

THE PARTNERSHIP GROUP

Notes of a Meeting held on Monday 28th February 2000

PRESENT: Mr Chris Hodgson [Chairman]
Mr Peter Stevens Deputy Chairman
Mr GRO-A Birchgrove Group
Mr GRO-A Birchgrove Group
Mr Andrew Evans
Mrs GRO-A
Mrs Ann Hithersay Chief Executive
Mr GRO-A
Mrs GRO-A
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Mrs GRO-A

Mr Peter Stevens had been invited to attend the meeting as he would become Chairman of the Trust with effect from the end of March 2000. Peter said that Alan Tanner would be 'a hard act to follow'. He had been responsible for founding the Trust and had steered it through more than 12 years of serving those in the haemophilia community who had contracted HIV as a result of treatment in the late 1970's and early 1980's.

Peter Stevens said that he had been one of the 'founder trustees' back in 1988. His impressions since being re-appointed as a trustee last July, were that the Trust had changed very greatly from an organisation that had been set up in 1988. At that time, the Trust had seen its main aim as provision of short-term financial assistance to help people live with the effects of HIV infection. Nobody in those early days had considered long-term survival as an issue, and little thought had been given to the continuing needs of those registered with the Trust and their dependants. The needs of today appeared to be very different to those presented in the 1980s. Peter said he looked forward to learning more about present needs from members of the Partnership Group.

1. Apologies for Absence

Mrs Pat Latimer had sent her apologies. She was ill and therefore unable to take the Chair at today's meeting. Mr Chris Hodgson had agreed to chair the meeting on this occasion.

2. Minutes of the Meeting held on 16th November 1999

The Minutes of the meeting were approved as a true record.

3. Matters Arising from the Minutes:

(i) Birchgrove Group - Hepatitis C Action.

GRO-A reported on progress of the campaign being run by Birchgrove Group on behalf of all those who were co-infected with HIV and hepatitis C.

There had been recent meetings with members of the Welsh Assembly, in particular the Labour Group who had offered considerable support. Birchgrove had received 73 letters of support from MPs in Westminster, and were planning to take the campaign to Europe. The Group was seeking recognition of their double blow, and recompense from Government that compared to settlements made in other European countries.

GRO-A spoke about the legal aspects of the campaign and said that it was proposed to take a test case to court to challenge the Undertaking given to Government in 1991 and to seek further recompense for hepatitis C infection. Two consultants in Newcastle had agreed to support the campaign. Dr Jones, Director of the Newcastle Haemophilia Centre had agreed to act as Expert Witness. **GRO-A** also reported on her researches and said that the Undertaking would be challenged as 'Unfair Contract'.

Chris Hodgson reported that the Scottish Health Minister had promised an Enquiry into all infected blood products used in Scotland. If such an Enquiry happened in Scotland, and possibly in Wales, it was probable that the Westminster Parliament would have to follow suit. Mr Hodgson reported that 72% of the Scottish Parliament supported the proposed action. Alan Milburn, Secretary of State for Health, had signed an 'early day motion' supporting recompense for those infected with hepatitis C when in opposition.

There had been a Public Enquiry into infected blood products in Ireland and as a result, recompense payments were being made on an individual basis to many people who had become infected with hepatitis C as a result of their treatment.

It was reported that Lord Hunt would be meeting members of the Birchgrove Group some time in March. Lord Hunt would also be meeting representatives of the Macfarlane Trust before Easter. It was important that Lord Hunt should not be presented with conflicting information, as this would weaken any case for recompense.

(ii) The Computer Project

It was reported that after much consideration, AppleMac had decided against setting a precedent by donating computers to Birchgrove Group for distribution. The company was planning to re-launch the AppleMac in Britain in 2000 and it was felt it would be unhelpful to 'flood the market' with 400 IMACS.

The Partnership Group recognised the importance of pursuing a source of free/cheap computers for all Trust registrants. Birchgrove Group reported that their web-site had been accessed 600 times in just two weeks.

After discussion it was agreed that because the Trust could not be seen to be fundraising, as this could jeopardise future Government funding for the main work. It was agreed that Birchgrove Group should take on responsibility for seeking funds for the computer project.

(iii) Macfarlane (Special Payment) (No 2) Trust. Cut-off Date 31.12.99

A Deed of Variation had been approved by the Department of Health and signed by Trustees extending the cut-off date for the MSPT 2 to coincide with the 'Perpetuity Day' of 2nd May 2012.

(iv) Costing of New Needs

It was agreed that this item be taken in conjunction with issues related to the Payments Review Group.

(v) Appointment of a new HIV Worker at The Haemophilia Society

It was reported that a new HIV Worker had been appointed and it was hoped that she would take up post in early April. GRO-A and Ann Hithersay had taken part in the selection of GRO-A as the new HIV Worker.

4. The Haemophilia Alliance

Chris Hodgson as Co-chairman of the Alliance reported that it was up and running. The first few meetings of the Alliance had been held, and work was continuing to agree a Mission Statement, seek funding and draw up a Constitution. One of the first aims of the Alliance was to agree a National Specification for Haemophilia Care. There would be Affiliated and Corporate members of the Alliance. Both Birchgrove Group and the Macfarlane Trust would become Affiliated members of the Alliance. It was hoped to have completed work on the National Specification by September 2000. No date had yet been agreed for the official launch of the Haemophilia Alliance.

In the ensuing discussion, Chris Hodgson assured the Group that there would be 'user involvement' in drawing up the National Specification for Haemophilia Care.

5. Update Day for Trustees - 13th June 2000

It was agreed that as Mrs Latimer was absent it was not possible to pursue discussion on the Day. Andrew Evans agreed to contribute to the day on behalf of all those registrants who were under 25.

6. Payments Review Group Report

Peter Stevens said that his aim in coming to the meeting of the Partnership Group was to listen. The issues arising today were quite different to those in the early days of the Trust. Some of these were beyond what the Macfarlane Trust would ever be capable of responding to. Others could and should be raised with Ministers through the Trust.

The Macfarlane Trust had been set up by Government in 1988 to do a job that was perceived at the time. It was not a campaigning organisation and therefore could not be joined in the present campaigning activities. However there were many issues raised today that had not been in the minds of those who campaigned to set up the Trust in 1987. The campaign for HCV needed to be seen as part of a shopping list of new needs. Whilst it was likely that if more Government money was made available, this would be channelled through the same organisation [the Macfarlane Trust], it was the Trust's job to report to Ministers on the new position facing the registrants, and to include co-infection as an important new issue, not considered by anyone in the late 1980s.

Peter Stevens reported that he would be meeting Lord Hunt in April and would be advising him of the increasing range and level of needs identified in the Strategic Review and its aftermath. He would tell Lord Hunt that Trustees had determined to increase payments to registrants from this year, and that the Trust would be increasing its annual expenditure from £2 million a year to £2.5 million.

Up until this year Trust spending had remained at around £2,000,000 a year. This had not been a policy decision by Trustees. It had just happened that way. In implementing the recommendations of the Strategic Review, greater outlay of funds would be required. As the Trust's new Chairman, Peter Stevens was committed to seeking this extra funding. There would be no begging. The needs had been identified. In order to meet these needs, top-up would be needed from The Department earlier than had been anticipated.

The Trust could support the hepatitis C campaign by making sure that Ministers and civil servants heard the same message that was coming from the campaign groups; it was particularly important that everyone united to give a consistent message about hepatitis C infection to Government.

Peter also reported that Trustees had agreed that from April 2000, two areas of 'payment anomaly' would be addressed: the Basic rate would be abolished and everyone would receive the Standard Rate, regardless of whether or not they were employed; those on Middle Rate DLA would also receive the Care Supplement. Further changes to monthly payments and single grants would be introduced in September. A Handbook detailing changes would be circulated to all registrants during the Summer.

7. Reports from Working Groups.

(i) Birchgrove Group Centres Monitoring Project.

Some Centres had already been visited as part of the project. It was expected that reports on these visits and of forthcoming visits to other Centres would be available in about 6 months time.

(ii) Complementary Therapies Review.

GRO-A had carried out a review of availability. There was little free therapy available outside the London area. There was no national database of therapists able to take on clients with HIV, and even less information about therapists with knowledge of haemophilia and HIV.

(iii) Body Positive Pilot Project.

GRO-A reminded the group that the project was being developed in conjunction with Body Positive and involved BP organising a 'taster day' for MFT registrants in the London Area. The Trust would send out letters to an identified group of registrants inviting the to participate in the 'day'.

GRO-A explained that Body Positive was a network of support groups, not an organisation. Therefore although the project model that had been developed for the Taster Day was appropriate for the area identified, it was not a model that would necessarily be easy to replicate in other areas.

(iv) Conferences and Meetings

It was reported that in the absence of Fran Dix there had been a meeting of the Conference Group to consider plans for the Partners Weekend and possible further initiatives for young people.

The Group had agreed that the Partners Weekend would be held from 9th to 11th June. A venue was to be found, probably in the Birmingham or Reading area. The Group had agreed an outline programme for the weekend.

Ann had had a meeting with **GRO-A** of the Haemophilia Society to see what further work could be done with children who were infected or affected by HIV infection. The plan to hold a weekend for under 18s had been put on hold due to lack of response to the mailing at the end of last year.

(v) Bereavement project.

There had been responses from people in the South East and Birmingham areas who wanted to join support groups. It had been agreed that prior to a decision on the Section 64 Grant application, the Trust should set up a pilot 'Bereavement Support Group' in the South East, and follow this up with one in the Birmingham area if possible.

A first meeting of the South East Group had taken place in February. A further meeting was planned for early March.

8. Any Other Business

(i) Social Work Provision.

It was pointed out that there was no Social Worker at the Birmingham Comprehensive Care Centre and agreed that the Centre Monitoring project being carried out by Birchgrove should include a survey of Comprehensive Care Centres and what social work service was available in each one.

It was reported that where there was a strong and well organised 'patient group' as in Wales, it was possible to influence services provided by the Centre.

9. Date and Place of next Meeting:

The next meeting of the Partnership Group would be held on Monday 22nd May at 12.30pm at Alliance House, 12 Caxton Street, SW1.