Group Seminar Proceedings

February 1983

Patron, H.R.H. The Duchess of Kent

Member of the World Federation of Hemophilia
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THE HAEMOPHILIA SOCIETY
P.O. Box 9
16 Trinity Street
London SE1 1DE
Telephone: 01-407 1010

INTRODUCTION

The 1982 Group Seminar was held from 12–14 March at the Kennedy Hotel, London NW1. The Seminar was well attended, once again, although on this occassion our organisation was able to take the strain.

The Seminar was organised as follows:

Session 1 — An introduction from Mr J. R. Hunter (Vice-Chairman) to the week-end and Dr B. Colin who began proceedings with his talk 'Haemophilia the State of Play 1982'.

CONTENTS

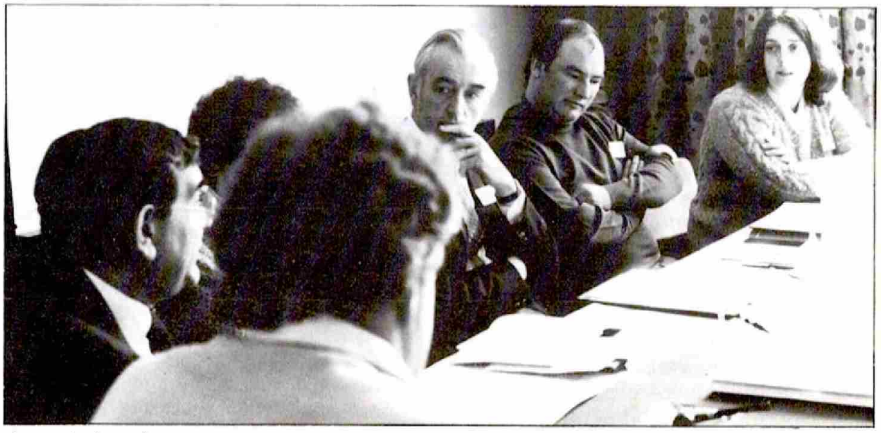
The Chairman Rev. Alan Tanner, Dr. B. Colvin, Vice-Chairman J.R. Hunter

Sessions 2,3 & 4 — These sessions were devoted to the Workshops which averaged ten participants to each. Workshop topics are given under Contents on this page.

Session 5 — At this session there were reports from each workshop followed by a general debate on their conclusions.

The Seminar was brought to a close with a discussion on the format to be followed on future, similar occassions.

Seminar Sub-Committee
Convenor — C. Knight
J. Prothero



A workshop in progress

HAEMOPHILIA – THE STATE OF PLAY

Since the Second World War our understanding of the nature of haemophilia has increased steadily but it has been within the last twenty years that really exciting advances have been made in management. These have resulted in entirely new prospects for the quality of life of the haemophiliac and his family together with a much increased life expectancy, which now approaches that of the whole population of the United Kingdom. The benefits of these advances have not, unhappily, been fully felt throughout the World and we have indeed been fortunate in this country to have the National Health Service, committed doctors and scientists and last, but by no means least, the Haemophilia Society. For the last year or so the ground gained in the immediate past has been consolidated and as we stand on the threshold of the new opportunities being created in the fields of biochemistry and genetic engineering, it is appropriate to review some aspects of our knowledge of haemophilia and of the many problems which remain unsolved.

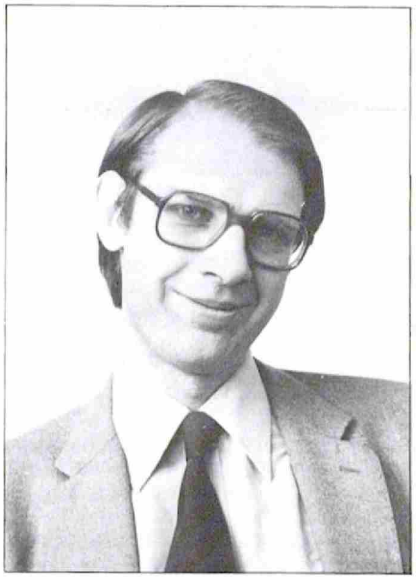
Home Treatment

It is now about 10 years since home treatment became available to any great extent and this approach would hardly have been feasible without adequate supplies of the stable freeze-dried concentrate which became widely available in the 1970s. The establishment of the home treatment programme was really an organisational problem and the close co-operation between hospital and community based staff has provided an excellent example of the way in which medicine should be practised. Patients, relatives, doctors, nurses, social workers and many others have worked together in a remarkable way so that most of the patients who might benefit from home treatment have now been offered it and the majority are receiving it.

One of the outstanding remaining problems of home treatment is the correct dose of concentrate to use. Dr. Tony Aronstam has studied this question very carefully at Treloar Haemophilia Centre and his work was the subject of an address to you last year. He has pointed out that the resting state of the joint, the frequency and site of bleeding and the delay before treatment affect the correct dosage as well as the actual severity of the bleed. It is now common practice in this country to treat minor bleeds immediately with as little as 4 or 5 units/Kg, though 8 units/Kg is perhaps more conventional. Serious bleeding into restricted target joints may require 20 units/Kg or more and muscle bleeds need to be treated with more respect than joint bleeds. It is interesting to note that higher doses have generally been used on the continent of Europe and the reason for this difference is still not entirely clear. Figure 1 shows a French view of the relationship between clinical response and dosage of factor VIII.

Prophylaxis

As more factor VIII has been made available prophylaxis has become a less controversial topic and most haemophilia centre directors now believe that it has a role to play in management. Many severely affected patients believe that prophylaxis prevents bleeding, reduces the amount of pain they suffer and limits the disruption of their lives. The obvious disadvantages are the frequency of injection, the cost and the possible long term side effects of regular concentrate administration. Prophylaxis is therefore particularly valuable in the management of a "bad patch" of bleeding and this is especially true for the adolescent haemophiliac whose schooling is so essential. We know that the frequency of bleeding falls during early adult life so it may be possible to return to on-demand treatment when a young man is well established at work or university, returning to prophylaxis at difficult times or to cover important events such as examinations, weddings and holidays. The final decision on when to start and stop must be made with the full consent of both patient and doctor but long term prophylaxis is now well established in severe Christmas Disease with limited prophylaxis being more commonly used for patients with haemophilia A.



Dr B. Colvin

Concentrate Production

Figure 2 shows the use of factor VIII since 1970 in this country. The increase in use of commercial concentrate has been roughly parallel to that of total use during this period and the contribution made by the NHS has consistently fallen short of total requirements for factor VIII although factor IX supplies are adequate. It is hoped that the situation will improve in the next few years but annual consumption of factor VIII may rise as high as 100 million units in the near future.

In the long term it may be possible to manufacture factor VIII in the laboratory but this goal is probably some way off. For the time being it will be necessary to continue to press for expansion of production facilities using the traditional source material, human plasma.

The Damaged Joint

Careful review of joint problems is an essential part of any home treatment programme and should be conducted with the help of a rheumatologist or orthopaedic surgeon. The first aim of this approach is to prevent joint damage but inevitably a substantial part of the work involves the care of the already damaged joint. Much can be done with the proper use of concentrate, physiotherapy and splinting to correct deformity, improve mobility and maintain stability but as surgical techniques improve joint replacement becomes more and more popular especially for the hip and knee (Figure 3). Despite these advances, the older techniques of realignment and arthrodesis may still have a place in treatment because they offer stability and do not involve the insertion of foreign material. There is also doubt about the durability of joint replacements, especially in young active people. In the circumstances patients may have to accept the possible need for a number of operations during their lifetime together with the small but undoubted risks that every operation carries for any patient but especially perhaps for the haemophiliac.

It is not surprising that opinions on the best form of treatment for the joints differ between haemophilia centres and only time will tell whether an aggressive surgical policy has more to offer than a conservative approach where surgery is used sparingly.

Genetic Counselling

There is still much ignorance amongst haemophiliacs and their families about the inheritance of haemophilia and the first duty of the counsellor is to explain this and to discuss fully the issues that will eventually determine whether carrier detection and antenatal diagnosis will be appropriate. Unfortunately, the tests currently available cannot *prove* whether a woman is a carrier or not although the results often point very strongly in a particular direction and are of real value in decision making, particularly in haemophilia A. Hopefully, the position in haemophilia B will improve as more assays for factor IX antigen become available.

We are very fortunate to have seen the development of antenatal diagnosis for

Figure 1 The relationship between clinical response and dosage of factor VIII

Figure 2 The use of factor VIII in the U.K. since 1970

Figure 3 Total knee replacement

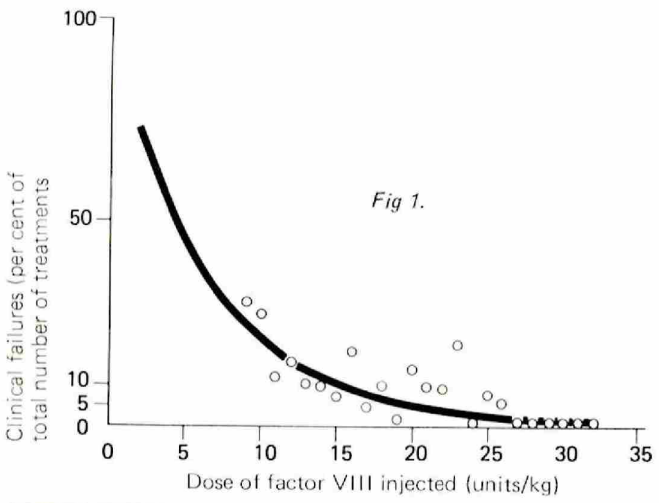


Fig 1.

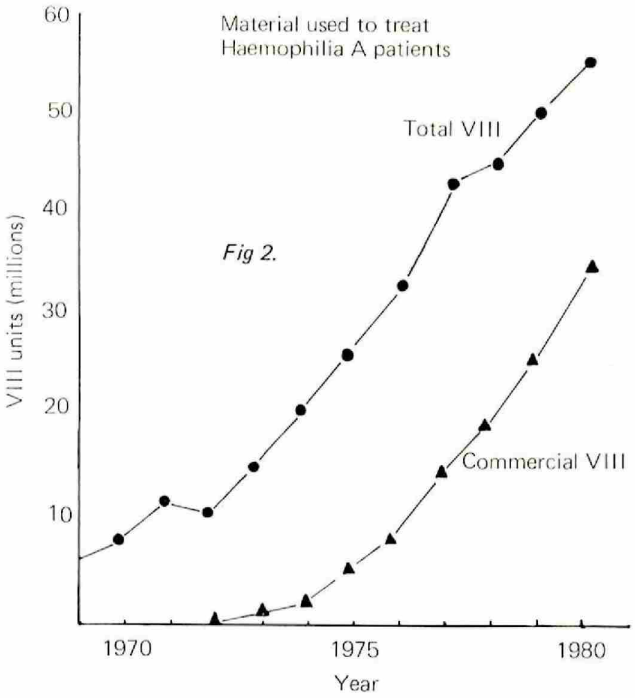


Fig 2.

haemophilia in the last few years. Dr. Reuben Mibashan, in collaboration with Professor Bloom's group, has now studied more than 80 pregnancies without any incorrect diagnoses and this is a very remarkable achievement. For the family at risk it is now possible, with proper advice, to avoid giving birth to a severely haemophilic child without the very unsatisfactory imprecision of the previous crude techniques. In the future it may be possible to study the haemophilic genes themselves rather than their products, factor VIII or factor IX and this would allow diagnosis rather earlier in pregnancy. This approach has already begun in the antenatal diagnosis of the haemoglobin disorders but much more work will be needed before it can be applied to haemophilia.

Inhibitors

The fact that there are at least six well established ways of managing inhibitors implies that none is reliably effective in every case and this is indeed true. Conservative treatment with rest and immobilisation sometimes works for minor bleeds and high dose human concentrate may be effective despite the lack of any response demonstrable in the laboratory. Plasma exchange is only really of value in the planned reduction of inhibitory activity before elective surgery or in a life-threatening emergency and it is essential for patients treated in this way to have good veins. Immunosuppression is rarely of value except for the occasional patient with acquired haemophilia.

Activated factor IX concentrates have now become one of the mainstays of treatment for patients with inhibitors and their value has been verified by controlled trials but they are not always effective and are exceptionally expensive. Recently there has been a renewed interest in the use of porcine factor VIII and some of the side effects of this form of treatment have been avoided by a new purification technique but the problems of severe reactions and the development of resistance to the concentrate remain.

Unfortunately, there is little prospect of a solution to the inhibitor problem in the immediate future and directors will continue to do their best to choose the treatment most likely to be effective in each individual case.

Hepatitis

The hepatitis which affects so many patients with haemophilia is caused by the concentrate they receive and, since the improvement in the detection of potential donors carrying hepatitis B virus, most of the new cases of acute hepatitis have been of the so-called non-A non-B variety. For this reason the recent introduction of a vaccine for the prevention of hepatitis B is unlikely to have a major effect on hepatitis in haemophilia. The problem is commoner following the use of large pool concentrates, particularly in the treatment of mild haemophiliacs who have had few injections in the past. Some patients develop the usual symptoms of jaundice and sickness but many are asymptomatic and the condition is then detected by measuring liver function tests in patients at risk. The vast majority of patients with symptoms recover within a week or two but there is growing evidence that mild inflammation of the liver can continue after clinical recovery and the long term consequences of this are not yet clear.

As no specific treatment is available for hepatitis, the most important method of control is prevention. Cryoprecipitate or DDAVP and tranexamic acid are useful for the treatment of small bleeds and for minor surgical procedures in mildly affected patients and it is worth trying to limit the number of different batches of

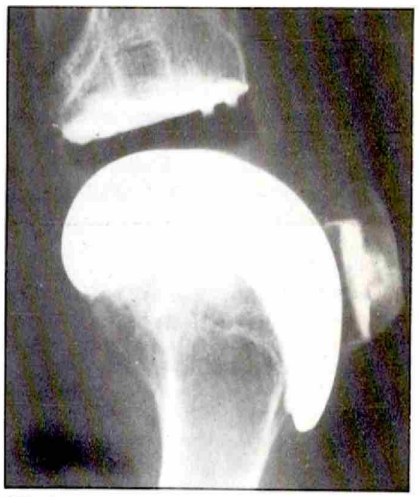


Fig 3.

concentrate used when this form of treatment is necessary. There are plans to produce a low hepatitis risk commercial factor IX concentrate and research on this type of concentrate is also taking place within the NHS. It is necessary to appreciate that any processing will reduce yield and it may also be difficult for manufacturers to substantiate the claim that a given concentrate is free from a hepatitis risk. The cost of this type of concentrate is likely to exceed that produced conventionally and physicians with limited resources could be faced with a choice between quantity and potential quality in terms of hepatitis risk.

Laser Surgery

Laser scalpels are now becoming more available and produce a narrow para-incisional area of necrosis which has a haemostatic effect by the welding of severed vessels. The amount of concentrate required during and even after surgery

may therefore be reduced together with the duration of hospital admission.

Unfortunately, the cost of lasers is substantial, the technique takes longer than conventional surgery and is said to be uncomfortable for the operating team. Further experience is needed before the role of this kind of surgery can be properly assessed.

Oral Treatment

If factor VIII could be given by mouth the quality of life of the haemophiliac would be very much improved. Attempts have therefore been made, particularly in Holland, to protect factor VIII by enclosing it in liposomes or chylomicrons in the hope that the active material might be absorbed and released into the circulation. Some success has been claimed for this technique but the work has not so far been confirmed in the United Kingdom and even if absorption of active factor VIII is eventually achieved problems will remain.

It is most unlikely that full haemostatic doses could be achieved by mouth and the yield from the starting material would almost certainly be very poor. Unless factor VIII supplies improve dramatically this means that such oral treatment would waste the limited resources available to us.

If factor VIII can eventually be given by mouth the most likely indication for it would be to convert the severe haemophiliac into a mild haemophiliac by daily doses of the material. This would be prophylaxis as we now know it but in a much more acceptable and possibly more effective form.

Conclusion

The delivery of comprehensive care for haemophilia is now well established throughout the United Kingdom and is rightly expected by every well-informed haemophiliac. Major scientific advances have made this approach possible but standards can only be maintained by the personal endeavour of haemophilia centre staff, haemophiliacs, their relatives and, of course, the Haemophilia Society itself. The growing number of local groups is very encouraging and we can look forward with confidence to the future if we know that everything is being done to provide the whole haemophilic community with the facilities which have become available so quickly in the last few years.

Dr. B. Colvin,
Consultant Haematologist,
The London Hospital.

THE WORKSHOPS

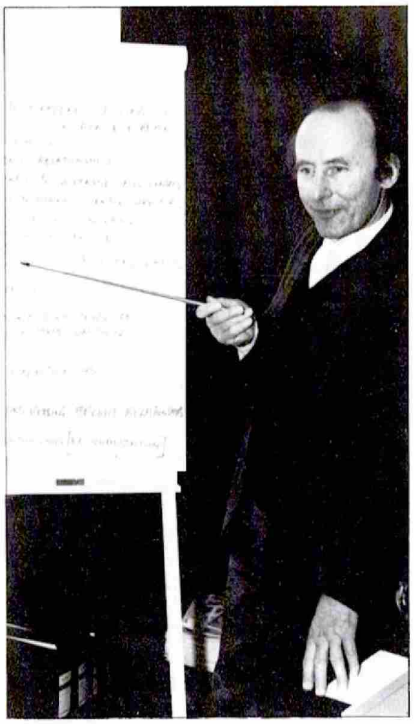
A NATIONAL SOCIETY: THEM & US

(Part 1) Executive and Council

LEADER: A. J. Tanner

In discussing the relationships between Executive/Council and Groups, ways in which direct communication between the Executive/Groups/Council were invited.

One of the difficulties was one of logistics, in ensuring that E.C./Council matters were available prior to meetings



The Chairman makes a point

of the Group to ensure that Group representatives acted with Group's mandate. Last minute grant applications for example were "not on".

Another area was that of "Partial information" in E.C. minutes, which prevented Group officers understanding the logic behind some E.C. decisions.

It was felt that a significant area of interest to Groups that was currently lacking was in respect of feedback on Research investment in projects as to progress/results etc.

The present involvement of Group representatives at Council in the decision making process was felt adequate although some improvement in information to Grant applications was felt necessary. The proposed document for discussion at Council on Sunday was a welcome step forward in this respect.

The role of the Co-ordinator and the effectiveness of the appointment was discussed and generally welcomed as being most satisfactory and valuable.

Participants felt that an evaluation of Co-ordinator's efforts, once systems are established, would be essential to ensure optimal benefit of his professional experience, to the Society. Groups may welcome an opportunity for input in this respect.

(Part 2) Local Group/Head Office

LEADER: Bill Johnstone

The perhaps provocative content of the abstract for this session was intended to signal to those participating that there was no area of Group/HQ role or relationship that was sacrosanct.

In the event, the session participants felt that the present constitutional responsibilities of the constituent parts of the Society was sound, and that to a large extent, any widespread notion of a "Them & Us" situation could be largely due to the fact that the HQ operation in general and the Executive Committee in particular was, as a result of unfamiliarity of individuals, with members of the Executive and to some extent viewed them with awe.

This could be overcome to a large extent by ensuring that the Executive be exposed to a wider cross section of Group members either by visiting them or by Groups ensuring a wider member participation at Council/Group representative meetings.

Members felt that some better understanding of Executive decisions could be achieved by more detailed communication and that Groups should be encouraged to communicate on such to a greater degree.

The Notes for the Guidance of Groups were felt not to be a constraint on Groups but perhaps could be extended to include and amplify Society Aims/Policy from time to time.

Wide ranging issues such as Youth participation and widening membership were discussed as being the responsibility of Groups to secure.

In concluding, participants felt that any perceived "Them & Us" issues were possibly unavoidable in associations as diverse as those involving haemophiliacs and indeed was not a phenomenon confined to Groups' perception of Head Office, but applied to members/Group Committees equally well.

The workshop produced the following additional notes:

A NATIONAL SOCIETY: THEM AND US (Part 2)

LOCAL GROUPS/HEAD OFFICE

The objective of the perhaps provocative abstract introducing this seminar session, was to encourage participants to feel free to explore all aspects of relationships as they exist between the different elements which together combine to form the formal structure of the Haemophilia Society in 1982, and to test the validity and effectiveness of such a structure in supporting Society aims into the 1980's and 1990's.

1. **The Organisational Framework**

   The framework of organisation, linking with various elements of Society activity together, and the role and responsibilities of each element, either as defined under the Rules and Notes for Guidance, or as adopted by custom and practice, were felt to provide an adequate and effective organisational vehicle from which to support the future needs of Haemophiliacs, at least in the near term.

The roles and responsibilities of the Executive, Council and Groups were sufficient to ensure timely execution of Society business, whilst containing within them sufficient checks and balances on each other, consistent with a voluntary organisation of our size and activity.

2. **Communications**

The effectiveness of communication between the various elements of the Society structure has improved dramatically since the appointment of a full-time Co-ordinator. Groups in particular were now better informed of developments in all aspects of health and social welfare to an extent where they are now better equipped to respond to local needs as they arise.

Some people felt that there was perhaps some room for improvement in relation to the timing and content of some recurring information documents such as Executive Committee and Council meetings minutes. Some consideration may be given to ensuring the timely distribution of such documents, to enable Groups to discuss relevant issues and so instruct Group representatives to Council on the expression of the Group Committee's collective opinion.

It was suggested, since Groups should be a move in advance of Council meetings for example, they arrange any necessary Group meetings some days in advance of such Council meetings by which time all relevant documents should have been received.

It was felt that some means was necessary to enable Group Officers to gain further insight into Executive Committee decisions on some issues, especially those of policy etc., and which receive perhaps scant reporting as a minute but which obviously are the subject of lengthy debate and consideration. Suggestions as to how this may be improved included

(i) amplifying details of important policy issues, e.g. Incorporation, creation of posts etc.

and

(ii) accommodation requests from Group Officers for further details on issues of specific interest and as required.

3. **Personal Relationships**

The effectiveness of any organisation can depend not only on the adequacy of the formal structure which defines the organisation's role at each level, but on the informal relationships that develop between individuals at each level.

It was suggested that there was considerable scope for improvement of *intra*-relationships at Group level in mobilising support and participation by members in local areas. Various mechanisms to generate such involvement were discussed, ranging from further social intercourse and activity, to involving all members as part of an "open committee". It was agreed that different areas would respond to different mechanisms and that Group committees should continue to pursue such wider participation with as much vigour as in the past.

Some improvements in *inter*-relationships between formal elements of the Society were considered necessary by exposing those involved at each level, to those at different levels, to a much greater extent.

Mechanisms suggested to effect such greater exposure and contact, involved members of the Executive Committee being seen more and more at Group meetings/functions/events, although considerations of travel/accommodation costs were not to be ignored.

Another, for action by Groups themselves, was to ensure that as wide a member involvements as was possible be achieved at Council/Group Representative meetings. This would ensure not only exposure of Group Representatives to Executive Committee members, but also to other Group members and stimulate interest and discussion on areas of mutual concern.

4. **Session Leader's Remarks**

Whilst the topics raised and discussed by participants were not necessarily raised under each heading in the discussions that took place, I have taken the liberty of marshalling the various points raised under these broad headings in the interests of clarity and relevance.

It was perhaps inevitable that a seminar weekend such as the one we have just completed, and comprising as many seminar topics, will produce summaries across the broad spectrum of topics which will to some extent overlap with each other. The extent to which this happens will, I feel, serve to highlight the important issues and those requiring our urgent consideration.

I thank you for your interest and participation. **Bill Johnstone**

REGIONALISATION

LEADER: Dr. L. Kuttner

1. Groups represented: N.W., Leics., Nott. & Derby, Lincoln, Bristol, S. Essex, Merseyside.
   General feeling was that link with groups within an area could be very useful for the following purposes:
   (a) Discussion of points of general interest before London meetings.
   (b) Representation at London by Regional representative when no group representative is available.
   (c) Joint events like lectures, parties, etc.
2. Slightly different opinion between large and small groups.
   (a) Small groups see a close link almost as a necessity, while the large groups feel that a loose link is all they want.
   (b) General opinion is that groups must retain their own identity and must not amalgamate at the cost of the closing of individual groups.
3. Leicester and Derby would like to co-operate closer.
4. North West and Merseyside have already discussed holding some events jointly. But not on a regular basis.
   South Essex have approached Colchester for the same purpose.

Regionalisation could and would help visits from David Watters, etc. greatly if all groups in a given region could meet for such a visit.

Children from a Region (or the whole country) to be sent on holidays together. Everybody praised North Wales holidays.

The summing up was:

It could be very beneficial for the small groups to have closer links to exchange ideas, organise lectures etc. But the large groups will attempt to visit on certain occasions, like lectures etc. where better audiences can be obtained and expenses be shared.

SOCIETY POLICIES

LEADER: K. Polton

Finance: Grants to Members

Priorities: For making grants to members are:—

(a) Aids for mobility, i.e. hand controls etc.

(b) Aid with telephone not only for those on home treatment.

Procedure re: grants

£50 as at present OK but suggest discretion given to Co-ordinator/Case Committee for additional £50 in an emergency in liaison with Group if possible.

Membership of Groups

Should encourage more outside interest and support.

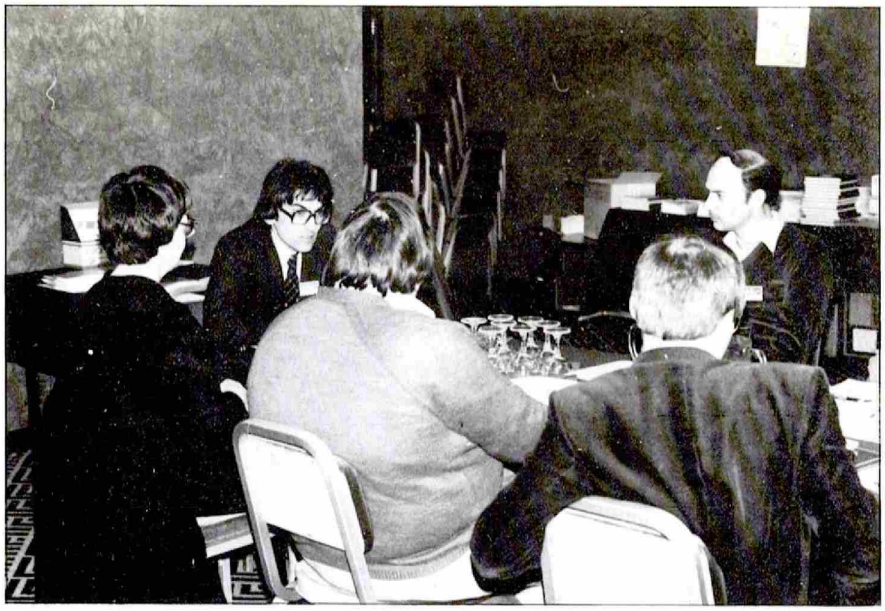
Bulletin

Agree excellent. Present material — mixture of scientific/general news of benefits etc./Society news etc. very good.

Perhaps add Question and Answer column.

Appeals literature

Our presentation of haemophilia is good but more and varied literature is needed urgently with a positive approach.



FINANCE – MAXIMISING SOCIETY RESOURCES

LEADER: H. Abrahams

We discussed in great detail the management and monitoring of Society's Finances and Cash Flow and basis of maximising interest rates. Mention was also made of "speculative" investments such as Gold, Dollar Market and works of art and it was agreed that this was not a viable proposition as far as Charity funds were concerned.

Interest was shown on the management of the Research Fund, the allocation of funds between General and Research Funds and the possibility of charging expenses to the Research Fund.

The Tax advantage of donating by way of Deed of Covenants was explained in detail and encouragement given to this form of donation.

Advice was sought on the standardising of Group accounts with a view to Consolidation.

A point was raised on the valuation of Group Stocks on hand at Balance Sheet dates.

With regard to accounts we discussed new professional auditing guidelines and the necessity for professional outside firms of auditors to deal with Group accounts.

Incorporation was also discussed and the current question of officers' personal liability.

There was also a certain amount of discussion on the question of bequests and informing solicitors and bank managers about the Society to assist them when advising on the preparation of wills including charitable bequests.

FUND-RAISING

A resumé of present sources of funds was given e.g. subscriptions, donations, legacies (on the increase), Annual Draw, Interest.

Group Representatives gave information on their fund-raising activities.

Possible future plans suggested include: TV or radio appeal, using Vice-Presidents more, asking Groups to set further Research Appeal targets, a grand fund-raising event to be attended by our Patron if possible attached to our 40th anniversary.

It was agreed that:

(a) maximum publicity should be allied to fund raising.

(b) Groups should supply details of any large fund-raising events (with photographs) for coverage in the Society Bulletin.

(c) A special feature covering appeals should be a regular item in the Bulletin.

(d) An ABC of fund-raising (draft discussed) should be printed and distributed to all members.

K. R. Polton
H. N. Abrahams
D. Rosenblatt

The workshop produced the following additional notes:

1. Subscriptions. These were a small percent of income and were usually enhanced by a donation.

   It was pleasing that the level of covenanted subscriptions had substantially increased.

2. An 'A B C' of Fund Raising was to be published in the Bulletin.

3. It was important for *each* group Committee member to ask for help from outside help, thereby forming several mini fund-raising Committees. Even if each member raised a small amount, by multiplying the number of people involved, much could be raised.

4. Fund-raising was important because all such activity includes an element of publicity which is of the kind we want.

5. Flag days were discussed and where possible. S.W. Essex Group outlined the Sponsored Marathon (all admin. by-passing Trinity Street).

6. Suggested that the Society puts on a Grand Concert in London at Barbican/Festival Hall by a Group such as the Spinners.

SOCIETY SERVICES

LEADER: C. Knight

This group discussed the problems and prospects for reaching uncommitted members and meeting their needs.

Problems identified

5000 haemophiliacs — only 1500 belong to the Society.

Good treament diminishes interest in the Society.

Apathy of members.

Misdirection of Society efforts — too much emphasis on fund-raising.

Desire of haemophiliacs not to be labelled as disabled by their membership of the Haemophilia Society.

More directives from the Executive and office would be welcome.

Methodology

After analysing those Group events which were most successful the following conclusions were drawn:

1. Less formal venues and meeting struc-

tures were useful.

2. Particular topics, such as dental care, pre-natal diagnosis etc. draw small but very committed groups with a real need and desire to talk about their problems.
3. In a wider sense it was suggested more use could be made of events organised by large charites – county shows and the like to attract new members.
4. New ideas and new faces at talks important to draw members in.
5. It was suggested and commended that small workshops could be set up by Groups, to discuss particular topics.
6. It was recommended that Group Committees should make a start on the above by meeting as a workshop and taking stock of the direction they have taken and might go in future.

RESEARCH

LEADER: K. R. Polton

A brief history of the Research Fund and grants given over the past 20 years or so was given together with a resumé of the general policy adopted.

It was reported that a grants committee has now been formed to deal with applications.

It was agreed that the Grants Committee should produce an Annual Report on the progress of projects, use of equipment etc., paid for by the Society.

Suggestions made by the Executive Committee and the Workshop regarding the administration of the Research Fund will be presented to the Council.

Priorities

It was unanimously agreed that any applications for grants should not be refused simply on the grounds that the money should be obtained from the NHS. Each case should be looked at on its merits, the criteria being if there are proven benefits to the patients.

A suggested list of priorities:–

1. Research such as investigations into site of Factor VIII production, pre-natal diagnosis, hepatitis, liver investigations, carrier detection, synthesis of Factor VIII.
2. Purchase of equipment combined with research workers and technicians.
3. Items such as extensions to facilities, other staff such as nurses, social workers, must be considered on the merits of the case. Data collection (computers etc.) were felt to be bottom of the list.

It was felt that the Society should consider sponsoring or commissioning a research study on the effects on family life following Genetic Councilling, pre-natal diagnosis etc.

UNEMPLOYMENT & HAEMOPHILIA – ARE THEY RELATED?

LEADER: John Prothero

It was felt that haemophilia and unemployment were related and the older the haemophiliac was the more dismal his prospects.

There seemed to be a small but significant number of haemophiliacs who are, as it was termed, 'professional' haemophiliacs – that is content to draw social security benefits and spend it on their beer and cigarettes, blaming it all on their haemophilia, but most were not felt to be in this category.

There is no easy solution but the workshop threw out very many ideas for future consideration to help alleviate the problem, through Groups, Centres and the Executive Committee.

THE SOCIETY AND THE YOUNG HAEMOPHILIAC

LEADER: GRO-A

1. It was felt that there was a conflict of interest due to the age range and that Haemophilia Youth should try to appeal to a narrower age group so it would be easier to stimulate interest.
2. Groups should give support to form local groups but should not interfere with its running so that Youth can evolve their own policies.
3. There should be a project to stimulate involvement such as Outward Bound Holidays and Exchange Holidays.
4. There should be some involvement in the problems associated with youth such as unemployment – this could be helped by improving communication. There should also be a section in the Bulletin given over to younger readers.

PUBLICITY – A TWO EDGED SWORD

LEADER: C. Knight

Group discussed at length the aims of publicity, these were:

1. Fund-raising.
2. Raising public awareness of haemophilia.

Problems: The approach to 1 could easily worsen the situation with regard to 2.

Recommendations were to supply and thereby control as much as possible information supplied to press, radio etc. This was greatly helped by lazy journalists getting pre-digested copy. Stress was laid on correcting public wrong thinking.

The ethics of using individuals as a focus for publicity – This was felt to be OK if publicity covered positive aspects of haemophilia (e.g. good treatment, achievement generally, normality of life-style) and, naturally, if the person concerned gave consent.

There was much discussion of present Society literature, both form and content and many disparate ideas as to new productions. This was clearly felt to be an area requiring prompt and searching re-examination. Stress was laid on simplicity, presentation, cartoons, audio-visual aids etc. Suggestions were made on the following:

1. Whether a large national PR firm might be cajoled into serving the Society for little, if any, money.
2. Whether a well-known personality could be recruited to build publicity value into events etc.
3. Whether an author with interest in haemophilia could be found to propagandise by writing a play etc.
4. It was strongly suggested that the Society could usefully get into the business of supplying information (in book form) to groups such as nurses who were currently ill served.

HAEMOPHILIA IN THE THIRD WORLD

LEADER: Peggy Britten

More should be done in training of doctors especially by workshops in other countries.

We should give more to Third World, to save even 1 or 2 lives.

Privileged countries to join (via WFH) to help underprivileged.

Propaganda and education important via doctors from e.g. Nigeria, India and Kenya working in this country maybe.

Sending our spare products to needy areas — e.g. home treatment materials, spin dryers/motors, out of date hospital equipment being replaced.

Need for the Society to have special fund for specific projects — in conjunction with WFH — Executive to take initiative. If we have a firm project would Blue Peter help? Companies?

Perhaps choose one special area, e.g. Calcutta. Investigating the problem might cost £5,000. Mother Teresa might help as she already has aided a local haemophiliac.

Executive should start to act *now* and then sell the plan to Groups.

The workshop produced the following additional notes:

THIRD WORLD

1) There was a strong feeling of urgency of action, however small the positive help it could bring.
2) There was full agreement that our action(s) should be with the approval of/in conjunction with W.F.H.
3) The £5,000 mentioned re: possible help in Calcutta was merely what it might cost to investigate all the problems. Much more would then be needed.
4) It was felt that special appeals should be made to raise funds for overseas aid, e.g. from firms with overseas interests such as Shell International.
5) Members felt that more could be done via foreign doctors working in the UK, i.e. they should be encouraged to pass on information to their colleagues at home.
6) It was felt that "on the spot" teaching, such as the W.F.H. and H.T.C. Workshops, was something we might help with.

A WORLD PERSPECTIVE OF TREATMENT & CARE

LEADER: K. Milne

We considered treatment in the UK compared with other countries, and recognised our privileged international position. We felt that in three aspects we should strive for improvement:—

(i) We should continue to fight for increased production of blood products.

(ii) We should help in removing inequality of care in different areas.

(iii) We should encourage the extension of comprehensive care.

We felt that we should help directly in providing haemophilia care in the third world.

Possibilities include:—

(iv) Paying for training of staff from such countries, or sending staff to those countries.

(v) Sending equipment — possibly in conjunction with other charities, and aiding the development of suitable "low technology" for them.

(vi) Producing educational literature for the third world.

We felt a task force should be set up to investigate the possibilities.

THE GROUP AND THE HAEMOPHILIA CENTRE

LEADER: Marion Gregory

Sister Marion Gregory

(a) Medical Advisory Panel should prepare notes and guidance on treatment for haemophiliacs for Junior Medical Staff.

(b) Invite Centre Directors to a Seminar.

(c) Hospitalisation — Local Groups to be notified of any haemophiliacs which may be receiving treatment out of their own area.

(d) Production of a Home Treatment leaflet giving guidance of storage of used and unused equipment.

(e) Centre to display a Samaritan list of telephone numbers.

(f) Centre Directors to be asked to hold social meetings each month — suggest Head Office approach Directors.

(g) It is essential that good relationships are formed between the Group and their Centre.

(h) Group can help the Centre by visiting mothers with newly diagnosed haemophiliacs.

The workshop produced the following additional notes:

THE GROUP AND THE CENTRE

This was a lively discussion, the delegates present covering Reference Centres to Associated Centres.

The care often given by Junior Medical Staff in Centres was not entirely satisfactory, and this could be improved by the Society producing notes and guidance on treatment for Haemophiliacs. This could be useful for General Practitioners as well as Junior Medical Staff. The session suggested that perhaps we could ask the Medical Advisory Panel to look into this.

It was thought that it would be a good idea if sometime there could be a Seminar week-end when we invited Centre Directors to join us. It was agreed that there are good and not so good Directors, and that they and we could all benefit from such a meeting.

The Centre could help us by notifying the local Group when a patient is hospitalised in another area, who will then notify the Group in that area so that they can assist with visiting.

It was rather distressing to hear that in some areas Home Treatment records are carefully kept by the Haemophiliac but do not appear to be required by the Centre. Equally distressing to some of us was to hear that used equipment was still being disposed of by placing in the dustbin. It was, therefore, suggested that the production of a Home Treatment leaflet giving guidance for storage and disposal of equipment should be looked into.

A further suggestion was that Centres should display Samaritan telephone numbers. Youths need to talk but often find it difficult to talk to their Centre staff.

It was felt to be essential that good relationships are formed between Group and Centre, and that Centre Directors could be asked to hold monthly social meetings, and that perhaps head office could approach Directors initially.

The Group can help the Centre by contacting parents of newly diagnosed Haemophiliacs; this relies upon good relationships between Group and Centre staff.

M. Gregory,
Haemophilia Sister,
Children's Hospital, Birmingham.

THE SUPPORTIVE ROLE OF GROUPS

LEADER: P. Wetherell

1. Support must be offered to individual members when asked for. We cannot approach newly diagnosed members – we must rely on Centre Directors/ Sisters passing our names on to patients.
2. Where Centres run efficiently and offer fully comprehensive treatment and counselling, the Groups' supportive role will often be mainly financial.
3. Members do not feel qualified to give support in counselling but our support may be therapeutic. This support can be given by passing on our own opinions and experiences.
4. We must press Centre Directors to improve conditions and begin such things as group therapy sessions on an informal basis. This will enable the therapeutic support role to come into its own.
5. A communication week/month within each region may stimulate more interest. This can be done by visits to members, extra newsletters, coffee mornings etc.
6. Encourage open meetings rather than a large number of committee meetings. Where an event is to be organised a sub-committee may be set up.

Major constraints are:

1. Apathy.
2. Transport particularly in rural areas.
3. Lack of interest of some Centre Directors.
4. Scotland has special problems where there is no Centre. The role must be a pioneering one to work with consultants to improve conditions.
5. The patient must understand that confidentiality is always preserved so that they may feel free to ask for support, especially of a financial nature.

The workshop produced the following additional notes:

The workshop considered ways in which members felt they were supporting the Centres. This seemed to vary enormously from one region to another. At the moment support seemed to be mainly under the heading of finance. Patient visiting, counselling, and publicity within the Centres seems to take second place. Scotland was felt to be a special case since they have no Centre to support.

The state of the Centre and the attitude of the Centre Director makes a great deal of difference to the way a Group functions, particularly where there is a special interest in Leukaemia as well as Haemophilia.

"Problem" Groups arise where the Centres run efficiently offering patients fully comprehensive care. Everyone in this lucky position felt that the Group's role has become supportive mainly in a fund-raising sense.

The Co-ordinator practises his spelling

Friendly persuasion must be used on the Directors of these and other Centres to keep the Group fully informed and also to make sure that patients are aware of the Group.

Home treatment is producing the problem of isolation. Maybe one way round this is for committee members to visit patients to see if their needs are adequately met. This might also help to overcome the apathy which exists, and was felt to be the major constraint on Groups.

Satellite Groups were discussed where Groups cover a wide area. Caution must be exercised when asking non-committee members to organise events. Letters of authorisation should be given. This might help to keep the interest of Group members who felt that travelling difficulties restrained Group activities, especially in rural areas.

Some members felt that meetings were better attended where they took place outside the hospital.

One Group held its committee meetings on the same day and at the same place every time and invited members to attend when they had any ideas or problems. They did not have a formal "committee".

It was felt that greater emphasis must be put on the therapeutic support which Groups could give. Therapy sessions organised with the help of the Centre Sister and Social Worker may be arranged especially for young mothers. These would be very informal and along the lines of a coffee hour.

The role of the Scottish Group was felt to be a pioneering one persuading the consultants and the authorities of the need for a Centre.

A communication week was considered especially if this could run in conjunction with the main Society.

HOME TREATMENT – PROBLEMS

LEADER: John Prothero

The main problem seems to be in training people to go on Home Treatment programmes. Very few Centres seem to provide details of the action to be taken in case of Anaphylactic Shock, or indeed the drugs to deal with it.

There also seems to be a marked reluctance in some Centres to maintain regular follow-up and assessment clinics.

By and large people found no problem in integrating Home Treatment into their family life and no particular problems were reported with regard to its effect on relationships.

Ways of dealing with the problems through Groups and the Executive Committee were discussed.

GENETIC COUNSELLING

LEADER: A. J. Tanner

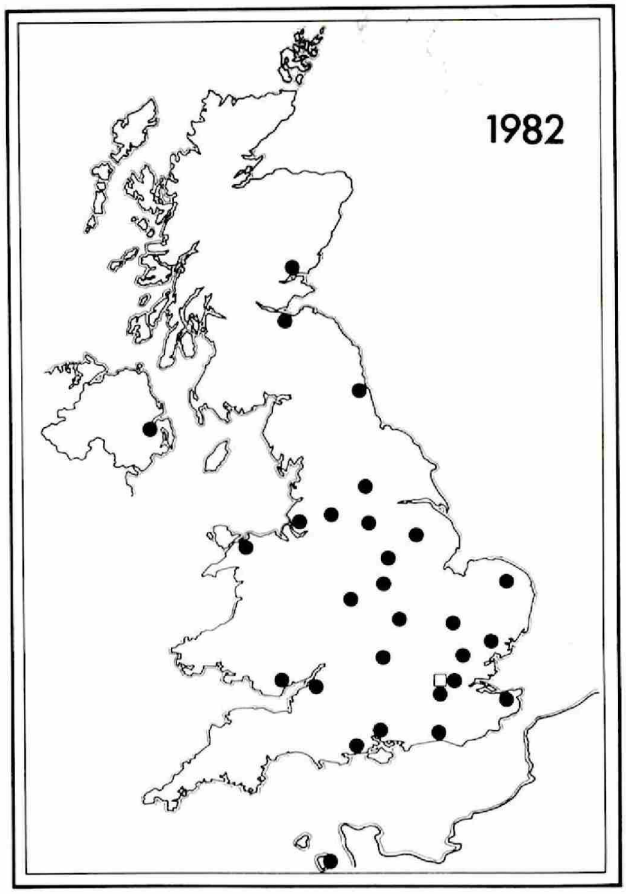
1. Meeting opened with sharing of personal experiences almost "Group Therapy". Discussion followed on what "genetic counselling" should encompass, not just an explanation of genetics but mental, physical, financial etc.
2. Is there an ideal age for telling a girl about carrier status? Earlier the better. Parents preferably the informers.
3. Good counselling facilities are minimal. Generally felt that Centre Director should give the counselling. Some Centres apparently have no counselling facilities at all.
4. Local Groups should be encouraged to set up sessions for discussions between parents which could encompass genetics and possibly give moral support to mothers who decide on termination of pregnancy.

PARENTS & HAEMOPHILIA

LEADER: Marion Gregory

Group support of the parents at the time of diagnosis, especially where there is no history, is considered to be vital from an educational aspect, and more particularly we include GP's and hospital Junior Medical Staff in this requirement. The recent literature produced by the Society is valuable in this area, but the session feels that attention should be given to producing similar concise notes for medical and nursing staff. Professional presentation of literature is worthy of some examination. Recent advances in medical science have brought with them new problems particularly related to the various choices or options now available,

THE HAEMOPHILIA SOCIETY



□ Head Office – London SE1

● Local Groups
Birmingham and Midlands Group (Birmingham)
Bristol and South West Group (Bristol)
Cambridge and District Group (Cambridge)
Colchester and District Group (Colchester)
East Kent Group (Canterbury)
Great Ormond Street Group (Great Ormond Street, London)
Jersey Haemophilia Group (Jersey)
Leicester and Rutland Group (Leicester)
Lewisham Group (Lewisham)
Lincoln and District Group (Lincoln)
Merseyside and District Group (Liverpool)
Norfolk and Norwich Group (Norwich)
Northampton and District Group (Northampton)
North Eastern Group (Leeds)
Northern Ireland Group (Belfast)
Northern Group (Newcastle)
North Wales Group (Bangor)
North West Group (Manchester)
Notts and Derby Group (Nottingham)
Oxford and District Group (Oxford)
Scottish Group (Edinburgh)
Sheffield and District Group (Sheffield)
Solent Group (Southampton)
Southern Group (Bournemouth)
South Essex Group (Harlow)
South Wales Group (Cardiff)
Sussex Group (Brighton)
Tayside Group (Dundee)

Statute miles
0 20 40 60 80 100
0 50 100 150 200
Kilometres

PARENTS AND HAEMOPHILIA

especially those associated with genetic counselling and pre-natal diagnosis.

The success of home treatment is without doubt but it appears that there are some Centres where no follow-up clinics are held, thus all contact with the Centre falls away.

The workshop produced the following additional notes:

During this 1¼ hour session we were not able to discuss this topic fully as time had to be allowed for relating personal experiences.

Group support at the time of diagnosis, which can be very traumatic to a family where there is no previous history, was considered to be vital and we would rely upon the Director or the Sister to give the necessary information regarding contact.

Mothers in the group expressed their distress at the number of times they took their boys to see Doctors pre-diagnosis, and were repeatedly told there was nothing wrong with them. They all said that they experienced a feeling of knowing there was something wrong.

It was thought that General Practitioners were not sufficiently informed about Haemophilia, and many refused to treat the Haemophiliac for problems other than their Haemophilia. There was some concern also about the care given by Junior medical staff.

The Society produce valuable literature covering many aspects of Haemophilia, and it was thought that perhaps this could be extended to include concise notes for medical and nursing staff. Professional presentation of literature is worthy of some examination.

The session felt that genetic counselling was beneficial, but, unfortunately, pre-natal diagnosis was not fully discussed as those present who voiced their feelings were not prepared to consider abortion.

As to the question of guilt, not one person was able to say that they felt guilty passing Haemophilia onto their sons but they did agree that over-protection was a problem initially, but this was eventually overcome to some extent.

There are many stresses on the family of a Haemophiliac, and the feeling was that the recent advances in medical science have brought with them new problems, particularly related to the various choices or options now available, especially those associated with genetic counselling and pre-natal diagnosis.

The success of home treatment is without doubt, but it appears there are some Centres where no follow-up clinics are held, thus all contact with the Centre and other parents and children falls away.

Some difficulty was being experienced with schools and school staff. Some school staff appeared to over-protect the boy with haemophilia, but neglected to contact parents where injury was sustained.

Participation allowed in Physical Education and games varied from centre to centre.

Education perhaps could form a useful topic for a future group discussion.

M. Gregory,
Haemophilia Sister

The Seminar Sub-Committee, C. Knight and J. Prothero would like to thank all those who attended the 1982 Group Seminar for all their hard work and enthusiasm. Our special thanks must go to David Watters and Irene Watson who made the week-end run so smoothly.