Department of Health Update **01.44**

Trustee Appointments

There has been no further progress with appointing two new trustees to fill vacancies left by the resignation of Kenneth Bellamy in 1999 and Patricia Winterton in February 2001. The Chairman has agreed to be a member of an Appointments panel to select new trustees but before this can happen, applications must be processed and appointments arranged. It had been hoped that new trustees would be appointed before the end of 2001; this is looking increasingly unlikely. Our solicitors have suggested a variation to the Trust Deed that would allow the Trust to nominate candidates to the Secretary of State to speed up the process.

Agenda for Proposed Meeting with Minister

The Chairman has asked that Trustees consider priority areas for inclusion in the agenda for a proposed meeting with Yvette Cooper, the minister for blood safety issues, when she returns from maternity leave. Continued funding to meet the changing needs of registrants, and increased funding to enable the Trust to better meet the needs of dependants of those who have died must come high on our list.

We are seeking to identify a date for meeting Ms Cooper early in the new year.

Meeting with Civil Servants

We hope it will be possible for the Department to identify a suitable candidate for secondment to the Trust to carry out some work on forward projections related to Trust funding into the future. It has been suggested that a second year Finance Trainee might be seconded to the Trust on a part time basis for about 6 months. We await more news on this.

We have again drawn attention to the staff costs overspend in the current Section 64 management expenditure, and hope it will be possible for the Department to respond favourably to meeting the overspend by way of a top up grant.

We understand that Charles Lister has a new assistant and look forward to meeting him soon. A date for a meeting before Christmas is being sought.

Ann Hithersay
15.10.01

Department of Health - Corporate Management Review **01.45**

Response to Executive Summary (attached)

1.2.1 a) Expenditure did increase by approx. 12% in 1999/2000 and 2000/2001. This was in response to work of the Payments Review Group during 1999. As a result of recommendations made to Trustees by the Group, Regular payments were increased by 11% in January 2000. This was because no inflationary increases had been made to payments since 1996.

In April 2000 a number of payment anomalies were addressed and in September Regular payments were increased by £100 a month to all registrants. The level of some Single payments were also increased at that time. It should not be assumed that payment levels will continue to increase by 12% each year.

It should also be noted that the Trust has received £25 million from The Department since 1988. Funds totalling £28,236,556 have been distributed to registrants to 30.09.01 and at that date the Trust had assets remaining of £5,752,770.

1.2.1 b) Noted

1.2.1 c) This assumption may not be correct. We have asked for more funds from the Department since the Report was prepared.

1.2.1 d) The Trust has 'sold capital investments' to fund its work since it was founded in 1988. In 1997 it was established that the Trust's investments should not fall below £4 million, and since that time The Department has always topped up the funds to ensure that this level is retained. It is accepted that as the needs of registrants and their dependants increase, it will be necessary to ask for more frequent and larger amounts of top up funding from The Department. Many registrants and many more dependants live at or below the poverty line. The Trust was set up by Government to meet the needs of these people. We should not shrink from asking for sufficient funds to carry out this work as well and fully as possible.

1.2.2 **Noted**

1.2.3 **Recommendations**

1.2.3. a) The Chairman's Strategy Group will develop a Business Plan that will address the areas included in the this recommendation.

1.2.3. b) The Trust will develop and submit a Business Plan to the Department by March 2002.

1.2.3. c) A further application for Section 64 Core funding was submitted to The Department in October 2001. The application included a budget for Management costs for the three year period 2002 - 2005. Further work is needed to prepare a detailed plan related to the future needs of registrants and their dependants. An application has been made to The Department for a seconded Management Trainee to assist in the work. The Trust is also proposing to take on a Finance Assistant to enable the Finance Officer to spend more time on long term financial projections, finance policy and drawing up procedures.

1.2.3. d) Monthly cash flow reports to all trustees and The Department are considered unnecessary. The Chairman, Hon. Treasurer and if required, The Department of Health, will receive monthly reports on all financial activity as soon as a Finance Assistant has been appointed to assist with more routine financial procedures.

1.2.3 e) The Hon. Treasurer is reviewing investment strategy in the light of recent world events.

1.2.3 f) Quarterly investment reports are prepared by CCLA and Principal. Both Fund Managers also report monthly portfolio valuations. It is not considered practical to duplicate this work in house. When the Finance Assistant has been appointed it will be possible to provide fuller monthly reports on investment sales and purchases, if required.

1.2.4 Areas for Improvement

1.2.4 a) Procedures and Policies will be documented as soon as additional staff time permits. It is hoped that a Finance Assistant can be appointed before the end of the financial year. However, there are no funds available to cover the new post, so this would result in a small staff overspend in the current financial year.

1.2.4 b) All staff will receive basic training in use of the Trust's financial database systems as soon as time permits.

1.2.4 c) Monthly bank reconciliation statements will be reviewed by the Chief Executive as soon as these can be made readily available. This is likely to be after the Finance Assistant is appointed.

NB At present the Macfarlane Trust is supported by a team of 4 full time and one part time staff. The staff team also carry out work for the Eileen Trust and continually seek ways to be more responsive to the changing needs of registrants and their families. It will not be possible to fully meet the recommendations in the Management Review without at last one more full time member of staff to assist the Finance Officer.

1. Executive Summary

1.1 Introduction

1.1.1 The Macfarlane Trust was established in 1988 to provide financial support to those people infected with HIV as a result of treatment with contaminated blood products. The Trust received £10,000,000 during 1988 from the Department of Health and has continued to receive capital grants to fund the financial support it provides to registrants and their dependants. **As a result of the increased life expectancy of registrants and their changing needs, the financial assistance provided by the Trust has increased above predicted levels causing significant financial pressures. This report has been commissioned by the** Department of Health, in response to such financial pressures, to review:

(a) the Trust's financial controls;

(b) the operation of the Trust's treasury management function;

(c) the current performance management arrangements; and

(d) the claims management process.

1.2 Findings

1.2.1 Based on the financial information available, we found that there are significant threats to the continuation of the Trust in its ability to provide financial support in both the medium and longer term. The most pressing issue is that of increased levels of expenditure, resulting in the 'short term' sale of capital investments to fund payments to registrants. Figure 1 below extrapolates the Trust's financial position over the next five financial years and is based on the following assumptions:

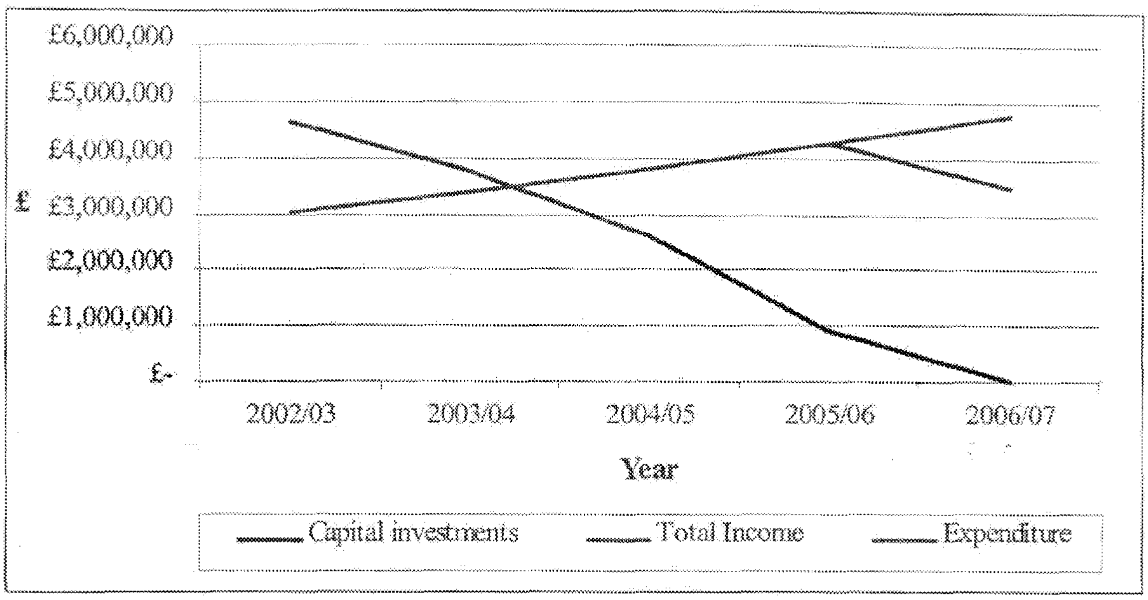
(a) payment to registrants increase by 12% per year, based on the average annual increase since 1997/98;

(b) returns on investments remain constant at 4% per annum;

(c) income from the Department of Health remains constant at £2.5million; and

(d) the sale of investments is used to fund any shortfall in income and expenditure.

Figure 1: Extrapolated expenditure, income and capital investments



1.2.2 Figure 1 above demonstrates that, based on the assumptions outlined above, capital investments will be exhausted during 2006 and as a result, the Trust, could not continue to make future payments. At the end of 2006/7, the Trust would require an additional £1.3million income to break even.

1.2.3 In light of the above, we recommend that the following action is taken:

(a) business planning processes should be carried out by the Trust which include:

- forecast of likely future financial requirements in respect of both registrants and dependants;
- cash flow forecasts;
- the evaluation of options for the current provision of funds to registrants and their dependants, considering the type and amount of expenditure which the Trust reasonably expects to be able to provide to registrants;
- the development of a financial planning strategy to enable the Trust to continue to meet its commitments; and
- an assessment in respect the additional management resources required to meet the recommendations included in this report;

(b) **the Trust should submit an annual business plan to the Department prior to the commencement of a financial year. The business plan should not only cover the projected activities for the coming year, but also provide, as far as** is reasonably possible, an early indication of pressures arising in subsequent financial years;

(c) the Trust should, where necessary, provide a comprehensive business case to the Department of Health for where additional funds, in terms of both management costs and expenditure relating to registrants and their dependants, can be identified. The business case should use the analysis resulting from a structured business planning process to support future requests for increases in the current levels of funding;

(d) monthly cash flow reports should be provided to the Board and to the Department of Health;

(e) a review of the current investment strategy should be undertaken, in view of the current requirement to sell capital investments to fund payments to registrants; and

(f) monthly reports to the Board and to the Department of Health regarding investment income and sales of capital investments should be produced by Trust staff.

1.2.4 Although we accept that the current practices in relation to the financial controls have provided the external auditors with sufficient comfort to enable the annual accounts to be signed off without qualification, we have identified several areas for improvement. These areas include:

(a) Procedures and policies should be documented and presented to the Board and the Department of Health for approval;

(b) Staff should be trained in basic financial procedures; and

(c) The monthly bank reconciliation statement should be reviewed by the Chief Executive or a trustee.

1.3 Conclusion

1.3.1 In order to continue to meet its role as stated in the Trust Deed, the Trust must, reconsider the way it utilises its financial resources, prior to identifying any additional funding requirements. To support any case for increased funds, the Trust should employ business planning processes to identify the anticipated future need as well as deciding on the level and type of funding that it should offer to registrants and their dependants in the future. In addition, financial policies and procedures should be documented and key financial controls should be present to provide the Department of Health with the assurance that, should further funds be made available, they will be applied for the purpose of benefiting registrants.

BEREAVEMENT WEEKEND 01.46

Background:

In 1999, letters were sent to all those who had been bereaved since the Trust was formed; just over 20 replies were received. More than half of these responses came from the South East and the others came from the North of England and Midlands. About half had indicated that they would like one to one counselling, whilst those remaining wanted contact with others in similar situations or would like both options. Unfortunately, things were slow to take off due to lack of money and resources.

The Project Group, Chaired by Chris Hodgson, has met regularly since Spring 1999. The Group oversees the development of the project and actively participates in working with bereaved families.

In the latter part of 1999, the Trust applied for Section 64 project funding to assist in this work with families who had been bereaved. Although this was refused, in January 2000 the SE Group was set up for widows and partners and continued to meet every 2 to 3 weeks for the next 18 months.

After approximately 1 year, two parents attended the SE Group and it was decided that another group was necessary for parents. This was set up in June 2000. During 2000, the SE Group proposed that a residential meeting for bereaved families should be held. Again, the Trust applied for funding and was refused. As a result of this, the Trustees agreed to fund more pilot groups and a residential meeting, which took place in September 2001.

Bereavement Weekend:

Date: 21 - 23 September 2001
Venue: The Sheffield Swallow Hotel
10 Facilitators, 32 Delegates, 8 Children

21/09/01

The Facilitators started to arrive at the hotel approximately 1.00pm. After checking in we had lunch where our expectations for the weekend were discussed. After lunch, we made our way to our rooms and agreed to meet at 3.30 in the lounge to prepare for the Staff meeting and Final Briefing.

The Staff meeting and Final Briefing took place between 4.00 - 4.30pm. It was decided that:

- the name badges (prepared prior to the weekend) would be worn by all as many of us were meeting for the first time.
- the Administrator would prepare a meeting place in Reception for the delegates to ensure that they were greeted by a friendly and informative person;

- the participants would be divided into 3 groups with 2 staff members in each consisting of:
  - Parents Group (2 Social Workers, one from Newcastle and one from The Macfarlane Trust);
  - Partners/Widows (one counsellor and a Social Worker from the Royal Free);
  - Siblings (one counsellor and another Social Worker from Newcastle);
- the remaining members of staff (consisting of 2 Organisers, a Clinical Nurse Specialist and an Administrator) were available to offer advice for Carriers, one-to-one meetings, hands-on support and other issues not covered on the agenda;
- evaluation forms (compiled by The Macfarlane Trust Social Worker) to be distributed at the end of Saturday's session and collected Sunday morning.

The Administrator took up her post before the end of the Briefing (just in case there were any early arrivals). The next couple of hours was filled with greeting and ensuring that the delegates had booked-in and knew where to congregate for the evening meal, which took place at 7.00pm.

The dinner proved to be the perfect ice-breaker. People were socialising/ conversing and it was a good opportunity to find out more about each other. After the meal was over, we all made our way over to the lounge to continue our conversations. There was definitely a need to talk, but at this stage everyone was just happy to keep it on a light-hearted level and laughter could be heard filtering through the lounge on a regular basis.

22/09/01

Breakfast was served between 8.30 and 11.00am. Although many people were tired from talking late into the morning hours, there was also a feeling of apprehension and concern as to what the day was going to bring. Many admitted they were nervous, and even though they had the option not to attend the meetings not one single person pulled out.

The Carers arrived approximately 10.15 and were given a base and instructions as to the timetable for the children. Between 10.30 - 11.30 the arrivals for that day were welcomed by the Administrator who ensured that they were given refreshments.

At approximately 11.30am, the staff and delegates met for a Welcome and Introduction meeting. One of the first things that took place was introductions from all the staff giving a brief description of who they were and what they did. This was followed by all the delegates giving their name and where they were from, which helped to build everyone's confidence. A run down of the itinerary was given and the group arrangements were confirmed.

The children were taken by the Carers around 12.15pm for lunch and at this time the delegates assembled into their respective groups.

Lunch was served from 1.00pm onward, but it was by no means light-hearted. It was obvious that many of the delegates had had an emotional time and it felt as if the lid of a pressure cooker was being released. Tears were shed by delegates and staff alike. People recounted how strongly they felt with regards to how they and their loved ones had been treated by many professional and medical staff, how they lacked support from their family and friends because they hadn't made the illness common knowledge due to the implications and lack of understanding of the disease, but others were just sad that their loved ones died the way they did and felt they could have done with more support after the death.

Once lunch was over, those who were able went back to their groups. Others, who were too distraught, found a listening ear by the staff members who were not involved in the sessions. This proved very necessary as people were dealing with emotional issues that had not been talked about since their loved one had died and these issues were deeply buried within them. To have the opportunity to get it off their chest was one of the first steps in dealing with the bereavement and this was made possible both in the group sessions and the one-to-one.

A tea break was to be taken at 4.00pm, but the groups finished a little after. By the time tea was served, everyone seemed more relaxed and able to talk about the issues that had arisen. It was obvious that there were less tears in the second part of the session and again laughter proved to be a great remedy for lifting the spirits of all those involved. All in all, it was felt that just being able to talk about their loss and the situations around it was helpful and the affect of talking could be visibly seen by the way they interacted and conversed with each other.

After the tea break we all had a big meeting to discuss support groups in new areas and identify other needs. This did not last very long as everyone was emotionally drained at this stage and the overall consensus was to end the meeting sooner rather than later.

A small group of people did feel the need to discuss setting up a group in their area as many issues needed to be addressed with regards to the way they and their loved ones had been treated and the lack of support and help for them. This took place about 5.00pm and involved the Chief Executive and Trustees of The Macfarlane Trust supported by the Clinical Nurse Specialist.

The children returned from their day out approximately 6.00pm and once their parents had been located leisure time was given until dinner, which took place at 7.30pm. By this time, we were socialising well with each other and there was a feeling that we had known each other for many years rather than a day. The taboos that had hindered those from talking before the weekend had vanished and it was nice that people confided in each other with very sensitive information without the fear that they would be ostracised.

The evening progressed well into the night and again it was with reluctance that in the early hours of the morning we finally retired.

23/09/01

After breakfast, the groups met up between 9.30 - 10.00 to give feedback on yesterdays session. Many observations and ideas were made and confidence had grown ten-fold.

Refreshments were given at 10.45 and gave everybody the chance to continue last nights conversation. This was followed by a Future Actions meeting, which involved the whole group. It appeared that everyone had found their voice and we were not short of information or suggestions. This meeting extended the allocated period but proved to be very worthwhile and gave everyone the opportunity to say how they felt. Also, out of the 28 evaluation forms distributed 25 were returned, the remaining forms were to be sent through the post.

Lunch was available from 1.00pm, which we all attended and once the children were handed back to their parents it was time to say goodbye. This was a very emotional time and hugs were freely given to cement the bonds made during this weekend.

Summary

It was a very valuable weekend and many issues arose as a result of it. These included:

1. New support groups required in Manchester, Midlands, Northwest & Newcastle.
2. The Trusts website should also include a section for bereaved period.
3. Chat room to be included on website (secured/anonymous).
4. More home visits and follow-up for bereaved families.
5. Special Handbook and Newsletter to be set up for bereaved families.
6. Feedback and information from conferences and seminars; follow-up and opportunities to talk to Trustees.
7. Training and information for people in the role of Carer.
8. A local help-line to be set up.
9. More support groups and weekends (extend weekend to 2 day and make them more central.
10. Support is needed for the early bereaved as it's a very sensitive time.
11. What happens to Carriers after bereavement - children/siblings.
12. Legal advice support line and access to legal help from The Macfarlane Trust.

Rosamund Riley
Administrative Secretary
16/10/01

Bereavement Project - Expenditure against Budget 01.46

In April 2001 Trustees approved expenditure to continue and expand the pilot work of the Bereavement Project, which had started in 1999. After two failed attempts to gain Section 64 Project funding, it was agreed that the Trust would fund a residential meeting for bereaved families and development of further support groups in the midlands and north west.

The residential meeting for families was held in Sheffield over the weekend of 21 - 23 September 2001. A total of 49 people attended: 31 parents, partners and siblings, 8 children and 10 staff. Families came from as far afield as Belfast, Cornwall and Glasgow. The meeting was a great success as attached reports from staff very clearly demonstrate.

The Trust has submitted a further Section 64 Project application to the Department of Health; we hope this one may meet with greater success than previous efforts.

A further support group will begin in Manchester before the end of the year and it is very much hoped that it will be possible to continue to develop this important work.

Trustees approved expenditure of £7,000 on a residential meeting and £7,000 on development of new support groups.

The Residential Meeting cost a total £11,860 against a budget of £7,000. Additional costs can be attributed to the number of staff and families staying overnight on Friday; the additional costs of increasing staff numbers to cope with the diverse needs of parents, partners and siblings, and the additional cost of child care for the 8 children and teenagers.

Hotel Costs	9,700
Staff Costs	1,430
Childcare costs	730

As yet no money has been spent on new support groups, but this work must begin as soon as possible for those who have indicated that they need this type of support as a matter of urgency. If the balance of £2,140 is spent on this work, it will be possible for at least one new support group to be started before the end of the financial year. Should our third Section 64 funding bid be unsuccessful, Trustees are asked to commit to continue to fund the Bereavement Project as an ongoing area of activity covered by the Trust Deed.

Summary Report of the Bereavement Weekend - September 2001

This bereavement weekend, attended by parents, partners, siblings and dependent children, highlighted the unmet needs of this special unique group. For many of them this was the first time they had been able to speak openly about their loss in a safe, supportive environment with people who had some understanding of their situation.

Very few of the participants had been offered helpful support. Most support had been inadequate, inappropriate and some very harmful. Participants had no idea about where to access services. It became very clear, during the weekend, that there are no specific services available for people coping with Haemophilia/HIV/HCV bereavement. Bereavement follow up in Haemophilia Centres is extremely variable. For many people, it is too painful to return to the place where their loved one died. General bereavement services i.e. Cruise do not have the specialist knowledge needed to work with this particular group. Participants at the weekend were able to illustrate this. Fears about confidentiality and discrimination continue to prevent disclosure of HIV status.

Many of the participants were still very traumatised by events surrounding their loved one's death. All of them were still coping with unresolved complicated grief relating to the catastrophic nature of the deaths. Living with Haemophilia, being given HIV and Hepatitis C and latterly, the worries about CJD exacerbate the grieving process.

The Macfarlane Trust is the only common link with all people who have died from HIV/HCV as a result of their NHS treatment. Therefore, this must be the organisation to provide and co-ordinate on a national level an effective range of services and support. Services must take account of individual need and circumstances. They should include professional counselling, individual informal psychosocial support, group support and networking with others in a similar situation. This support can only be provided by professionals who have the specialist knowledge base necessary to help this unique group of people.

Pat Latimer
Social Worker/Counsellor
Newcastle Haemophilia Comprehensive Care Centre

EVALUATION RESULT

Reason for evaluation:

As a result of long discussions and the forming of a bereavement group it was felt that the Trust should offer the bereaved families an opportunity to come together and discuss their feelings and problems that they might have and might still be facing. A weekend was arranged in Sheffield and this took place on the 21-23 September 01.

Following the main introduction session those in attendance were split into three separate groups in accordance to their connection with the Trust registrant now deceased.

These groups were as follows:

PARENTS 13 = DARK GREEN EVALUATION FORM Given out 9

PARTNERS 10 = ORANGE EVALUATION FROM Given out 10

SIBLINGS 9 = YELLOW EVALUATION FORM Given out 9

The total number of form that were given out over the weekend were **28**
The total returned completed at the end of the weekend were **25 = 89%**
Of the **11%** remaining I was told to expect these through the post.

HOW EVALUATION ASSESSED:
12 short and uncomplicated questions, which required the individual to tick or circle three different faces and / or make a brief comment in the space provided.

PARENTS:

Forms given out 9.
Returned 8.
Of the 8 forms returned the result are as follows.

Q.1. GROUPS = 7 were happy with the groups.
Q.2. FACILITATORS = they were all happy with the facilitators.
Q.3. CHILD CARE = was only applicable to **2** and they were happy with arrangement.
Q.4. SUPPORT = 7 were able to get mutual support.
Q.5. BREAKS = 6 were satisfied with the breaks.
Q.6. VENUE = all 8 were happy with venue.
Q.7. EVENT = 7 were satisfied with event as a whole.
Q.8. FUTURE EVENT = all responded **YES** for future event.
Q.9. DISTANCE TRAVELLED = for the majority of delegates it was quite a distance to the venue
Q.10. MILEAGE TRAVELLED = the minimum distanced travelled for the delegates was 45 miles, and the maximum 330 miles.
Q.11. DONE DIFFERENTLY = the general consensus was that everything had been taken into consideration and that nothing could have been done differently.
Q.12. PERSONAL CHANGES = for a few this will mean contacting others, however for the majority there are no plans to change anything as a result of this weekend.

COMMENTS/SUGGESTIONS

The majority of the parents were pleased that they had been given the opportunity to meet others in the same position as themselves. It was suggested that if a future event took place that the groups are made smaller.

SUMMARY OF GROUP RESPONSES:

The overall response from this group about the weekend and its content is that it was very useful and that it allowed them to make contact with others that have been similarly bereaved and are aware of the issues and feelings of the situations. They would like to see similar event set up for the future.

SIBLINGS

Forms given out 9.
Returned 9.
Of the forms returned the result are as follows.

Q.1. GROUPS = all were happy with the groups.
Q.2. FACILITATORS = this group was also very happy with the facilitators.
Q.3. CHILD CARE = this was only applicable to 2 however they were happy with the arrangement.
Q.4. SUPPORT = they were all able to get mutual support from the others in the group.
Q.5. BREAKS = this group was very happy with the timing of the breaks.
Q.6. VENUE = entirely happy with the chosen venue.
Q.7. EVENT = all were satisfied with the event as a whole.
Q.8. FUTURE EVENTS = all responded **YES** for future events.
Q.9. DISTANCE TRAVELLED = the majority of the delegates had to travel long distances in order to attend this event.
Q.10. MILEAGE TRAVELLED = the minimum journey travelled was 60 miles and the maximum was 330 miles.
Q.11. DONE DIFFERENTLY = It was felt generally amongst this group that more time and structure might have been better which would have resulted in extra space to talk to each other.
Q.12. PERSONAL CHANGES = the response for the majority is that they intend to made changes such as getting more information about haemophilia and been a carrier of the condition. They will also be making an effort to keep in contact with others.
COMMENTS/SUGGESTIONS = for the majority it was a successful weekend and they have no further suggestion.

SUMMERY OF GROUPS RESPONSES:
The overall response of the group, was that for them, the weekend turned out to be a very successful one. For a couple of people they had, had no intention of making contact with the others but by the end of the weekend they had in fact done so and was very pleased that this had happened.

PARTNERS

Forms given out 10.
Return 8.
Of the 8 returned the results are as follows.

Q.1. GROUPS = 7 members of this group were happy with it.
Q.2. FACILITATORS = all the members were happy with the facilitators.
Q.3. CHILD CARE = this facility was relevant to the majority of this group and they were very happy with the arrangement.
Q.4. SUPPORT = for 7 finding support was not a problem.
Q.5. BREAKS = all were satisfied with the number of breaks.
Q.6. VENUE = this group was very happy with the venue.
Q.7. EVENT = again this group was satisfied with the event as a whole.
Q.8. FUTURE EVENTS = all responded **YES** for any future event.
Q.9. DISTANCE TRAVELLED = the majority of delegates travelled quite a number of miles for the event.
Q.10. MILEAGE TRAVELLED = the minimum miles travelled was **40** the maximum I would say exceed **500**.
Q.11. DONE DIFFERENTLY = some members of this group felt that the weekend could have been longer.
Q.12. PERSONAL CHANGES = this response to this was around **50/50** in that it was left not completed however for those that completed it, the response was to keep in touch with friends.

COMMENTS/SUGGESTIONS:
For all that attended it was a very good weekend and they would like to have more of the same. The main suggestion was that the weekend could have been longer.

SUMMERY OF GROUP RESPONSES:
The over all response of this group was that the weekend was a success. For some people it was a very emotional time and they felt frightened with the amount of anger and bitterness that people were feeling. This prevented them from getting too involved.

OVER ALL SUMMERY OF EVALUATION

When all the groups are taken into consideration and their responses are looked at. It becomes quiet clear that for them the weekend was a great success and that if it were arranged again that the attendance would be good.

Questions 1-7 the responses from all the groups were favourable. This leads into question 8 which was to do with future event. All the delegates would like to this or something similar again soon.

The distance that people had to travel did not hinder their need to attend, and for some this distance was great. For the vast majority of the delegates meeting other in the same situation and been able to talk freely was a large boost. This as also allowed them to make contact with individuals that they will now be able to keep in touch with.

The response of other is that it provided them with the place to feel comfortable to feel the anger and pain of their situation. For some question were answered but for other it was felt that dwelling on the past without thought for the future is not health and they have no wish to do this so stayed on the edge of the group.

Claudette Allen
Social Worker

BEREAVEMENT WEEKEND - 21st to 23rd September 2001 - SHEFFIELD

CONFIDENTIAL report for Trustees of Macfarlane Trust

Friday, September 21st

Ann, Claudette, Ros and I arrived in Sheffield in time for lunch. Chris, Joanna and Sylvie were already there. We had a staff meeting at 4.30 when Pat, Dot and Maureen arrived from Newcastle. At this meeting it was decided that the participants would be divided into three groups - **Parents - Partners/Widows - Siblings.** Each group would have two facilitators with them.

PARENTS GROUP	-	**Pat and Claudette**
PARTNERS/WIDOWS GROUP	-	**Sylvie and Elizabeth**
SIBLINGS	-	**Joanna and Dot**

Chris and Maureen would be available during the Group sessions in case they were needed for specific issues.

The evening was spent talking with those who arrived on the Friday evening because of the distance they had to travel to get to Sheffield. There were families from Scotland, Cornwall and Hampshire and individuals from Gloucester and Northern Ireland.

A young family from the Manchester area joined the table I was at for supper and it became very evident straight away that this young widow needed to talk about her family's experience at MRI. As a result of this it was decided that a separate time would have to be given to the families attending the weekend who had also attended the MRI. This meeting took place at 4.30 pm on the 22nd September with Chris, Pat and myself as Trustees of the Macfarlane Trust and Ann as well as members of the five families who had attended MRI Haemophilia Centre. Maureen Fearns sat in in order to answer any questions relating to treatment. The issues from this meeting will be dealt with separately.

Saturday, September 22nd

We had breakfast with the Manchester City football players who were due to play a match against Sheffield Wednesday in the afternoon! This included their manager - Kevin Keegan. The eight year old son of one of the young widows was a great fan of Manchester City and his weekend was made when Kevin Keegan stopped to talk to him, gave him his autograph and had his photograph taken with the two children in the family!

By 11.30 am everyone had arrived and the three carers employed to look after the children had taken charge of the children.

Chris and Ann introduced themselves and went through the programme for the weekend. The other eight members of staff also introduced themselves. All the family members were then asked to say who they were.

At 12.30 everyone assembled into their groups in three separate rooms.

The group I was with was the **WIDOWS/PARTNERS GROUP.**

There were 12 in this group - 10 widows/partners, Sylvie and myself.

We started by reiterating the confidentiality of everything that was said in the room. If anyone felt they needed to leave the room they could do so and could return whenever they felt able to.

We then asked each of them in turn to introduce themselves to the rest of the group and to say as much or as little as they felt they wanted to. This proved extremely emotional and painful for several of the group.

One of the group volunteered that she was HIV positive and understood that there was someone else attending the weekend who was also HIV positive and she was very anxious to meet with her. This did happen as the other widow who had been diagnosed HIV positive did share this with the group. Some of their experiences of being HIV positive were also discussed within our group. For example, the way they had been told. One had been informed by letter after her husband's death but the letter had been sent to his first wife! Both felt that they would soon need false teeth because of difficulty in finding a dentist to treat them. Treatment of their HIV was not gone into in depth but one certainly found it difficult initally being treated by the Haemophilia Centre her husband had attended and actually sitting in the same chair to give blood as he had done! The feeling was that some staff in the Haemophilia Centre were insensitive. A question asked was where was the most appropriate section in the hospital for them to be seen and receive advice and treatment.

All felt very isolated - lonely but not alone. Because of the nature of their husband/partner's illness they felt unable to let go when discussing their husband/partner's death for fear of disclosing too much - therefore they were always very aware and guarded about what they said to friends and relatives. One of the group had only told her eldest son - aged 31 - about his father's HIV. This was done because he had asked her a direct question about HIV when she was very upset. Her husband had been very angry that he had been told and had asked her **not** to tell the other two sons - both in their late 20's. They still don't know. It was very evident that very few, if any family members knew about the HIV. The very interesting exception to this was one of the group who lives in a small village community where both she and her partner of 11 years grew up. Everyone in the village knows that her partner had haemophilia and HIV. Everybody in the village - including old ladies in their 90's - have been totally supportive of her and her partner's family since his death.

At least three of the group - two from MRI and one from Basingstoke Hospital - felt extremely angry at how their husbands had been treated by doctors and one particular nurse/counsellor. In our group we had four from the Haemophilia Centre at MRI plus the one from Basingstoke - so half of the group had had very unhappy experiences from their Centre/Hospital. It was obvious that the five other members of the group were shocked and overwhelmed at what they heard and I think this probably did inhibit some of them expressing themselves as they would have wished. They felt that their problems were minimal and not important when compared to the other five. We did contain most of the anger by telling those from the MRI that we would meet with them as a group later in the afternoon. Nevertheless, their horrendous experiences must have had an effect on those who had had a more normal experience.

There was some discussion about carrier daughters and that they should have an opportunity to talk about this. It was felt it was not always appropriate or desirable to return to the Haemophilia Centre their fathers had attended.

A very poignant moment for one of the group was when she was able to voice for the first time her guilt about how her feelings - both physically and emotionally - towards her husband changed when they were told of his HIV status. Others agreed.

One positive issue that was raised by the group was that their husband/partner's Motability car had to be given up when he died. This caused great financial stress as not only did they have to finance another car for the family but also had to fund the insurance. As none of them had a No Claims Bonus to reduce the cost of the insurance - the cost was in the region of £900! The return of the Motability car is only an issue with the widow/partners of registrants - ie those registrants who are actually married or have a long-term partner and I would like the Trustees to consider helping these families to purchase the Motability car when the husband/partner dies.

After a very emotional afternoon session we stopped for tea.

At 4.30 pm Chris, Ann, Pat, Maureen and I met with the five families whose husbands/son had attended the Haemophilia Centre at the MRI. This meeting will be dealt with separately by Ann.

The Staff De-Brief scheduled for 5.30 - 6.15 - did not start until 6.20 when Chris, Pat, Ann, Maureen and I left the meeting with the families from the MRI. This was combined with drinks as dinner was scheduled for 7.30!

The rest of the evening was spent eating, socialising and listening.

Sunday, September 23rd

The following morning we all re-assembled at 10 am and went into our Groups again for 30 minutes in order to decide what we each would like to feedback to the larger group - ie all three groups.

We asked the Group to consider the following questions relating to the weekend:

WHAT HAS HELPED?
WHAT COULD HAVE HELPED?
WHAT COULD HELP IN THE FUTURE?

The groups responses were written on a flip chart and three of the group volunteered or were coerced (!) into feeding back the responses to the large group - Parents and Siblings. The three did very well and even managed to bring a sense of humour to the weekend.

WHAT HAS HELPED?

Talking to people who understand

Going deeper - "They don't know the half of it"

Listening to other people's experiences

Lessens the isolation/loneliness

Not being with couples

"All partners and all female"
"How do you go to pub on your own"
"Holidays are hard"
"Perceived as a threat"
"You'll find someone else"

Sharing what happened to relationship with partners

WHAT COULD HAVE HELPED?

Longer weekend

A pamper!!! - massage or facial

Manchester City Footballers!

Should **not** have been sent list of names (List of delegates giving number of registrant, status etc. Plus list of children attending with date of death of father)

What is difference between "widow" and "partner"

WHAT COULD HELP IN THE FUTURE?

More of the same

Get together more often

After each group had fed back their conclusions it was agreed that there was a need for a Bereavement Group to be organised for the area around Birmingham and Manchester. This group to be led by Sylvie Boulay who is a Bereavement Counsellor. Goodbyes were said and the hope was that another group would be organised in the future - next year!
Lunch was then available for those who wanted to stay. Ann, Claudette, Ros and myself then caught our train back to St Pancras.

Impression of the weekend

My own view is that the weekend was a success in that it achieved most of what we set out to achieve. It meant that everyone who attended did manage to meet and talk to others in a similar situation. There is still a stigma attached to HIV and it is for this reason that these bereaved relatives are not able to "let go". It is sad that even after 16 years of HIV there exists a need for secrecy even within families. By attending this weekend they all knew why there were there and so were able to discuss their feelings in more depth. Some of the people attending - especially the widows and partners - did feel apprehensive about coming on their own but when they knew there would be others like them this made it much easier for them attend.

In the group I was with I saw a difference in all of them by the end of the weekend. Most importantly they were relaxed and able to cry and to laugh. One of those who had young children but did not bring them with her said how good it was to be able to sit down and actually eat an entire meal without interruption! Those who brought their children felt at ease as they knew their children were being looked after.

I feel strongly that there is a need for more weekends for bereaved families. All attending the Widows/Partners Group said they would like more opportunities to talk with others who have experienced what they have experienced as they felt safe and were able to share their most personal feelings. Sometimes for the first time.

It may be that with the experience we have all amassed from the Sheffield weekend that there are things we could do better or differently. What is always difficult is to make it possible for those less assertive individuals say what they would like to say in a group setting. The more assertive individuals do tend to dominate a group.

The weekend has given me a lot to think about. It is important for everyone to realise just how isolated the majority of these individuals are - even within their own families. This makes these weekends so important and worthwhile.

Elizabeth Boyd
3rd October 2001

SIBLINGS GROUP **MFT 22 / 23RD SEPTEMBER 2001 SHEFFIELD**

9 PARTICIPANTS

4 Sisters
1 Brother
1 Sister's partner / husband
1 Brothers partner / Wife
1 2nd Cousin
1 Niece

2 FACILITATORS (1 X SOCIAL WORKER 1 X COUNSELLOR)

- Group consisted of one family group of 4 members.
- One couple - the remaining 3 members were individuals and not known to each other. One of the members had had multiple bereavements including a wife and child whose deaths were traumatic and not related to Haemophilia / HIV.
- Some emotional and distressing issues were covered, but the group concentrated more on practical and information issues.
- Those who had the deepest emotional needs / issues contributed the least, perhaps feeling that they could not bring out their own very profound concerns to a large group.
- Emotional issues such as "being the strong one", "being side lined" or guilt at surviving were touched on by some members but not taken up by others.

MAIN AREAS OF CONCERN WERE

- Secrecy and isolation
- Lack of support and counselling
- Lack of information on own status i.e HCV carrier issues
- Safety of blood products for survivors / children
- Stigma resulting out of ignorance in general public as well as medical profession (in other clinical areas)
- Post code treatment – wide variation in the support available from centre throughout the Country.

WHAT WOULD HAVE HELPED

- Knowledge about the condition and likely deterioration's at time of death
- Honesty (from medical profession)
- Opportunity to ask questions / obtain information
- Knowing about arrangements after death i.e body bags, not able to view the body, death certificate

WHAT HAS HELPED?

- Celebrating the life of the person who has died
- Freedom to remember and talk about the good times, revisiting good memories / places
- Safe environment to express emotion

WHAT COULD HELP IN THE FUTURE

- Accessible counselling for all
- Support groups (safe environment)
- Educating the general public and those with Haemophilia / HIV / HCV through a website
- Confidence about blood product safety and supply
- Continued contact between young haemophilia families
- Building network of support

The Sheffield Weekend

I arrived in Sheffield filled with apprehension. I was unsure how I would relate with relatives who had suffered so much. Even the thought of starting a conversation was daunting.

What actually happened took me completly by surprise. The people I met had such a need to share their experiences that none of the usual trivialities of conversations applied. I felt immediatly drawn in at the deepest level.

It is hard to describe what happened in the partner group Elizabeth and I facilitated. I can list all the issues the partners shared with each other: the secrecy, the fear of telling children the truth, treatment and mistreatment, financial problems, sex and contraception, decisions about HIV testing, place and time of death, funerals and disposal of bodies. There were no taboos and no euphemisms; they told it as it was, with unbelievable honesty and courage.

What I cannot do adequately is explain the atmosphere in the room. Some of these women had not been able to share their terrible experiences and their pain. As each spoke in turn it was as if the burden was thrown into the circle and picked up by one or more of the other partners. Being allowed to witness ten women sharing their stories and holding each other through the pain was an extraordinary privilege. They gave each other support, reassurance and at times gently challenged each other in a way that no outsider could have done.

My guess is that having the opportunity to share their experiences and their feelings will have been an intensely healing experience. One woman on the Sunday said to me that in spite of being very tired, she had not gone to bed until the small hours because she had to make the most of her time with the other partners.

I was shocked by the secrecy the partners had to live with and the discrimination they had endured. The strength of their anger was at times almost overwhelming. I was full of admiration for what they had coped with and the way they had managed to survive. Most of all I was struck by their power. In the feedback session on Sunday morning, Elizabeth and I made notes of the discussion but the partners themselves reported back. It felt as if they had found their voice and their strength in the group. They spoke with passion and with humour and it was deeply moving to witness. I very much hope that they will have the opportunity to meet again and continue helping each other through their grief.

Sylvie Boulay
4.10.01