the various electricity boards as part of their responsibilities to promote energy efficiency.

The scheme applies to people on means-tested benefits. Disability Living Allowance or state retirement pension if this is the only pension and covers faults such as damaged door seal; cracked walls; damaged or missing fittings etc. I have a few application forms if anyone would like to apply.

# Information

## New Publications

NAM have recently published three new booklets which may be of interest:

1. Viral Load
2. Nutrition
3. Clinical Trials

Copies of these booklets can be obtained from:

NAM Publications

16a Clapham Common Southside

London SW4 7AB

Phone: 0171 627 3200

Avert Aids Education and Research Trust has just published a booklet entitled:

'A Guide to the Treatment of HIV Related Diseases'

This publication costs 25p and can be obtained from:

Avert

4 Brighton Road

Horsham

West Sussex RH13 5BA

Phone: 01403 210202

## Holiday Insurance for people living with HIV - World First

Another Travel Insurance Scheme for people with ongoing medical conditions including HIV is available from:

Rothwell and Tyler

PO Box 1

Sidmouth Devon EX10 8YT

Phone: 0845 90 80 555

## Motability

The Motability Applications Brochure contains a lot of relevant information for those intending to take on a vehicle for the first time, or to renew an existing contract with Motability.

The Brochure can be obtained from:

Motability

Goodman House

Station Approach

Harlow

Essex CM20 2ET

Phone: 01279 635 666

## Sigma Research

**Living with HIV in the UK** We have been asked to circulate the above Research

Questionnaire by SIGMA who, like the Trust, is seeking to update information on 'living with HIV in the era of combination therapy'.

**Completing this Questionnaire from SIGMA** is completely optional; however we do believe it is important that those people with haemophilia and HIV are adequately represented in the sample required in this National study, and as you may be aware, Macfarlane Trust is the only organisation in the country to have records of all of you, therefore we will inevitably be approached from time to time by bodies interested in contacting you.

## Notice for Kent Members

On 12th October Jenny will be coming to the Haemophilia Centre at Kent & Canterbury Hospital to talk about this. The meeting will be between 7 and 9pm and members needing transport should contact either Martin or Tilly at the Centre (GRO-C)

# Readers Column

Hello, I'm GRO-A

## Body and Soul Newsletter - Extracts

We have received permission from the Editor of Body and Soul Newsletter to reproduce two important Reports from from the National AIDS conference in Geneva on 'Adherence' and 'Nutrition'. I hope these will be useful.

For some time I have been wanting to meet other haemophiliacs who are in the same situation as myself and are living in the West Midlands area. I thought it would be nice to meet on a social basis in neutral surroundings to just 'have a laugh' and get to know each other.

I know I'm not the only one who would like to meet new

## Body and Soul Newsletter - Extracts

We have received permission from the Editor of Body and Soul Newsletter to reproduce two important Reports from from the National AIDS conference in Geneva on 'Adherence' and 'Nutrition'. I hope these will be useful.

MEMORANDUM

TO: ALL TRUSTEES

FROM: ADMINISTRATOR

3rd August 1998

**ADDITIONAL ALLOCATIONS COMMITTEE - WEDNESDAY 19TH AUGUST**

Due to the very high number of applications for grants outside Office Guidelines, it has been necessary to call an additional meeting of the Allocations Committee to take place during August.

The meeting will be 'round the table' here at the office on Wednesday 19th August, from 11.00am until about 2.00pm. Chris Hodgson and GRO-A have agreed to attend.

The extra meeting of the Allocations Committee, and decisions made, will be reported to Trustees at the next Board Meeting on 15th September for 'retrospective approval'.

Ann Hithersay  
Administrator



JUNE 1998