Witness Name: Katherine Victoria Burt

Statement No.: WITN6391001

Exhibit WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392004

Group Seminar Proceedings

December 1981

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

Member of the World Federation of Hemophilia
Registered in accordance with the National Assistance Act 1948 and the Charities Act 1980 (230034)

THE HAEMOPHILIA SOCIETY
P.O. Box 9
16 Trinity Street
London SE1 1DE
Telephone: 01-407 1010

INTRODUCTION

The Group Seminar was held from 13–15 March 1981 at Hendon Hall Hotel, London NW4. It was embarrassingly well attended so that the value of a seminar format, which implies relatively small groups exchanging information and ideas, was somewhat reduced. The Seminar sub-Committee will consider how to overcome this problem on future and similar occasions.

There were five sessions as follows:

Session One: was concerned with the production, use and the associated problems of concentrates.

Session Two: dealt with Society relationships with outside bodies such as BASW and the Haemophilia Nurses' Association.

Session Three: was largely devoted to Society organisational matters.

Session Four: 'The Future', was followed by a very useful discussion amongst delegates.

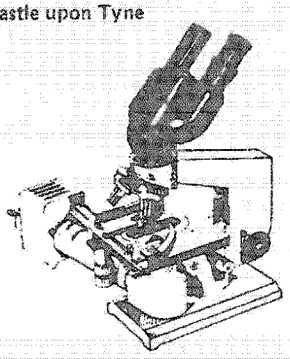
Representatives of the drug companies spoke in Session One. Their talks have not been included in these Proceedings because the accompanying, and impressive, visual presentations were integral to their contribution. Also a great part of the value of their polished performance lay in the question and answer periods which followed each talk.

Last, but not least, there was a poster session in the foyer, which was on display throughout the Seminar, organised by J. Ritchie. This session was devoted to the work of the Groups and gave a very good picture of their work and diversity.

CONTENTS

THE ROLE OF THE LABORATORY WITHIN THE HAEMOPHILIA CENTRE

Alan Oxley F.I.M.L.S., Chief M.L.S.O.,
Department of Haematology,
Royal Victoria Infirmary,
Newcastle upon Tyne



The prime requirement for accurate laboratory diagnosis of a suspected coagulation abnormality is the provision of a blood sample obtained by clean venepuncture. The specimen is taken into plastic tubes containing a liquid anticoagulant, usually 3.8% or 3.13% sodium citrate. Since the anticoagulant is a liquid it is most important that the correct ratio of blood to anticoagulant is maintained in order to prevent errors due to dilution effect. The usual ratio is 1 part anticoagulant mixed with 9 parts of blood.

Anticoagulants are used to prevent the blood from clotting because most coagulation factors are consumed during this process, particularly factor VIII. Plastic tubes are preferred since glass can activate the coagulation sequence.

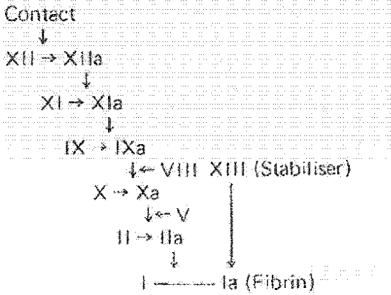
The in vivo situation can never be mimicked perfectly, but an attempt is made by performing the laboratory tests at body temperature using either water baths or automated solid-phase heated machines. Although whole blood is collected it is generally only the plasma portion which is used for investigation.

Haemostatis, that is the cessation of blood flow from a damaged vessel, is the result of the action of a series of forces, the blood vessel itself, the platelets and the coagulation factors. In order to standardise the nomenclature of the plasma coagulation factors it was agreed in 1963 that the factors be identified with Roman numerals, from I to XIII, although some factors are still known more popularly by their synonyms.

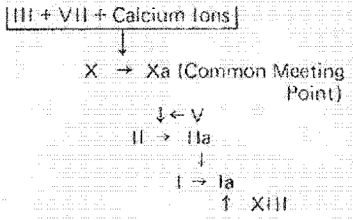
Table 1

FACTOR	SYNONYM
I	Fibrinogen
II	Prothrombin
III	Tissue Thromboplastin
IV	Calcium
V	Labile Factor
VII	Stable Factor
VIII	Antihaemophilic factor/ Globulin
IX	Christmas Factor
X	Stuart – Prower Factor
XI	Plasma Thromboplastin Antecedent
XII	Hageman Factor
XIII	Fibrin Stabilising Factor

The coagulation factors react in a stepwise cascade or waterfall system in order to produce a stable fibrin clot. In its simplest form the cascade can be expressed thus:



Each inactive, circulating protein is converted into the active, enzymatic form by its predecessor. Unfortunately this scheme does not take into account the so-called **extrinsic** system of coagulation which is initiated immediately after release of tissue fluids into the blood stream following injury to blood vessels. This system involves fewer factors than the **intrinsic** pathway illustrated above, but the two do have a common meeting point and both are naturally concerned with the generation of a fibrin clot. The extrinsic system can be depicted thus:



The two systems work independently of each other, but are stimulated simultaneously.

Laboratory tests are designed to mimic these pathways in order to facilitate identification of a factor deficiency. The prothrombin time (PT) is a measure of the extrinsic pathway and also all factors below the common meeting point, the partial thromboplastin time with Kaolin (PTTK) will detect deficiencies throughout the length of the intrinsic system, notably factor VIII and factor IX. The PTTK is also known as the Kaolin Cephalin Clotting Time (KCCT) and the Activated Partial Thromboplastin Time (APTT).

Approximately 95% of all bleeding disorders are due to a deficiency of either factor VIII or factor IX. This will result in a prolongation of the PTTK, but a normal PT. Screening tests in the laboratory are based on the time taken for a clot to form in a test tube at 37°C and by comparing a normal control pool with the patient. If a deficiency is suspected then specific assay of the actual amount of the factor can be performed.

PT	PTTK	Possible Deficiency
Abormmal	Normal	VII
Normal	Abnormal	VIII IX XI XII
Abnormal	Abnormal	I II V X

Factor assays are either one-stage, i.e. clot formed in a single tube, or two-stage techniques, i.e. incubation mixture transferred to another tube containing other substrates before end-point (clot formation) determined. The amount of the coagulation factor present is measured by comparing the corrective effect a normal control and the patient have on a plasma completely deficient in the factor under investigation. The time taken for a clot to form is directly proportional to the amount of the factor present in either the control or the patient.

A factor VIII assay will confirm the diagnosis in approximately 90% of congenital factor deficiencies. Not all of these deficiencies can be labelled Haemophilia A, since absence or depletion of factor VIII can occur in classical Haemophilia A (affecting males only), Haemophilia A carriers (affecting females only) and Von Willebrand's Disease (affecting both males and females).

Differentiation of these three disorders can be accomplished by measuring different entities of the factor VII molecule. In its simplest form the molecule can be depicted thus:

High Molecular Weight (H.M.W.)

Low Molecular Weight (L.M.W.)

The component concerned with clotting and which can be assayed biologically is the LMW portion of the molecule known as VIII:C, the end point of the assay being a clot. In order to measure the factor VIII RAG component an immunological technique is employed. This method is based on an antibody/antigen reaction which is demonstrable after staining. All of which simply means that an antibody which specifically reacts with factor VIII is incorporated into a gel. After applying plasma from patients and controls to one end, an electric current is passed through the gel for a set time. After staining the gel the movement of the plasma through the gel becomes apparent. The distance travelled can be converted into the amount of VIII RAG present. The technique is known as Laurell Rocket Immunoelectrophoresis. Measurement of VIII RAG is particularly useful in assessing carrier status. In normal males and normal females an equal relationship between factor VIII RAG and factor VIII:C exists, in Haemophilia A males the VIII RAG remains normal despite the VIII:C being depressed or completely absent. Female carriers of Haemophilia A have a lower than normal VIII:C, but a normal VIII RAG. If a ratio is expressed of

$$\frac{\text{VIII:C}}{\text{VIII RAG}}$$

84% of carriers are found to have a ratio of 0.7 or less. Because of the lack of 100% certainty one can **never** tell a lady she is **not** a carrier.

Patients with von Willebrand's Disease may be found to have depressed VIII RAG and VIIIC levels but still in a 1:1 ratio. The measurement of another part of the VIII molecule, VIII RWF, will always show lower than normal levels in von Willebrand's Disease whereas the level will be normal in Haemophilia A and in carriers of Haemophilia. In the case of male patients with sex-linked recessive disorder associated with a deficiency or absence of factor VIIIC the role of the laboratory can be considered in two parts:

1. the monitoring of the in vivo response to replacement therapy and,
2. the detection of resistance to the infused product, i.e. the development of inhibitors or antibodies to factor VIII.

Obviously the target level of circulating factor VIII depends upon the procedure being undertaken, but a minimum haemostatic level must be maintained.

Usually the first indication of the presence of an antibody is the lack of response to an infusion of factor VIII. With the post operative in-patient this will become apparent more quickly than with the out-patient, since assays will have been performed regularly to assess haemostatic status. With out-patients on a home therapy or prophylactic programme an antibody screening test can be performed at regular intervals in order to detect the presence of an inhibitor induced by infusion of factor VIII. This can be carried out at three monthly intervals or when replenishment of supplies is necessary, whichever is the sooner. Antibodies appear to be produced by 12% of all Haemophilia A patients regardless of severity, but are not linked with either the frequency or amount of the infusion. The presence of an antibody does not prevent treatment being given, but obviously presents difficulties in treatment. Neither will the presence of an antibody debar a patient from being placed on a home therapy or prophylactic programme. The laboratory is simply a means of early detection, **not** a deterrent to treatment.

The organisation of a Haemophilia Centre depends upon team work, and laboratory staff are an essential part of that team.

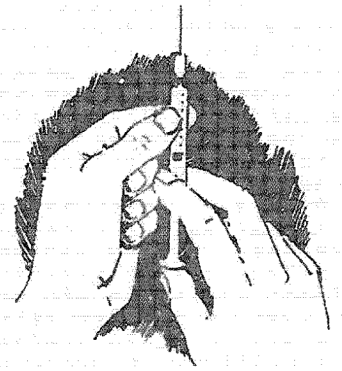
THE DOSE OF FACTOR VIII IN THE TREATMENT OF HAEMOPHILIA A

by Dr. A. Aronstam, Director, Treloar Haemophilia Centre, Lord Mayor Treloar Hospital

Factor VIII is expensive and is a finite resource, certainly in Britain. There are very serious constraints on financing of our treatment programmes and a constant pressure to reduce the amount of factor VIII given. At the same time we should all be aware of the crippling consequences of under-treatment. Our approach to resolving these conflicting pressures has been to try to find the right dose of factor VIII in various clinical situations.

Introduction

The Lord Mayor Treloar College is a boarding school which normally has about 50 severely affected adolescent haemophiliacs. These boys are all treated on the College site which means that we can review the progress of bleeding episodes at 8 to 12 hourly intervals until complete resolution and thus gain an almost unique insight into the behaviour of bleeding episodes. It had for a long time been our practice to treat all haemarthroses with what we called a 20% dose and all muscles with what we called a 30% dose. I will come back to these definitions later. We had not been doing this regular monitoring for very long before we realised that different types of haemorrhages in different situations responded differently to the same dose of factor VIII.



Factors affecting response to factor VIII infusions

The actual dose given or the recovery of that dose in the plasma after infusion can vary. The access to the bleeding site of the delivered factor VIII might also vary, because of the varying vasculature supplying the different sites and the degree of synovial hyperaemia. The size of the haemorrhage needing to be stopped would limit the effect of smaller doses of factor VIII and there are diverse factors which would influence this such as the size of the joint space available which in turn might vary with anatomical variations in different joints or with the degree of fibrosis in similar joints. The size of the joint space itself is likely to limit the time taken until presentation. Finally, delay in treatment would affect the size of the haemorrhage in different situations.

THE SEARCH FOR THE CORRECT DOSE OF FACTOR VIII

The retrospective survey

The first step was to find out how our haemophiliacs were behaving on their standard universal doses of factor VIII. To do this we examined all our records from 1973 to 1977 and extracted details of around 5,500 bleeding episodes. We wanted to know where the bleeds were occurring and what we learnt was that haemorrhages into the arms and legs accounts for 90% of all our bleeding episodes and 60% of all haemorrhages are into the knees, elbows and ankles. So it became apparent that if we could sort out the ways of treating these major joints we could have beaten a major component of the problem.

The next intriguing factor which turned up was that elbow incidents were the most frequent in our series and I have not been able to find a record of any other survey which agrees with this. It seemed reasonable to suppose that this discrepancy was in some way related to the age of our haemophiliac population, and when we broke down the bleeding incidence by age we found something very interesting. Until the age of 14 the knee was indeed the commonest site of bleeding. However, the incidence declined steadily through adolescence from 28% of all bleeding incidents at age 10 to 18% of all bleeding incidents at age 16–17. By contrast haemorrhages into the elbow joint increased in frequency from 19% of all haemorrhages at age 10 to 27% of all haemorrhages at age 17. This pattern is similar for most upper and lower limb bleeding episodes, and a composite picture of bleeding into the lower limbs shows a decline from 60% to 39% of all episodes occurring into the legs from the age of 10–17. This is contrasted with a rise of bleeding episodes into the arm from 32% to 50% of all episodes. The message as we set out to find the correct dose was clear. Bleeding into the upper limb in early adolescence needs special care and one should be thinking of higher rather than lower doses for bleeding episodes in early adolescence in this situation, particularly the elbow.

One other effect of age which may have some bearing was the number of transfusions given per episode in various age groups. If we take this as an index of severity, then it is clear that the severity of bleeding increases in early adolescence and peaks at age 14–15 and drops off presumably as the excesses of adolescence become tempered with greater responsibility – another reason for higher rather than lower doses in early adolescence.

We then looked at transfusion requirements for bleeding episodes at the various sites and found other pointers to high risk areas. Bleeding into the illipsoas muscle, retroperitoneally, into the abdominal wall, buttock, thigh and calf was the most troublesome, and needed most retransfusions. These high risk sites are obvious candidates for higher initial doses of factor VIII.

The recovery of transfused factor VIII

It is now necessary to establish what we mean when describing a given dose. The two most common ways of describing a dose are in terms of either units/kg or by predicting the post/transfusion rise of factor VIII in terms of percentage of average normal. Thus it is common practice to talk about a dose of 10 units/kg producing a 20% rise, and

allowing the two terms to become interchangeable. But there are claims that the response in children is poorer than in adults. If these are right, then the change over from the paediatric to the adult type of response is likely to take place during adolescence and we have looked at the responses on 69 occasions over the past year in adolescence. We express the response as the percentage rise per unit of factor VIII administered. Thus if one unit/kg induces a rise of 2% our response is 2, but if it only produces a rise of 1.5% then we call our response 1.5. Our results show clearly that while there is considerable overlap nevertheless a response of 2 only starts to become the norm once you get over a surface area of 1.7 sq. metres or weight of 60 kg. In our practice we now assign a response rate of 1.5% per unit of factor VIII/kg if the surface area is under 1.7 and of 2% if over. It follows that to talk of the dose per kg does not mean very much on its own and we find it more logical to express the doses used in terms of the percentage rise we expected to achieve.

The prospective dose trial

Now I would like to tell you about our prospective study of three dosage regimes in treating bleeding episodes into three major joints – knee, ankle and elbow. In this trial we studied 339 consecutive bleeding episodes in these joints. Each episode was assessed medically and graded 1 or 2 according to the amount of joint limitation. If more than 50% of the baseline movement was still present we called it a grade 1 and if less than 50% of baseline movement was present we called it a grade 2. For ethical reasons we excluded bleeding episodes where there was no movement at all as we did not think it right to treat these bleeding episodes with the lowest dose. We also excluded possible episodes when there was no movement limitation at all. In the first place we were never sure if the patient was bleeding in this situation and secondly we would have had no objective way of measuring response. In fact these two excluded categories accounted for less than 10% of the episodes which presented consecutively.

The graded patients were then passed on to nursing staff who opened a previously randomized envelope which indicated a 10, 20 or 40% dose. Nursing staff administered the dose and medical staff assessed the joints at 12 hourly intervals unaware of the initial dose. We noted the time taken for complete resolution of tenderness and restoration of function and the percentage of cases which required retransfusion. Now I would like to discuss the effect of various factors on the progress of some of these haemorrhages on different dose regimes. If we group all the episodes together, there appears to be no difference in response to any of the three dosage regimes. This supports the approach of some recent trials looking at the effect of low dose regimes on all bleeding episodes. I hope to convince you that this is a fallacious approach. We grouped together all the grade 1 bleeds, that is those who still had more than 50% of baseline movement at presentation: this group shows no difference between the various dose regimes but when we looked at the grade 2, more severe bleeds, we found that lowering the dose appeared to affect the result in terms of time taken for movement restriction to disappear, so that using our criterion of movement limitation as an index of severity, it is obviously not a good idea to lower the dose for the more severe episodes. There was just a suggestion here that raising the dose above the 20% level improved matters for this broad group of bleeding episodes.

We next looked at the underlying state of the joint to see if this had any bearing on the response to the three dose regimes. We looked at joints which had baseline restriction of movement assuming that these had had previous joint damage. A bleeding frequency of more than one a month during the study was assumed to indicate active joint problems. We designated these joints target joints. The 339 bleeding episodes were distributed approximately equally into target joints, restricted joints, joints that were both and joints that were neither. These were termed 'normal' joints for the purpose of the study.

We found no difference between the three dosage regimes for normal joints with grade 1 bleeds. The more severe grade 2 episodes showed a dose related difference in favour of the highest dose. The milder target joint episodes appeared to show a disadvantage when lower doses of factor VIII were given. This was not apparent when we looked at the more severe grade 2 episodes. Bleeding into joints that are restricted but not target joints appeared to respond just as well whether mild or more severe. When a restricted joint becomes a target joint, however, this low dose regime was much worse when the haemorrhage was mild and positively disastrous in the more severe episodes. There is a clear indication that when bleeding frequency in a previoysly damaged joint increases, low dose regimes should be abandoned.

Now let us look at the specific sites. Bleeding into the knee joint responded worst at low dose if mild and very much worse if severe. The elbow joint appeared to benefit from a high dose if mild and did very badly on a low dose if bleeding was more severe. Combining these results with our experience of increasing frequency of bleeding into the elbow joint through adolescence we now believe it is quite wrong to lower the dose for any bleeding episode in the elbow joint. Ankle joints, however, appeared to do well with a low dose whatever the severity of bleeding, mild or severe.

Lower doses for ankle joints

Following this trial we halved our standard dose for bleeding into the ankle, giving a 10% dose for all episodes provided the joint was not frozen and was not a target joint. After about six months when results of another study which I will describe shortly became available, we began to exclude those bleeding episodes presenting with what we call the high risk factors, that is pain, tenderness and more than 50% limitation of movement. We ended up with 95 ankle episodes which had been treated with a mean of 7.46 units of factor VIII per kg and needed to retransfuse only 10 of them, that is 10.5%. During the same period we treated 106 ankle haemorrhages with a mean of 13.93 units per kg and needed to retransfuse 24 of them, 22.6%, so it looked as though our selection for low dose was right. The average weight of our boys is about 45 kg so that a saving of 7 units per kg in 95 bleeding episodes had conserved about 30,000 units of factor VIII in a year. This is not an awful lot but potentially a significant saving if repeated nationally and internationally.

The high risk bleeds

Next we turned our attention to elbow and knee haemorrhages which failed to respond to our standard treatment, judged by the need to retransfuse within 48 hours. Our criteria for retransfusion are currently a worsening situation at 8–12 hours and poor progress after 24 hours. The implication is that blood has persisted in the joint, setting it up for synovial inflammation, hyperaemia, recurrent bleeding and ultimate progression to crippling arthropathy. It seems important to try and prevent this situation and if we can identify the episodes likely to do badly it is possible that the selective application of high initial doses of factor VIII might improve response and retard the progression of arthropathy, without causing too much of a drain on our limited resources.

The elbow joint suffers an increasing incidence of bleeding through adolescence and thus seemed a reasonable starting point. We reviewed the records of 144 consecutive elbow haemorrhages which had been treated with a 20% dose and found that 31 or 21.5% had been retransfused within 48 hours. We termed these episodes failures.

A history of trauma was elicited in 21% of the successes and 23% of the failures, and therefore did not affect the outcome. We then reviewed the underlying state of the joints and found no significant difference whether the joint was restricted, target, both or neither. One interesting feature was that 62% of successfully treated haemorrhages were into target joints but only 42% of failed episodes were into such joints.

Looking at the main presenting symptoms we saw that presentation with what is called 'stiffness' alone is a highly significant pointer to a successful outcome while pain alone is more likely to signal a failed outcome. When the two symptoms coexist no inference can be made.

We then looked at the physical signs in the two groups and found that 30% of the successfully treated bleeding episodes presented with tenderness but 77% of the failed episodes did so. This difference is highly significant. The other significant

sign is the loss of more than 50% of the baseline range of movement.

Finally, we examined the time taken from the onset of symptoms till treatment was administered, and found no significant difference up to three hours. Episodes treated after three hours formed a significantly higher percentage of failures than of the successes. I must stress that this finding does not imply that any delay is safe, merely that a delay of more than three hours makes matters much worse.

The risk factors for elbow haemorrhages are thus pain, tenderness, the loss of more than 50% of baseline of movement and probably a delay of more than three hours from the onset of symptoms. The more the number of risk factors at presentation the higher the likelihood of failure and as much as 62% of episodes presenting with 3 of the 4 risk factors required retransfusion. Only 3 episodes presented with all 4 risk factors so not much can be gleaned from that result. In fact we found that 40% of all haemorrhages into the elbow joint which presented with 2 or more of the risk factors needed retransfusion, and this group should provide a fruitful field for studying the effect of higher initial doses of factor VIII.

We have done a similar survey on 137 haemorrhages into the knee joint which had been treated with a 20% dose and found that we needed to retransfuse 32 or 23%. Trauma again had no bearing on the outcome and neither did the underlying state of the joint. Target joints again formed a higher percentage of successful incidents than of failed incidents. Pain was again a pointer of failure as was tenderness and the loss of more than 50% of movement. Delay of treatment up to three hours did not influence the outcome of treatment and as only 3 bleeding episodes were treated more than three hours after the commencement of symptoms we were unable to draw any conclusions about this delay. The risk factors for bleeding into the knee are therefore pain, tenderness and restriction of movement beyond 50% of baseline. We saw again the rising proportion of failed bleeds which went with increasing numbers of risk factors at presentation and found that 40% of the episodes associated with 2 of the 3 risk parameters needed retransfusion. Another fertile field for the study of higher initial doses.

We are at present conducting a double-blind controlled trial of the effects of a 20 or a 40% dose of factor VIII for bleeding episodes into the knees, elbows and ankles of our patients who present with two out of the four risk factors – pain, tenderness, loss of more than 50% of movement or a delay of more than three hours from the onset of symptoms, but the numbers entered so far are too small to report. If, however, this trial works out, and we can reduce the number of protracted bleeding episodes into major joints I believe we will have gone some way to arresting the ever present problem of progressive arthropathy.

THE HAEMOPHILIA NURSES' ASSOCIATION

Sister Maureen Fearns

Sister Maureen Fearns

As I embark upon this talk about the Haemophilia Nurses' Association I know that most of you will never have heard of it. This is because it only became official yesterday, Friday 13 March. You may also ask yourself 'Why do nurses need an association?' In the following ten minutes I shall attempt to answer that question for you.

During the last ten years the role of the nurse has expanded as legislation in the nursing profession in general has changed. In particular the haemophilia nurse has a very different and specialised role to play as part of a team caring for haemophiliacs.

Many disciplines must join together to care for haemophiliacs. If all of these people, including the haemophiliac, work together then you have what is known as 'team care'. Those of you who have haemophilia, or are part of a haemophiliac's family or circle of friends, possibly have a greater understanding, in a broad sense, than any individual professional involved in your care will ever have. However, each person in a haemophilia team contributes their own special skills, which no other member of that team could provide. In latter years many associations and societies have been set up for the patient, the doctor and the social worker. Although all of these can help to teach the nurse many aspects of care, we feel that none can teach her specific nursing skills or fully define her role in team care.

The role of the haemophilia nurse has been created, in practice, by those of us who took it upon ourselves to become a Sister, or nurse, in charge of a Haemophilia Centre. When our patients see us carry out treatment, or training for home therapy, hopefully with great confidence, they may not have realised the nervous apprehension often felt by 'the efficient lady in the starched uniform'. Those of you trained in home therapy can take consolation when I liken the nurses' feelings to your initial fear of having to go off and do it all yourself. In the past nurses have not been taught about haemophilia except for very superficial lectures during nursing training. Suddenly we were faced with many new practices which were completely foreign to our prior knowledge of the disorder. There were no special training courses available, so how could we learn new ways of working? Until now, much of our knowledge has been gained from the haemophiliac and his relatives and, occasionally, via another nurse already practising in a haemophilia centre. The Haemophilia Centre Directors have been our greatest, professional source of information without which we could not have functioned. However, the Directors themselves recognise that often their information has been extremely technical and so there remains a need for more basic information. This, we feel, will best come from those nurses already established in Haemophilia Centres. The difficulty has been how to exchange information and gather together as a group.

In 1976, 1978 and 1980 we were fortunate to be given financial support, by drug companies, to hold a Haemophilia Nurses' Conference. At these conferences, nurses met each other and exchanged ideas for the first time. We were given the opportunity to hear some eminent doctors speak on many aspects of haemophilia care. Although we all appreciated these symposia, we felt there were still some missing links in the chain.

Trish Turk and I realised our good fortune in working at very good Centres, which are well organised, offer good services and excellent medical care to the patients. As we have been established in our jobs for several years, we felt an obligation to pass on our knowledge to other, less fortunate, nurses. (*How I would have welcomed the opportunity to learn from others! The logistics involved in our job are extremely difficult and I cringe at the thought of how naive I was when I began working in a Centre*). We decided that, this year, we must take some positive steps to form an association through which we could tackle specific problems. Hence the creation of our Haemophilia Nurses' Association of which I will be Chairman and Trish Turk will be Secretary and Treasurer.

The Haemophilia Nurses' Association has obtained official recognition from Professor Bloom, who is chairman of the Haemophilia Centre Directors, and the Haemophilia Society has agreed to take us under its umbrella. The drug companies

have also offered to help us fulfil our aims which are, initially, as follows:

1. To produce an annual newsletter and bibliography of up-to-date literature.
2. To hold biennial symposia with guest speakers who will keep us informed of new developments in the management of haemophilia.
3. To provide a basic observation and/or training period in an established centre for those nurses embarking upon a career as a haemophilia nurse.
4. To tie in and communicate with the International Nurses Committee which will be established this year.

The initial aims are of limited but great importance, as we believe that a well informed nurse can offer much to improve the running of a Centre, which will ultimately benefit the haemophiliac and his family. Eventually we hope to link with other, already established, societies and associations. I hope today will be the beginning of that link.

RELATIONS WITH B.A.S.W. AND THE HAEMOPHILIA SPECIAL INTEREST GROUP

Elizabeth Wincott, Principal Officer Health Services, Lothian Regional Council

I am going to talk about the position of social workers in Haemophilia Centres, how they fit in to social work structures. The needs experienced by these social workers and the potential links with B.A.S.W. I shall trace the development of the Haemophilia Special Interest Group and look to its future. I shall not however be specifically talking about the role of social work with Haemophiliacs and their families since this is a huge topic which merits a paper of its own.

The Local Authorities are the principal employers of Social Workers based in Area or Community-based teams and in Hospitals as well as some other specialised settings. Prior to Local Government Re-organisation, hospital based Social Workers were employed by individual hospital management committees but at Regionalisation in the mid 70's Local Authority Departments took over the employment of hospital based Social Workers.

There are few, if any, Social Workers within the U.K. who work exclusively in Haemophilia Centres. The assignment to work in a Haemophilia Centre is usually a part of a wider area of responsibility. Commonly Social Workers in Haemophilia Programmes cover the whole of Haematology but they could cover other services as well. Taking the example of Haematology the hospital Social Worker therefore works with Leukaemics and their families and very often there will be great pressure on the Social Worker to spend much of their time working in this area. The Social Worker therefore needs to be able to make a balance between the many demands on his or her time, and sometimes this presents a considerable conflict.

The Social Worker in the Haemophilia Centre is almost invariably the only Social Worker in that area or region who has a knowledge of and commitment to Haemophilia. This, it will be appreciated, can be a rather isolated position.

It is therefore very important that mutual support links and an opportunity to exchange ideas are available not only between the Social Worker and the other Haemophilia Centre staff but also the local branch of the Haemophilia Society and the central Haemophilia Society personnel. As with the Haemophilia Nurses Association, the Social Worker is unlikely to have received any specific training in working with Haemophilia or indeed with other chronic genetic disorders. They need to learn "on the job". They also need to be able to describe clearly to those who employ them what tasks they undertake and if necessary, be able to make a clear case for being able to spend more time in working with the Haemophilics and their families in the Haemophilia Centre.

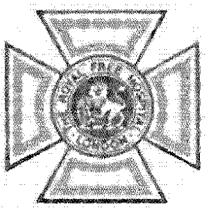
There are therefore areas of isolation and gaps which it is important to try to help the Social Worker fill. These gaps clearly began to be met by the Seminars offered by Vicki Stopford whom most of you knew as the Research Social Worker to the Society. The focus was on non-medical psychological and social issues in relation to Haemophilia care. Their popularity in itself demonstrated the need they were beginning to meet. It was encouraging to note that they were attended not only by Social Workers but also by many other Haemophilia care staff.

B.A.S.W. is the professional organisation in Great Britain for Social Workers. It is able to offer professional guidance and support through its own central organisation and local branches. Two journals are published in association with B.A.S.W. One is the weekly journal "Social Work Today" the other is the quarterly "British Journal of Social Work" which publishes more academic and theoretical articles. The weekly journal "Social Work Today" is a useful vehicle for publicising activities of Social Workers and also is a source for disseminating further information. As I mentioned earlier there is a need for a two way flow in mutual support. Not only can B.A.S.W. offer support to Social Workers but Social Workers in Haemophilia programmes need to describe clearly the role they feel they undertake in their Centres. Bearing in mind the perspectives of the two organisations, B.A.S.W. and the Haemophilia Society, it was felt that it would be potentially of great value to establish a Special Interest Group principally for Social Workers working with Haemophilia and other related Haemostatic disorders. For the past two years discussions have taken place with Senior Staff at B.A.S.W. and the Haemophilia Society. We have been very fortunate to build on a knowledge base and links already created and developed by Vicki Stopford.

In September 1980 the Special Interest Group for Haemophilia and related Haemostatic disorders was formally recognised by B.A.S.W. By this time the Haemophilia Society had also given its blessing and a commitment for support. So far as I know this is the first time that B.A.S.W. as a professional organisation have co-operated with a voluntary agency in forming a Special Interest Group. I think we all welcome this as a very constructive step forward.

A feature of the Special Interest Group is that while it has been formed principally for Social Workers to help them improve their ability to support and work with Haemophilics and their families, it is essentially multi-discipline. We also have Haemophilia Society members which we greatly welcome. There are a substantial number of Centre Directors who have become members and our membership list now stands at about 30, over half of these being Social Workers.

The Committee is currently chaired by Vicki Stopford and on the Committee there are members of the Haemophilia Society, a Nurse and Social Workers. We are delighted to have this broad based representation. Following an initial discussion to explore the development of the Special Interest Group in Birmingham in November 1979 and a meeting of the Committee in April 1980 we had the first formal meeting of the Special Interest Group at the Royal Free Hospital in



December 1980. About 50 people attended this meeting and the topic was genetic counselling. A variety of papers were presented followed by a series of small discussion groups which then fed back to the main meeting. The consensus of opinion was that it had been a most useful meeting.

Currently we have decided to hold two meetings per year, each in association with a Committee Meeting and one of those in association with an A.G.M. The next Study Day and Committee Meeting will be held at the Manchester Royal Infirmary on Thursday May 7th when the topic will be "Entitlement to Benefit – the role of the Centre and the Social Worker". There will then be several discussion groups in this area. In addition there will be a discussion group following up the topic of Genetic Counselling examined at the first meeting.

The Special Interest Group hopes to publish a Newsletter twice a year probably coming out prior to each meeting. The first full Newsletter is in draft form and should be going out by April this year.

Already some unanticipated positive spin-offs have occurred and I should like to mention just one. A person associated with Huntington's Chorea attended the first Special Interest Group meeting and since attending that meeting she was so impressed by the potential of Special Interest Groups that she has now approached us as she wishes to set up a Special Interest Group for those working with Huntington's Chorea.

In terms of the future we need to explore and develop ways in which B.A.S.W. and the Haemophilia Society through the Special Interest Group can develop working together and offer constructive support to the members of the two organisations. Already this appears to be happening. B.A.S.W. holds two annual study conferences. There is one due in September, the title of which is "Collaboration in Caring". The Special Interest Group has been asked to provide a speaker to talk about the role and development of the Special Interest Group and I am glad to report that we have suggested that Vicki Stopford undertakes this.

THE ROLE OF GROUPS

GRO-A

GRO-A

Mr. GRO-A

1. Introduction

In attempting to articulate the role of the Groups in relation to the policies, aims and objectives of The Haemophilia Society, it would be naive of me to believe that we in Northern Ireland Group, have any special understanding of what that role should be.

It is my intention, therefore, to present to you our interpretation of the Role of the Group as we have come to understand it, and to illustrate some general aspects of our activities in support of that understanding.

2. Group Geography and Committee Structures

Before discussing the Group's role and support activities it may be useful for some to be reminded of the catchment area and organisation involving the Group.

2.1 *Geography*

The Group's area of responsibility covers the whole of Northern Ireland and whilst few will need reminding of the precise location of Northern Ireland, the essential Geography of the Province is shown in ***Figure 1*** attached.

The main centre is designated a Haemophilia Reference centre and is located at the Royal Victoria Hospital, Belfast. Associate centres where in/out patient emergency treatment is available, are located mainly at Londonderry in the North, and Craigavon in the South.

The Group is involved with approximately 130 families covering Haemophilia A, B and von Willebrand's disease, and hence may be considered among the larger Groups within the Society.

2.2 *Group Committee Structure*

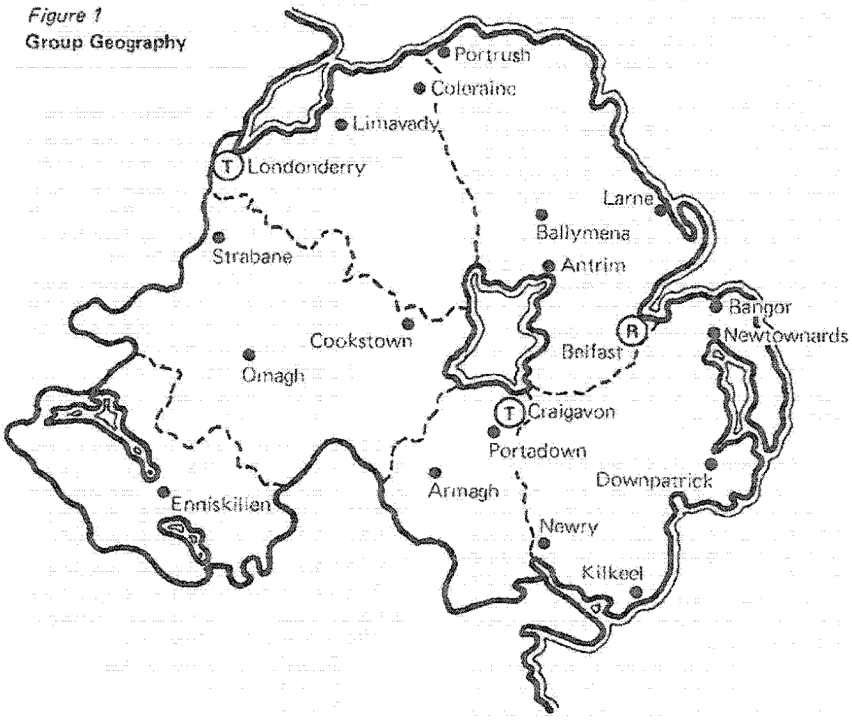
The structure of the Group committee and organisation is shown in ***Figure 2*** attached.

The Committee of 13 elected members themselves in turn elect the office bearers (3) as designated, viz:— Chairperson, Honorary Secretary and Honorary Treasurer. The Committee is served by a part time Administrative Assistant (salaried) and a Voluntary Magazine editor from among the general membership. Further support for the Committee is acknowledged by the existence of Area Volunteer Organisers in most of the main centres of population throughout the Province, and as shown on map at Figure 1. This arrangement is very effective in relieving the burden of mobilising local support for events/collections etc. from the main committee, by focusing public attention at a local interest level.

The Haemophilia Centre Director sits on the Committee as Medical Advisor. The Centre's Medical Social Worker also attends the Committee by request or as necessary.

A member of the Committee is nominated to represent the Group's and hence the Society's interest on the Northern Ireland Committee for the Handicapped (NICH) which represents the interest of all voluntary organisations throughout the Province, via the Council for Social Service.

Figure 1
Group Geography



NORTHERN IRELAND GROUP

® Haemophilia Reference Centre, Royal Victoria Hospital, Belfast

Ⓣ Haemophilia Treatment Centres:
Altnagelvin Hospital, Londonderry
Area Hospital, Craigavon

Haemophilia Centre Director: Dr. E. E. Mayne.

● Main towns and cities

No. of families: 130 (all categories)

The Committee meets monthly, usually in Belfast although several meetings per year are held in provincial locations to encourage member participation.

The Group's Annual General Meeting has become something of an event with creche facilities, guest speakers from all parts of the UK and even Father Christmas, to ensure a good turn-out of members. Usual attendance at the AGM is between 80 – 110 people – a good proportion of our membership.

3. The Role of the Group

Within the aims, objectives and policies of the Haemophilia Society, we see our Group role as being essentially ***supportive*** of the Society function. This supportive role can be articulated at Group level at 4 different interfaces each requiring its own response to particular requirements.

These interfaces may be defined as follows: –

(a) The Parent Society interface.

(b) The Haemophilia Centre interface.

(c) The Haemophiliac and Family interface.

(d) The General Environment interface.

3.1 *The Parent Society Interface*

The supportive aspect of the Group's role on this interface is seen as being primarily financial in nature. Since the main on-going benefits to the Haemophiliac, in the immediate future at least, will stem from the positive results of research and development into treatment philosophies and materials availability, it is essential that such research programmes are adequately supported by Society funding.

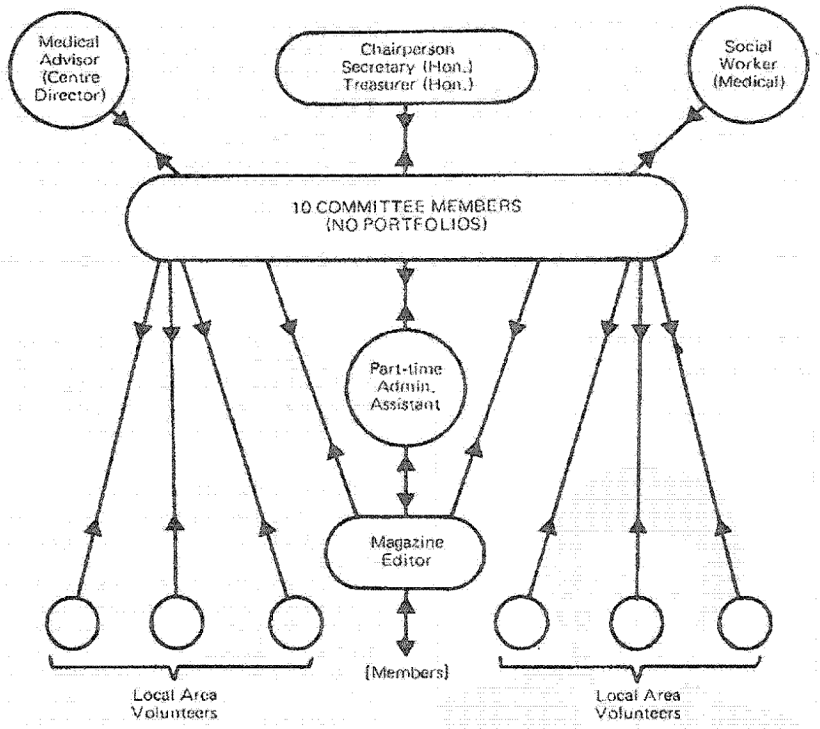
Generally, the extent of funding required for research project support is beyond the resources of any individual group, and hence the need to subscribe such funds centrally to ensure proper and adequate control and support.

Implicit in this aspect of role is the Group's requirement to receive and disseminate information to members arising from the central application and control of subscribed funds and in addition, the news, activities and views of other Groups, Society and outside agencies, in all matters relating to the welfare of Haemophiliacs and their families.

3.2 *The Haemophilia Centre Interface*

Whilst it should be the Society's concern to strive to ensure the adequate and equitable availability of treatment and care for Haemophilia patients throughout the UK, we feel that the Group can have a significant part to play in transforming an adequate, or sufficient, centre into a good one.

Again the implications in this aspect of role may be predominantly financial to the extent that such extensions to the Centre's capability by way of laboratory equipment, clinical research support and patient education, comfort and care, as are not supplied from the public purse, should become the responsibility of the Group to secure.



GROUP COMMITTEE STRUCTURES *Figure 2*

Main Committee Location: Dept. of Haematology, Royal Victoria Hospital

Frequency of Meetings: Monthly.

Meetings Location: Royal Victoria Hospital, Belfast
+ 4 other locations throughout year.

News Magazine: CLOTT – quarterly, free to members.

Associations:
1. The Haemophilia Society
2. Northern Ireland Committee for the Handicapped

3.3 *The Haemophiliac Patient Interface*

The supportive role on this interface is satisfied by ensuring, as far as is practical,

(i) the availability of adequate information about the disease, its treatment and its implications, to the patient and his family

(ii) the availability of equitable social, educational and occupational opportunity for the Haemophiliac within the community

(iii) access to adequate and sufficient welfare entitlement and support where necessary

in addition to providing the opportunity to promote the ***fellowship*** required amongst sufferers and their families and friends, by organising meetings, discussion groups and social gatherings as required.

3.4 *The General Environment Interface*

The role of the Group on this interface can be considered largely one of education.

This includes the education of,

Social/Community Workers
Educationalists
Employers
The General Public

into the needs, aspirations and limitations of Haemophiliacs in all aspects of activity in order that he may make a full and meaningful contribution to the community in which he lives.

4. Financial Aspects Implicit in the Group's Role

In attempting to satisfy several aspects of the Group's supportive role, the need for the Group to raise funds and to expend funds as required becomes obvious.

The Group's success in raising adequate funds will depend on a number of factors, including,

(i) The size and extent of the area covered by the Group.

(ii) The enthusiasm and commitment of the Committee and supporters.

(iii) The flair and imagination put into fund raising schemes.

(iv) The extent to which your cause is known and publicised.

As an aid in identifying likely sources of income and hence those areas into which a Group may wish to concentrate limited fund raising resources, the following analysis of where the Northern Ireland Group's income came from over the period 1976–1980 may be of interest.

The Group's year by year income and expenditure is shown in ***Figure 3*** attached.

4.1 *Analysis of Income Sources 1976–1980*

A statistically weighted analysis of income over the period October 1975 – September 1980 is shown diagrammatically in ***Figure 4*** attached.

As can be seen, some 43% of the Group's income derived from private and institutional donations, 37% from flag days/street collections and the remaining 20% from organised events and activities.

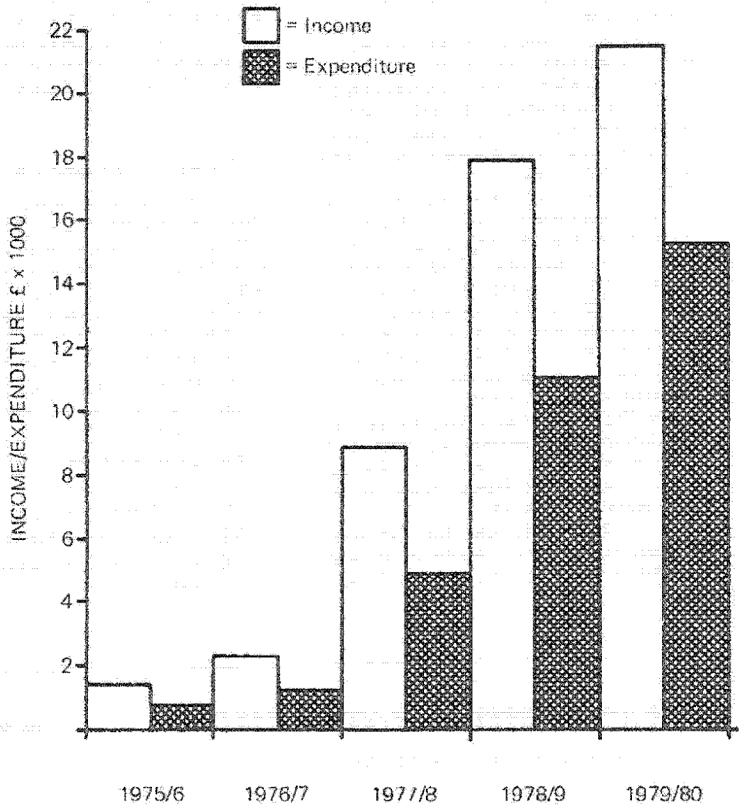
Thus slightly less than half of our income over the period has relied on the response of individuals and organisations to direct appeals for funds thus indicating the importance of continuous publicity and exposure of the Society and its aims. In some cases, underlining an appeal for funds for a local need is necessary, since some firms and institutions insist that such donations be so used. This is entirely acceptable since this would help satisfy the financial support on the Centre's interface to the Group and release other funds to support the Parent Society requirements.

Flag days and street collections are organised throughout the year and yield some 37% of income on average, over the period. Whilst this form of fund raising can be demanding in terms of manpower, local schools and colleges can be canvassed for pupil support usually with some success and especially at weekends.

The return obtained from the investment of time and bodies in organising events should not be too readily dismissed, although generally it can be quite modest. Some projects however can return large amounts of money for a minimal investment of time and organisation by the Group committee, as the 'SNOWBALL LUNCHES' event by the Scottish Group shows.

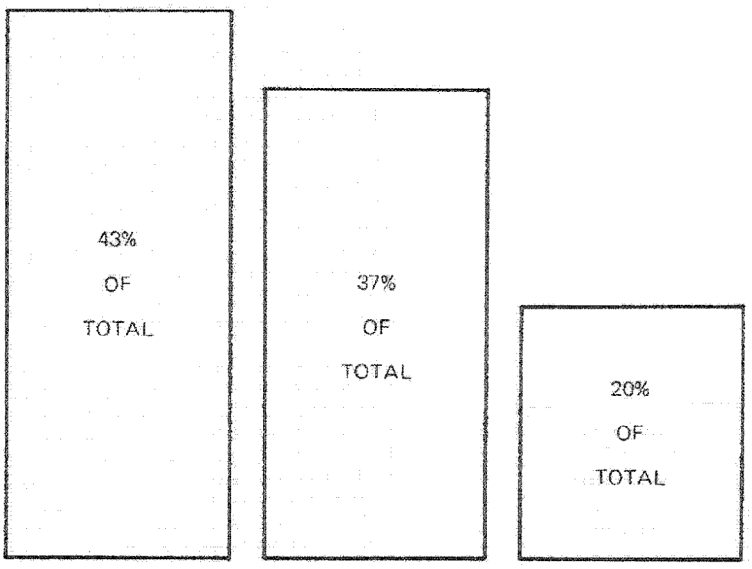
It is important to encourage friends and supporters to organise events on your behalf and it may even be necessary to underwrite certain costs, such as hiring of rooms etc., to enjoy some very good returns for little direct involvement.

INCOME/EXPENDITURE CURVES *Figure 3*



GROUP'S NET INCOME CLASSIFICATION 1976/80 *Figure 4*

TOTAL INCOME = £35,250.00



Donations
(i) Private
(ii) Institutional

Collections
(i) Street (Flag Days)
(ii) Door-to-Door

Activities
(i) Garden Fetes
(ii) Fashion Shows
(iii) Social Events

4.2 *Analysis of Expenditure 1976–1980*

An analysis of the Group's expenditure over the period is shown in *Figure 5* attached.

Consistent perhaps with the priorities set out in 3 above in defining the support roles of the Group, it can be seen that some 54% of expenditure was directed to the Parent Society to support both research projects and other Society Activity.

The relatively significant Admin costs at some 16% of expenditure were distorted by the employment of a salaried fund raiser for a period when the Group organisers were over committed with special appeals and events programmes. This situation was terminated at the beginning of 1980 and our experience in this area was not such that we could recommend it to others. However, making necessary allowances, the true admin costs are reckoned at approximately 8–10% of expenditure over the period and such investment is considered worthwhile for the degree of "professionalism" such expenditure attaches to the Group's appeals literature and correspondence, and the extent to which such nugatory expenditure transforms an idea into a successful fund-raising event.

5. Communications

The supportive role of the Group towards the Haemophiliac and his family on the one hand, and the general environment on the other, is essentially about communications.

The Group therefore has a duty to ensure adequate and up to date information is available to all members on all aspects of treatment and welfare and to provide the necessary mechanisms where free and frank interchange of ideas and views can take place.

This duty is discharged by the Group in the maintenance of a library of literature and in the regular publication of the group magazine "CLOTT" free to all members. The magazine may be used as a two-way mechanism with the free access to members of articles, letters etc., for publication, and the imparting of information to the members from the Group or Society committees.

The Group also has a duty to educate and inform the welfare agencies and public at large into all aspects of Haemophilia – education needs, employment needs and limitations etc.

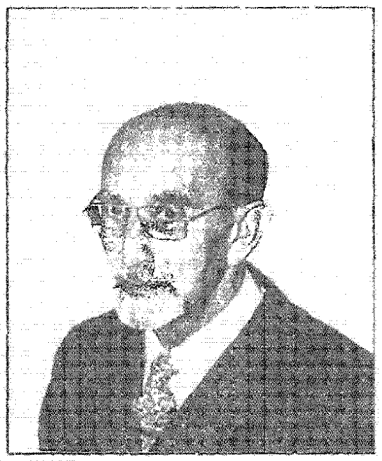
In satisfying this role, the Group is represented on the Northern Ireland Committee for the Handicapped and through them, the Council for Social Service, with free access for our literature and needs to the agencies and public via their official organs.

Additionally, the Group can act in support of families directly with schools, employers and social/community workers by supplying information as required and to meet local specific needs.

6. Future Plans/Aspirations

In articulating future plans for strengthening the supportive role of the Group, we are concerned to ensure the continuation of our modest success as suggested by the last 4 years activities and results. To this extent therefore, our short term fund-raising plans suggest more of the same as in the past and include

(i) Radio and TV appeals (April 1981)
(ii) Flag days/street collections (all year)
(iii) Sponsoring darts and other sporting/social events
(iv) Direct institutional appeals
(v) Snowball "Fork Supper" project
(vi) Dinner Dance/Cabaret (March 1981)



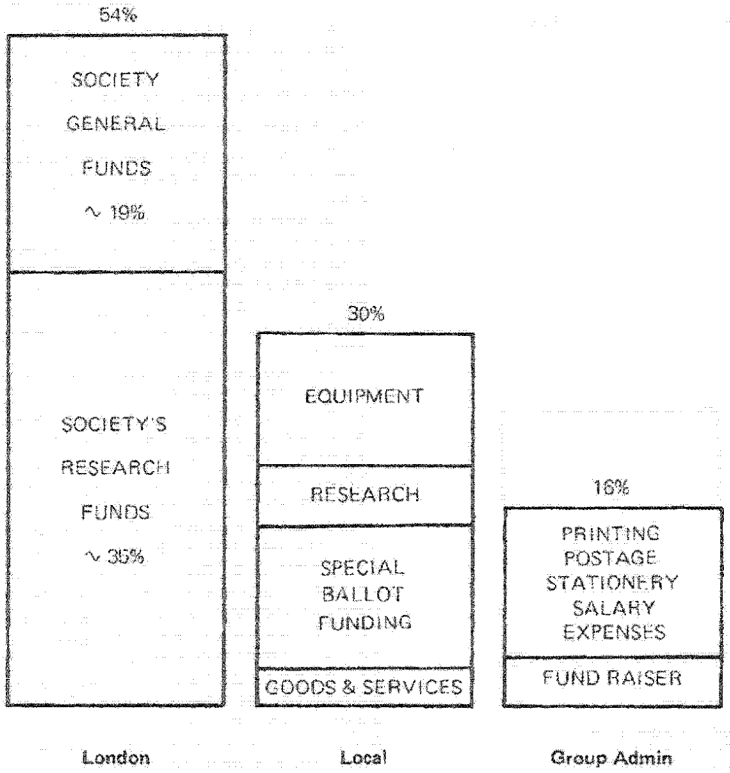
Dr. Ludwig Kuttner — Group Liaison Officer

The income generated by these events will be used, as always, to ensure the continued improvement in the well being of all Haemophiliacs, with emphasis on immediate areas as follows:—

Continued pledge to Research Appeal Fund, Establishment of Permanent Holiday Caravan facilities, Purchase and installation of VISCOMETER in Haematology Labs, Provision of Equipment and Services as required for centres.

GROUP'S NET EXPENDITURE CLASSIFICATION 76/80 *Figure 5*

TOTAL EXPENDITURE = £29,100.00



7. Concluding Remarks

In considering the future success of the Society as a whole, I feel that now may be the time to consolidate what has so far been a successful period of growth.

Whilst it is important, for any number of reasons, to allow a certain autonomy amongst the Groups in their activities within the areas of their interest, the Society should be looking to formalise the structural relationships with the Groups at Council level, by suggesting that Groups assign a permanent (2 years?) delegate to Council in addition to one floating member. This would ensure that some measure of continuity in representation is achieved from both a Society, and Group, point of view and would thus serve to ensure consistent and concerted action and interpretation of Society policy.

I thank you for having given me the opportunity to speak on this topic. If, in attempting to articulate what one may see as being the role of the Group within the Society, agreement can be reached in formalising such a role, then this exercise will have served its purpose and perhaps lead to a strengthening of the purpose and fellowship which unites us all.

THE WORLD FEDERATION OF HEMOPHILIA

D. Rosenblatt B.Sc.

For those of you who have little or no knowledge of the World Federation of Hemophilia, there will be many questions that you will want to have answered. This I shall attempt to do.

You may ask what need is there for WFH? The same question might be asked about the need for the national society when we have twenty-five or more local groups. The reasoning is that WFH deals with the same general aims and objects on an international scale as do WFH members within their own countries and individual groups locally. Through the global concept individuals benefit from the world operation. In reverse WFH benefits from the collective strength of numbers of members.

In a nutshell, WFH bears a similar relationship to national member organisations as our own Society relates to our Groups. The concept is rather like those Russian wooden dolls which fit one within the other. The first doll is the individual member – usually the haemophiliac himself – or one of his parents; the next is his local group; this, in turn, fits within the national society, which, again, is encompassed by WFH.

Mr. David Rosenblatt

The aims and objectives of WFH will illustrate what I mean –

Objective: The objective of the World Federation of Hemophilia is to assist haemophiliacs and persons with related disorders in every possible way, and to contribute by all means placed at its disposal, to the advancement of the scientific, technical, social and ethical problems related to such disorders.

Membership: There are 53 national member organisations from Algeria and the Arab Republic of Egypt down to Venezuela and Yugoslavia at the opposite end of the alphabet.

Status: WFH has official relations with the World Health Organisation and the International Society for Thrombosis and Haemostatis; is an Associate Member of Rehabilitation International; a Member of the Council of World Organisations Interested in the Handicapped and co-operates with the League of Red Cross Societies, International Society of Blood Transfusion and International Society of Haematology.

Activities: An important function of WFH is to provide the know-how that will assist in the formation of national member organisations. The knowledge and experience of others, gained by comparing methods, techniques and procedures, enable a haemophilia organisation to improve its services and to find solutions.

Congresses, symposia and workshops: There have been one or more meetings every year from 1963 to 1980. These meetings have been a major influence in clarifying the status of treatment and research. They also define the areas of neglect and accelerate the utilisation of existing knowledge.

There are other sub-organisations within the WFH framework –

a) There is the new Heidelberg (Germany) Clearing House for the collection of non-medical and para-medical information.

b) There is the European Advisory Board within the main international WFH.

c) WFH has a Medical Advisory Panel which enables top opinion to be expressed on any contentious matter.

d) One small example of WFH's work, yet of paramount importance, is the investigation into the cost, distribution and availability of concentrates throughout the world. This arises from the recent Bonn Conference, as a specific topic raised there.

e) WFH produces Bulletins several times a year.

You would probably have expected these sort of activities, even if you had not been given the detail before.

However trite and oft-repeated it may sound, we all know that the standing and value of an organisation depends on the people who make it up.

In this case, we think haemophiliacs are fortunate to have the dedicated services of its President, Frank Schnabel, who formed the Federation in 1963.

Mr. John Prothero
European Liaison Officer

Here is a man of immense individual talent, tremendous driving force, old enough to be badly disabled GRO-A GRO-A but nevertheless an inspiration to all who meet him.

Is it all worthwhile? Meetings are undoubtedly very expensive. Fares, hotel accommodation and hire of halls are costly. Medical experts might be better employed in their own countries, rather than chasing round continents. There is one expression which I have used previously in our own Bulletin and recently I have seen it in literature elsewhere. It is the "catalyst" effect in encouraging interchange of information between societies and doctors accelerating development of existing Societies and as an aid to forming new societies, as well as injecting new enthusiasms.

What has been achieved has already been set out and, for the future, slowly, but steadily, WFH will grow stronger until, paradoxically, WFH will attempt to become so effective that it is no longer needed. What are the dangers and problems?

The largest, as I see them, is the size of the organisation, the number of different parts and the spread across the world (which, of course, is also one of the strengths). Meetings, I feel, tend to be a little formal, somewhat ponderous and almost pompous in relation to the friendly nature of the participants. Let us not, however, fall into the trap of adopting a parochial attitude by thinking of ourselves alone.

Oddly enough, as in so many other similar instances, we can find that by setting out to help others less fortunate than ourselves, the abundant harvest of benefits is reaped by ourselves in disproportionate measure to our own efforts.

I hope I may have helped you understand a little more about the work of WFH.

THE AIMS AND OBJECTS OF THE HAEMOPHILIA SOCIETY

(Based on a talk by Ken Milne at the Society's Seminar held on 15th March, 1981)

Mr. Ken Milne

The aims and objects of the Society are set out in the Society's constitution. They are:—

(a) **To provide a fellowship for sufferers from Haemophilia and allied conditions, their families and those concerned with their health and welfare.**

This is, in my view, rightly given as the Society's first aim. The idea of fellowship and mutual support is fundamental to the Society and the way it operates. As a consequence, of course, a Group which is not successful in fund-raising, for example, need not be regarded as a failure. The only requirement of a Group is that it meets a local need for contact and support between haemophiliacs or their families.

(b) **To safeguard social and economic interests of such sufferers.**

This is to a certain extent self-explanatory. The Society tries to safeguard the economic interests of sufferers by, for example, opposing the excessively strict standards applied in granting Mobility Allowance. Similarly, we try to make it widely known to employers that treatment advances mean that haemophiliacs can usually carry out a normal job. Often, however, it is not easy to say what the social interests of sufferers are. For example, this is the International Year of Disabled Persons. Clearly many of our members are disabled or partly disabled. Equally, however, many members are fairly fit, and resent being labelled as disabled. Consequently it is difficult to know whether we should place special emphasis on the IYDP.

(c) **To promote the study of the cause and treatment of haemophilia and allied conditions.**

The need for funds to support research and routine treatment has steadily increased over the years, and is likely to increase further as the recession deepens and government funds become harder to obtain. The Society tries to limit grants to a restricted period, so that the grants we make are to be regarded as for "pump-priming" purposes only. We hope that usually the value of a project will become readily apparent, so that health service funding is made available. This has happened with most of the Haemophilia Nurse posts we have helped to set up.

(d) **To gather and publish information useful to sufferers and the general public.**

This is an aspect of the Society's work on which we place great emphasis. We regard our publications as of great importance, particularly The Bulletin, but also the pamphlets we produce, such as "Notes for Teachers". These are all distributed throughout the world, as many other Haemophilia Societies find them useful.

(e) **To co-operate with the medical and allied professions for the furtherance of the objects of the Society.**

The value of the Society's co-operation is recognised by most professionals in the field of haemophilia care. The Society has been involved in the setting up of the Haemophilia Nurses' Association and the Haemophilia Special Interest Group of the British Association of Social Workers. Moreover, the Society is invited to send observers to the annual meeting of the Haemophilia Centre Directors.

(f) **To co-operate with any other Societies or bodies having similar aims.**

Notable among other bodies with whom we work is the World Federation of Hemophilia, the relationship with which has been described during the Seminar.

(g) **To provide financial help where necessary and practicable.**

This is self-explanatory. It is worth emphasising, however, that the Society's policy is not to provide funds which should be provided by national or local government. Thus, for example, we will pay salaries only for a restricted period until the NHS can take over. At a different level we will provide only restricted help with such things as telephone installation, which should be provided by local authorities under the Chronically Sick and Disabled Persons Act, 1970.

(h) **To do all other things which may legally be done in the furtherance of the Society's objects.**

As one might imagine, this clause exists in case anything has been forgotten in the first seven.

It is perhaps worth pointing out two things that the constitution does **not** say. First, the Society exists to help all haemophiliacs, not just its members. Although obviously we like people to join, we can provide help or advice to any haemophiliac or relative. The only restriction is that we cannot give financial help to non-members without Council's approval, for reasons connected with the legal terms of our registration as a charity. Second, we are not restricted to helping haemophiliacs in the United Kingdom alone. While most of our help to haemophiliacs overseas is directed through the World Federation of Hemophilia, it may happen that we will soon feel the need to offer direct aid to third world countries to ease the plight of haemophiliacs who still receive no, or purely rudimentary, treatment.

●●●●●●●●●●●●●●●●●●●●●●

SOCIETY FINANCE

H. N. Abrahams, FCA

It is extremely important that, before accepting appointment as Honorary Treasurer to a charity, one should be fully aware of the responsibilities and duties of such an office. There are many legislative provisions that a Treasurer should be aware of and it is of considerable advantage if he is a member of, or involved in some way with, the accountancy profession as it is important that he has a sound knowledge of book-keeping methods and the maintenance of financial records. As you are all probably aware, I am a Chartered Accountant and I would not have accepted the appointment as Treasurer if I did not have the experience gained as a member of that profession.

Mr. Howard Abrahams

My own work as Treasurer consists of the following major items:—

1. Maintaining all financial books of account, including monthly cash book reconciliations with bank statements.
2. Dealing with all staff salaries and Pay As You Earn matters and reviewing, when necessary, staff salary increases and making consequent recommendations to the Executive Committee.
3. Maintaining the Deed of Covenant records.
4. Constantly monitoring our cash-flow situation, so as to ensure that our deposit investments are maximised and that call notice is such that large

amounts can be obtained, when required, for paying research fund grants.

5. Controlling the settling of all bills and remitting payment of all research or benefit fund grants — ensuring that proper approval has been given, where appropriate, by either Executive Committee or Council.

6. At the end of each financial year, which in our case is the 31st December, the books of account have to be balanced and I then prepare our accounts, which are then forwarded to independent accountants for annual audit. Careful preparation of the accounts is essential so as to ensure that all funds reflect their individual movements throughout the period of account. It is essential that the actual books of account are meticulously kept and adequately analysed so that accounts can be easily prepared, ensuring that it is easy to extract from those records any relevant information, which may be requested or required at meetings, e.g. the accumulative amounts raised towards our £¼ million Research Fund Appeal.

It is worth noting that, although the Honorary Treasurer usually fulfils the necessary obligations to keep proper books of account, the Charities Act of 1960 imposes such obligations on *all* Charity Trustees.

The lack of adequately kept records could prejudice the various taxation exemptions afforded to charities. One of these is that registered charities are exempt from taxation of their investment income and are able to reclaim any such tax, deducted at source, on any interest or dividends paid net. Repayment claims are usually made annually and have to be submitted to the Inland Revenue with supporting documentary evidence of income paid under deductions of tax. That evidence would consist of the dividend or interest counterfoils obtained when income is received. To avoid the extra work involved in preparing and submitting to the Revenue repayment claims, it is far better to invest charity funds in investments where interest is paid gross. Such investments also ensure that the cash flow arising is not distorted by the income initially being paid net and then the tax repayment being received possibly several months later. Over the past two years, I have invested the Society's funds on the money market, through our bankers National Westminster. The monthly payments of interest are made to us gross, thus ensuring, as regularly as possible, a desirable cash-flow. Moreover the larger the amount of the deposit, the greater the interest rate which can be earned. Obviously the funds which the individual Groups hold may not be large enough to place in this way, and, therefore, it is advisable at present, to put them into ordinary bank deposit accounts or National Savings investment accounts. However, in the latter case, note that interest is only paid once a year in December. I would stress that you should not allow Group deposit balances to get too large, as if they are transferred to central funds we can obtain higher interest rates by having the benefit of investing much larger amounts through our own bankers. When investing our deposits I have to consider that interest rates vary depending upon the period of the investment; at present our funds are re-invested monthly and, as I have already said, the interest is received at the same interval.

I am sure that many of you here today have far more experience in the grass roots aspects of fund raising and GRO-A has given a considerable insight into Group fund-raising activities. Ken Polton, our Honorary Secretary, and our office staff are extremely experienced in sending appeal letters to the Chairmen and charity committees of large companies, institutions and livery companies. The response

Mrs. Irene Watson
from the Society's office

to such letters has been tremendous; one often finds that organisations repeat and increase their donations each year. When companies or individuals, for that matter, wish to donate to a charity on a regular basis, there are several advantages in doing so by a Deed of Covenant, particularly since the improved taxation legislation in the 1980 Finance Act. Prior to that Act, a Deed of Covenant had to be for a minimum period of seven years; this has now been reduced to three years. The major advantage to a charity of a donation by Deed of Covenant is the taxation repayment which can be made thereon. Assuming a basic tax rate of 30%, say a person wishes to donate £70 per annum net, that amount has a tax credit attaching to it of £30, which the charity can reclaim from the Revenue, thus making the total gross deed £100 per annum; the tax credit of £30 being equal to 30% thereon. It is always easier if the deed is prepared on a net basis as, if it is gross, the donor has to ensure that he, or she, deducts the tax at source at the prevailing rate, prior to making the payment to the charity. By having net deeds the charity has a clearer idea of what its cash-flow position is, as the instalments will not be subject to variation due to change in tax rates.

To obtain the benefit of repayment claims for income tax credits, attaching to the deed of covenant payments, it is essential that the following points are always complied with:—

1. The Deed must be for a minimum period of 3 years.

2. The Deed must be dated on the same day as the first payment or before the first payment.

3. The charity's financial records must be meticulously kept with cash book folio numbers being noted next to each payment received, when listed in the formal repayment claim forms. The date of receipt must also be noted; there is always the possibility that the Revenue may wish to inspect the financial records, so the better the records, the easier it is to process the repayment claim.

4. In the first year of a deed, the original deed together with a Form R.185 must be sent to the Inland Revenue in support of the repayment claim. Thereafter, a Form R.185 is not necessary, as long as the net amount of the Deed does not exceed £130 per annum. The R.185 is merely a simple form to be completed and signed by the donor certifying that the appropriate amount has been paid to the charity under a Deed of Covenant, and the date of payment and the deed has to be recorded thereon. In addition, the donor should complete details of his address and employer (if relevant). Finally the R.185 should show the amount of the attaching tax credit.

5. The repayment claim forms, deeds and forms R.185 have to be sent to the Claims Branch, Charity Division of the Inland Revenue and although usually submitted annually, if large enough may be sent quarterly or more frequently.

Finally, with regard to Deeds of Covenant, since the introduction of the Finance Act 1980 provisions, there are further advantages to higher-rate tax payers making donations by this method. Let us say that a person who is paying Income Tax at the top rate of 60% plus a 15% investment income surcharge, wishes to enter into a net deed for £70 per annum. That effectively grosses up to £100 per annum while basic rate tax is 30%. The donor will be able to deduct from his assessable, investment income £100; with his total tax rate of 75% the actual net cost would only be £25. The donor would be able to deduct a further £45 from his Income Tax liability; the first £30 having been obtained by way of relief, when paying the net deed of £70 to the charity.

Because of these tax advantages to high rate tax-payers, consideration might be given by the donor to increasing the net amount of his donation, without effectively costing more than the original commitment, taking into account the tax savings. Obviously the bigger the net deed the larger the tax refund which can be obtained by the charity. Not only individuals but also limited companies can enter into Deeds of Covenant and obtain Corporation Tax relief thereon at

rates of between 40% and 52%. While on the subject of taxation it is perhaps worth bearing in mind the exemption from Capital Transfer Tax of life-time gifts made more than one year before death, and of the recently increased tax exempt limit of £200,000 in respect of willed gifts or those made within one year of death. Charities also enjoy other advantages under the Community Land Act of 1975 and the Development Land Tax Act of 1976.

The area of taxation which causes most hardship to any charity is VAT. There has been sustained lobbying of the powers that be for exemption from VAT on expenditure. It was hoped that some form of announcement along those lines would have been made by the Chancellor in his 1981 budget speech. Unfortunately, no such announcement was forthcoming except for some expansion of existing provisions relating to the exemption of VAT on the purchase, by a charity, of equipment or special aids for the benefit of some disabled persons, or certain hospitals associated with their treatment. It is unfortunate that full exemption on all expenditure could not have been granted, as in our particular case, VAT on expenditure accounted for approximately £500 of our income for 1980. This figure does not include the VAT on expenditure incurred by Groups, so one can see that a considerable saving would be obtained if the Government were more lenient in this respect.

The last point which I would like to raise is a particular hobby horse of mine. How do we ensure that a consolidation of the Society's accounts, including all Group accounts, can be prepared? The reason for my question is that by such a consolidation it would be possible to ascertain the entire amounts the Society has raised and expended annually. At present our main accounts merely reflect the amount of the donations to central funds from individual Groups. These donations are not the full amount raised by each Group, as the Groups incur their own expenses in raising such funds and also wish to retain balances on their own bank accounts to cover future operating expenses. When accounts are presented to outside bodies in support of appeal applications, a full picture should be given of everybody's efforts to raise funds for the Society. It would be necessary to incorporate in such a picture the full amount, not only of central office expenses, but also of those incurred by Groups. I appreciate that a lot of extra work would have to be put into establishing such a system, but I feel that such a consolidation would be very useful and would yield valuable information. I would be only too pleased to discuss the proposed workings of such a system with all Group treasurers.

I hope I have given you all a more detailed insight into my work, duties and responsibilities as the Society's treasurer, and the problems and issues that I have to consider in fulfilling those duties.

ROYAL PATRONAGE

by Mr. Ken Polton

Mr. Ken Polton

Mr. Ken Polton spoke on the benefits of Royal Patronage to a comparatively small charity such as ours.

He related a series of events which, although apparently unrelated, have contributed towards the high regard in which the Society is held and which have been invaluable, particularly in the field of fund-raising.

1970 was a momentous year starting with a Marks and Spencer Fashion Show, at which H.R.H. Princess Alexandra was present, which raised over £2,000. Shortly afterwards Robert K. Massie's best selling book "Nicholas and Alexandra" was published; Mrs. Suzanne Massie was the guest speaker at our Annual General Meeting, and later in the year we met and talked to the then Prime Minister, Edward Heath. A donation of £5,000 came from the Drapers' Company in the City of London.

In 1971 the Royal World Premiere of the film "Nicholas and Alexandra" took place from which we received a proportion of the proceeds, just over £7,000. Because of illness, H.M. The Queen could not attend, but was represented by H.R.H. Princess Anne escorted by the late Lord Mountbatten. A number of representatives from the Society were introduced to the Royal guests.

In 1972 we were included in the New Year Honours List(when Mr. Ken Polton was invested as a Member of the Order of the British Empire. **Editor's Note**)

Twice during the next three years we were contacted by a charitable trust enquiring about the work and plans of the Society and the result each time was a donation of £25,000, which enabled us to finance and complete a number of projects.

For some time we had been making enquiries regarding Royal Patronage and eventually we were delighted to be able to announce that H.R.H. The Duchess of Kent had agreed to become our Patron. For those who had been involved in the Society's work for many years this was an ambition realised and the ultimate "seal of approval".

The Duchess has been keenly interested in the work of the Society. Her participation has included attending the World Federation of Hemophilia European Congress held in London, opening the Newcastle Haemophilia Centre extension, and visiting Travenol Laboratories in Norfolk where many items used in the treatment of haemophilia are produced.

Mr. Polton closed by saying how strongly he felt that the Society was extremely fortunate in having Her Royal Highness as Patron. Since the start of her sympathetic involvement the Society's role, views and opinions have become more important and influential which could only be to the ultimate benefit of all haemophiliacs.

H.R.H. The Duchess of Kent

CO-ORDINATOR'S MINUTES OF THE GENERAL DISCUSSION

After a short introduction by the Chairman, the Rev. Alan Tanner, the following points were raised by delegates.

1. There was a suggestion that Group Publicity Officers should meet regularly with the Co-ordinator to talk about publicity, activities etc., thereby ensuring a free flow of information throughout the Society. It was stressed that *nothing* should happen in or through Groups without the knowledge of the Co-ordinator.

2. A delegate spoke of the difficulties her Group faced when dates etc., for national meetings were not fixed in advance. It was pointed out that the AGM was always held on the last Saturday in April and that Spring Council was always six weeks prior to that.
   This also caused problems with local and national Fund Raising. While the Draw is normally at the same time each year, this may not be widely recognised.

3. Discussion took place on a suggestion that Groups pay bulk membership subs. It was put to the meeting that Groups should be in the business of recruiting members of the Society and close identification with the Society was of great importance in order that members gain a broadly based and wide understanding of the work of the Society, as well as of their own Group. To this end it was seen as important that as much literature as possible be fed into Centres by Groups, in order to encourage membership of the Society.

4. A detailed discussion centred on back-up publicity — the need for such material to be of a high professional standard — avoiding duplication. One Group told how it had produced its own up-dated version of *'He Has Haemophilia'*, unaware that the Society were producing a new one at the same time. Should there be professional campaign based Press handouts? ***Delegates with ideas undertook to contact the Co-ordinator with any ideas they had to improve the existing leaflet.*** Do Groups need their own regional material? — it was felt not to be the case and overprinting or labelling could handle this well. A delegate spoke of how parochial he felt some Groups could be and that this appeared to emerge through a lack of information of what was happening across the whole field.

Mr. David Watters

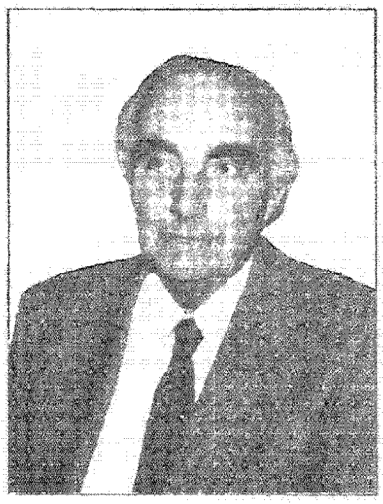
5. Delegates were told of a meeting which had taken place between representatives from Birmingham, Oxford, Notts and Derby, and Northampton Groups — a minute of the meeting will be made available through the Co-ordinator. Concern was expressed at the meeting about the position of the older haemophiliac and the following questions arose from the meeting:
   Could a comprehensive list of all Research Fund allocations be published once a year? Could all recipients of such grants be required to report back on their findings periodically and those findings be made available to Groups? Should Research Fund allocations be concentrated on a few major projects rather than dissipated over a wide spectrum? Should investigations be made on (a) laser surgery (b) oral therapy (c) joint replacement?
   This 'grouping' of Groups was welcomed — it was felt that they could serve as a forum for Groups to meet on a more regular basis to thrash out their thoughts, which could then be passed on to the Executive, or the Co-ordinator, at regular meetings. This could lead to an increased sense of national direction in the Society, better communication and more effective servicing of Groups by the Executive through the Co-ordinator.
   If not a flag day, should there be a national fund-raising effort once a year, so that Groups could co-ordinate their thrust on local fund-raising to fit in with increased publicity, hence increasing funds raised?

6. It was suggested, and the suggestion was warmly received, that seminars should be held annually on the same weekend in March. They could perhaps look at particular themes with informed medical in-put, group workshops and general discussion etc., to produce an Action List for discussion with other Groups during the year.

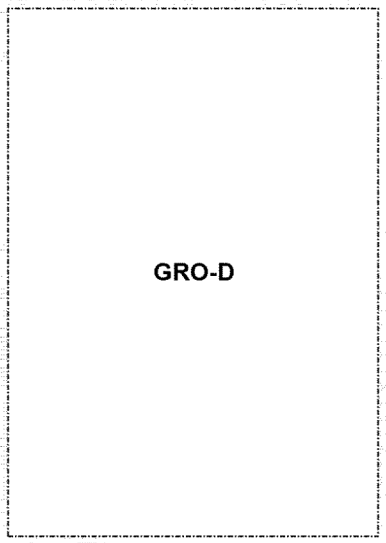
7. Information Flow: Groups to submit ideas and requests for literature to the Co-ordinator. Groups to be supplied with a list of all publications available. A list to be produced of speakers, films, slides etc., suitable for Group meetings and general meetings organised locally. Reprinting of the Society Rules and Constitution, WFH membership forms to be sent to Groups was recommended.

N.B. The reprinting of Rules and Constitution is receiving attention and we are looking into producing a Society Handbook type publication to replace both the old R. & C. and the former "Haemophilia Society" leaflet. **David Watters**

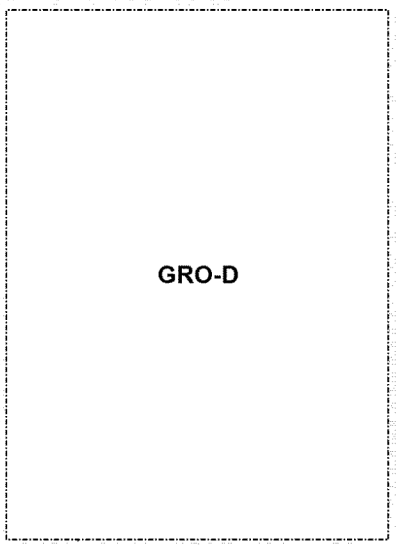
Some other members who attended the seminar



Mr. Jim Hunter — the Society's Vice-Chairman

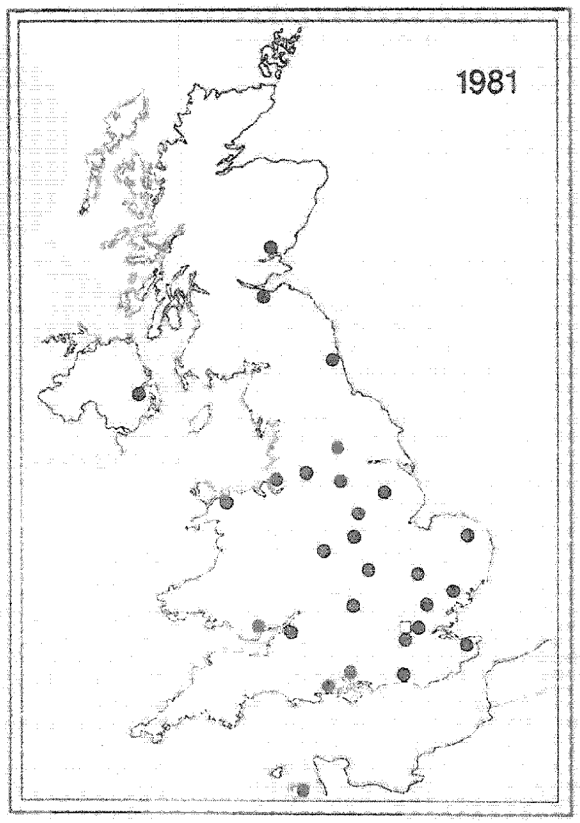


committee member



committee member (elected since seminar)

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)

0 50 100 150 200
Kilometres

THE CHAIRMAN, EXECUTIVE COMMITTEE AND STAFF OF THE HAEMOPHILIA SOCIETY WISH ALL READERS A MERRY CHRISTMAS AND A HAPPY NEW YEAR

NEW YORK MARATHON

We are happy to announce that GRO-D successfully completed the course in the New York Marathon and finished number 6883 out of 16,000 runners. We congratulate him on his splendid achievement and thank him for his generosity. It is now up to you to collect sponsorship monies and send them to the Research Appeal Fund. We have already received over £200 . . . . help to swell the Research Appeal Fund by letting us have the money you have raised through sponsorship.

N.B. If you want a receipt please enclose an addressed envelope when you send the money to us.

Enclosed with this Bulletin you will find a collecting stocking. It is now some time since we distributed stockings with the Bulletin – please try to get your local shop, pub or office to put it up . . . . we have lots more for those who need them!! All proceeds go to the Research Appeal Fund.

Opinions expressed in the Bulletin do not necessarily reflect those of the Haemophilia Society.