THE PARTNERSHIP GROUP

Notes of a Meeting held on Thursday 23rd September 1999 at Alliance House, 12 Caxton Street, London SW1

PRESENT Mrs Pat Latimer Chairman
Mr Alan Burgess
Mr GRO-A
M/s Fran Dix
Mr GRO-A
Mrs Ann Hithersay
Mr GRO-A
Mr GRO-A
Mr GRO-A
Mr GRO-A
Mr GRO-A

Introduction:

Pat Latimer introduced herself to the Group and said that she had hoped to have an opportunity to 'work herself into the role as Chairman' beside Tim Hunt at her first meeting. However the demands of Tim's new job as Director of Pembrokeshire MIND had made this impossible. Pat explained that she had been a Social Worker attached to the Newcastle Haemophilia Centre for more than 10 years. She was therefore very familiar with the issues faced by people with haemophilia and HIV and their families; but very unfamiliar with her new role as a Trustee of the Macfarlane Trust. Her first Trustees meeting had been a surprise, and she realised that she had always seen herself as an 'advocate' of those with haemophilia and HIV. As a Trustee, she hoped to bring greater understanding of needs to the Trustee Board. However she had become aware how very difficult the process of decision-making could be.

Members of the Group welcomed Pat as the new Chairman

1. Notes of a Meeting held on 14th May 1999

Issues arising in response to the Notes of the first meeting included:

(i) The term 'registrant' was not liked by all. Whilst it was recognised that Trust beneficiaries were not 'members' in the true meaning of the word, this had been better than the word 'registrant'.

(ii) Those present would like to see a registrant on the Trustee Board eventually. And more involvement with the Trust decision-making process.

(iii) Had the Trust received acknowledgement of the Strategic Review Report from the World Federation of Haemophilia? The Trust should be represented at the World Federation.

(iv) Was the Trust a member of the newly formed Haemophilia Alliance? If not Why not?

GRO-A had written to the Haemophilia Alliance asking about 'user representation' on the Alliance. No response had been forthcoming.

Ann Hithersay said in response to the above issues that as yet, the Trust had not received an acknowledgement from the World Federation. She would find out whether it was possible for the Macfarlane Trust to become a member of the World Federation, and would also ask for confirmation that copies of the Report had been received by the Federation.

Ann also said that she had spoken to the Chairman of the Haemophilia Society, and to Dr Winter about Trust participation in the Haemophilia Alliance. She had been told that this would be considered by the members, as it could be construed that the Trust was adequately represented by Chris Hodgson and Mark Winter, both of whom were Trustees of the Macfarlane Trust.

The Partnership Group felt that both Trustees were there as representatives of other organisations, and happened by chance to also be Trustees of Macfarlane. The Group felt that the Trust, and their interests, should be represented in their own right.

Ann said she would write formally to the Alliance proposing that the Trust be represented on the body.

GRO-A said that the Haemophilia Society provided a Secretariat for the Alliance, which had no separate funding at present.

It was agreed that if Trustees approved, a letter should be written to the Chairman of the Alliance asking that the Trust be formally represented. The letter should include an invitation for the Alliance to send a representative to a future meeting of the Partnership Group in order to discuss issues about user involvement in the Alliance.

The Notes of the previous meeting were approved.

2. Matters Arising

(i) Membership and Representation

The issue of the role of the group, and its remit was discussed at some length. It was agreed that whilst members recognised the need for more formal 'user involvement' in the Macfarlane Trust, the Partnership Group had been set up as a means of response to those recommendations in the Strategic Review that required multi-agency participation in implementation.

Those invited to the first meeting of the Group had been there as representatives of The Haemophilia Society, The Birchgrove Group, The Trust and as independent registrants.

At the first meeting it has been suggested that other groups of interested parties should participate in the Group. These included women as or/and with bleeding disorders themselves

partners/carers and as 'infected intimates'. Bereaved families and parents also had a stake in the Trust.

Ann Hithersay said that the Partnership Group had been mentioned in the September Trust Newsletter. All those interested in participating in the Group had been invited to contact the Trust. To date only about 4 people had been in touch. Two had joined the Group today; two were partners who had been advised that we would get back to them when it had been agreed what the make-up of the Group should be.

After considerable discussion it was agreed to recommend that the group be made up as follows:

Birchgrove Group	2 representatives
Independent Registrants	2 representatives
Under 25s Registrants	1 representative
Partners/carers	2 ~~1~~ representative
Positive Women	1 representative
Strategic Response Group	1 representative
Haemophilia Society	1 representative
Macfarlane Trust	Chairman representing Trustees Chief Exec. and Social Worker

It was agreed that Ann and Fran would identify and invite women to fill the roles of Partners and Positive Women.

It was further agreed that parents would not be represented on the group, since there were only 12 registrants under 18.

(ii) Amalgamation of the Partnership Group with the Conferences Working Group.
The amalgamation had been accepted by the Strategic Response Group and reported to Trustees.

(iii) Representatives from other organisations.
The possibility of inviting other organisations such as Terrence Higgins, body Positive and others has been suggested. It was agreed that representatives of organisations as above, or UKHCDO and Haemophilia Alliance, might be invited to address the Group, but need not be permanent members of it.

3. Reports on Feedback Meetings

Two Feedback meetings had taken place during the Summer: one in Manchester and one in London. Approximately 12 people had been at each meeting. The Manchester Meeting had been addressed by Dave Hill, as a Trustee of the Macfarlane Trust and the Haemophilia Society. The Reverend Alan Tanner, as Chairman of the Macfarlane Trust, and Karen Pappenheim, as Chief Executive of the Haemophilia Society had joined Ann Hithersay and Fran Dix at the London meeting.

Many issues had been raised. In particular participants at both meetings wanted to learn more about possible ways for registrants to become more involved in the decision-making process of the Trust. GRO-A provided copies of a letter he had circulated to Haemophilia Society Trustees seeking greater registrant involvement in the process of selection of Haemophilia Society nominees to become Trustees of the Macfarlane Trust. Mr GRO-A proposed that there should be a job description for trustees, and a ballot of registrants to select candidates to go forward as potential Trustees to the Haemophilia Society's Trustee Board for selection.

4. Future Feedback Meetings

The possibility of holding up to two more Feedback meetings was raised. The Group felt that the process of the Strategic Review and Feedback had been long-drawn out, and further meetings could hardly be termed 'feedback', and related to the Strategic Review. Nevertheless there was a great need for further meetings which gave registrants the opportunity to come together and discuss issues of great importance to them all. The meetings in London and Manchester had provided valuable forum to meet others in a similar situation and share concerns. However, there were many people who, for one reason or another, had been unable to attend either meeting. After discussion it was agreed that, if funds were available, further meetings for registrants should be held in Glasgow and Cardiff.

Registrants expressed their frustration that it had taken so long for Trustees to realise that the needs of registrants were increasing. Payments had fallen in value, and many registrants needed more money badly, to help them cope with the increased costs of HIV, and difficulties of living on little more than State Benefits. A number of those present had had excellent prospects of successful careers before they became infected with HIV. People in similar circumstances in other countries had received substantially higher capital payments. It was time that the UK Government recognised this and gave another payment. Registrants felt that it would be necessary for them to campaign for a third capital payment from the Government, since the Haemophilia Society 'seemed not to be interested in them', and the Macfarlane Trust did not campaign on their behalf.

Ann said that she would ensure that Trustees reported to representatives of the NHS Executive that registrants believed they should receive a third payment.

The Strategic Review had not addressed this issue because it had been decided that 'now was not the right time to ask for another payment'. She explained that this was because the Secretary of State for Health had very recently turned down a request made by the Haemophilia Society on behalf of those with hepatitis C Virus for a capital recompense payment. Government could hardly give another payment to those with HIV when those with hepatitis C had received nothing.

Members of the Group were unhappy with the argument offered, and said they would pursue the matter further

Members of the Group asked when, if at all, Regular Payments and Single Grants would be increased again. The Strategic Review had identified needs. When was the Trust going to do something to meet these needs?

AH said that the Payments Review Group was working on recommendations that would go to the next meeting of the Trustee Board in October. She hoped that Regular Payment increases would be brought in by the end of the year.

Participants suggested that certain Single Grant areas such as clothes for those suffering severe weight gain or loss were not being considered. This was an example of 'new need' that was not being met, despite what the Strategic Review had led people to believe it was all about, more than a year ago. The side effects of combination therapy were costly and often unpleasant. Single grant guidelines did not taken these new trends into account.

5. Reports from Working Parties.

(i) Development of Local Services for People with Haemophilia and HIV

Body Positive Initiative.

Fran GRO-A had had a ~~number of~~ meeting~~s~~ with contacts at Body Positive. As a result a Draft Proposal for an Open Afternoon/Evening had been circulated.

It was proposed that a Pilot might take place in London for 'London and surrounding areas'. A costing for the Pilot, for about 40 registrants, should be worked out and fed back to the Working Group. It was hoped that the Pilot could be funded through individual grants to participants. If successful, the project could be developed to cover other areas where body Positive Groups operated.

(ii) Treatment Information

It was pointed out by several Group members that there was excellent Treatment Information on the Internet, but computers and Internet connections were needed to enable registrants to access this information.

One member of the Group suggested that it would be possible to bulk buy for a low price some Apple Mac computers. It was also suggested that an approach should be made to Drug and Computer Companies for donations to help towards the availability of computers for all that would use them.

It was also suggested that some people might need training on use of the Internet, and that other registrants might be able to deliver such training, if expenses were covered.

Hepatitis C Treatment Information

GRO-A reported that he and GRO-A at the Haemophilia Society were doing a survey of Hepatitis C treatment available at Centres throughout the UK. Glaxo Welcome was funding this research.

It was also reported that other surveys had been carried out into treatment for hepatitis C and HIV, but little information was available at the present time.

AH said she would be attending the BHIVA Conference in London in October, and would see whether any new information on this area of co-infection was reported on.

The Haemophilia Society had prepared a Co-infection Factsheet which could be circulated to those who wanted it.

(iii) Promotion of Alternative and Complementary Therapies.

It was reported that at present the Trust only routinely funds grants for an 'introduction to complementary therapy'. It was recognised that NHS funding for complementary therapy of any kind was very patchy.

It was also reported that Birchgrove could provide a list of complementary Therapists who provided therapy free.

6. Date of Next Meeting

The next meeting of the Partnership Group would take place on Tuesday 16th November from 1.00 to ~~5~~.00pm at Alliance House.
4.