The Bulletin

Edition 31, No. 1 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 1960 (230034)

THE HAEMOPHILIA SOCIETY
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ANNUAL REPORT 1980

Introduction

In the annual report for 1979 the Chairman looked forward to the 1980s, stressing the Society's need and desire to find new ways to improve facilities for the membership. 1980 has been much occupied with our efforts to do just this. Priority has been given by the Executive Committee to preparing the ground for the appointment of an administrator, to be known as the Co-ordinator, who will work at the Society's head office. This step, together with others, has been necessitated by the growth in the number of Groups; the greatly increased volume of routine business dealt with by the office; and by our wish to concentrate the efforts of the Executive on policies rather than on administration. This preliminary work was completed by December 1980 when the new post was advertised. Doubtless there will be more to say on this subject in our next annual report.

Another central concern of the Executive has been the issue of blood products. A Blood Products Sub-Committee has been formed to look into this subject and promises to be a very valuable addition to the Executive.

Towards the end of the year increasing concern was felt at the unsatisfactory situation regarding supply of Factor VIII Concentrate. The main causes for concern were:

1. The possibility of the Elstree Blood Products Laboratory (BPL), where most of Britain's Concentrate is produced, being placed under commercial management.
2. Inadequate supplies of Concentrate to meet present and future demand.
3. Increasing reliance on imported commercial material, contrary to the World Health Organisation policy that countries should be self-sufficient in blood products, and with the possibility of greater risk of hepatitis infection.

Although the DHSS has decided not to involve commercial organisations in managing the BPL, the other problems are not yet resolved, although the DHSS has agreed to embark on the first stage of an expansion programme at the BPL. It is intended to monitor the situation much more closely than in the past, and a new sub-committee of the Executive Committee has been set up to do this, in co-operation with the Haemophilia Centre Directors, and to assist in pressing the DHSS to provide adequate supplies of Factor VIII.

Case Committee

In 1979 Mrs. Vicki Stopford relinquished her appointment as Research Social Worker to the Society. On the occasion of a Council meeting in September 1980, referring to her five years with us, the Chairman said that he hoped the momentum of her work would not be lost, and the Secretary that a most valuable part of her work was in establishing Seminars for Social Workers and others professionally engaged in helping haemophiliacs. There is indeed now a network of Social Workers throughout the country with something of a special relationship with the Society and a knowledge of haemophilia much greater than before. An individual member can now hope to find personal contact and help in dealing with his difficulties directly from a professional worker in the Centre or on the staff of the local authority social work department. This process of keeping Social Workers informed about haemophilia will be furthered by the British Association of Social Workers' Special Interest Group for Haemophilia and Haemostatic Disorders. The Society has guaranteed funds to help establish this group in the formation of which our former Social Worker was instrumental.

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Individual cases of difficulties arise nonetheless and have been dealt with by the Case Committee to the best of its ability. Twelve grants were made to help members in times of hardship, sometimes at the instance of a local social worker or one of our own Groups, or in co-operation with another charitable organisation like ourselves. Grants were made towards the installation of telephones for members and also for other more special reasons. These latter included help to a Regional Council for Preparatory Training for the Disabled in sending a member on an organised educational visit abroad; grants to enable two members to attend a special camp in which a haemophilia centre doctor was actively interested; and meeting, for a member, an increase in his Open University fee — as an alternative to abandoning his course.

ANNOUNCEMENT

Mr. Ken Polton, Honorary Secretary of the Society is entering hospital for surgical treatment, which is likely to put him out of action for two or three months. Mr. John Prothero has very kindly agreed to be Acting Honorary Secretary during this period.

The Groups

The Group Liaison Officer reports that the Groups in general had a good year and not only did they hold a great number of events, but also collected a substantial amount of money towards the £250,000 Research Fund Appeal.

The new Groups formed in 1979 did very well in 1980 and have become a real asset to the Society. During the year only one new Group was established — SOUTH ESSEX & DISTRICT (No. 28) — although it has yet to be formally recognised by the Council.

Group Representatives meetings were held three times in the course of the year, and, for the first time, an all-day meeting was held in Birmingham at the request of the Groups. This meeting was a disappointment in terms of attendance; most Groups found it more than difficult to get to Birmingham and back to work on time on Monday. The meetings held in London, however, were well attended, with most Groups represented.

The Group Liaison Officer informed the Council that he wished to give up his work for the Groups, which he has been doing since 1972, or at least to reduce it in 1981 as far as "visiting" is concerned. With this in mind he suggested the linking of Groups into "Areas". It would be possible for him to visit an "Area" perhaps consisting of 4 to 5 Groups. This would be more practical than visiting 28 separate Groups once a year as had been envisaged when there were only some 10 Groups. Because of illness at home the Group Liaison Officer was not able to fulfil all his engagements during the year but he had kept in close touch by letter and telephone. He had made visits to Prestatyn and Basildon in addition to London and Bournemouth, where he is on the Group Committee, and where he attended the opening of a new Haemophilia Centre and also represented the Society at the Group's AGM.

The Group Liaison Officer concludes that 1981 promises to be a busy year for him as visits have already been arranged to the following Groups: Scottish, Tayside and Northern.

In 1980 the Executive gave considerable thought to improving the flow of information and the exchange of views within the Society, and to this end began working on another new project: namely the Group Seminar, to be held in the coming year.

The Royal Patron

The highlight of the year was undoubtedly the visit made by Her Royal

OBITUARY

It is with deep regret that we inform members of the death of our President, Sir Weldon Dalrymple-Champneys, Bt, CB, DM, FRCP, DPH, at the age of 88, at his home in Oxford on GRO-C GRO-C

Sir Weldon was an undergraduate at Oriel College, Oxford, and St. Bartholomew's Hospital, London. Following the interruption of his studies caused by the First World War, throughout which he served as a Captain in the Grenadier Guards, he qualified in 1922 as MB, BCh (Oxford). After holding a number of hospital appointments he joined the medical staff of the Ministry of Health in 1940. From 1941 to 1944 he was Honorary Physician to HM King George VI.

He was an accepted authority on undulant fever and bovine tuberculosis in man but whilst at the Ministry of Health as Deputy Chief Medical Officer he became interested in haemophilia. In 1950 he organised the Ministry of Health's first conference on haemophilia and later had meetings with representatives of the Haemophilia Society which, at that time, was becoming established as a registered charity. These discussions led to certain hospitals being designated as "Haemophilia Diagnostic Centres" where the proper diagnosis of patients was made and Haemophilia Identity Cards issued.

Eventually, as knowledge grew and facilities were improved they became "Treatment Centres". All of this came about as a result of the combined efforts of the Medical Research Council and the Ministry of Health following the report made by Sir Weldon, which led to a joint Haemophilia Committee being formed.

Sir Weldon retired from the Ministry of Health in 1956 and in 1957 he accepted an invitation to succeed the late Sir Lionel Whitby as President of the Haemophilia Society.

As a doctor he obviously had an interest in the medical aspects of haemophilia but he also concerned himself with the social problems and was always keen to be kept informed of this part of the Society's work. Until he moved his permanent home from London to Oxford he regularly chaired the Annual General Meetings and many members will recall his presence at the Children's Christmas Parties.

In 1968 our Oxford and District Group established a "Hostel for Haemophiliacs" at Headington, Oxford, adjacent to the Churchill and Nuffield Hospitals. At that time, because of the reputation of the Oxford Haemophilia Centre, many haemophiliacs moved to the Oxford area and the Hostel provided temporary accommodation until they could establish themselves on a more permanent basis. The project was given impetus by a generous gift of £1,000 from Sir Weldon, at that time a considerable sum.

We are well aware of the debt that all haemophiliacs owe to Sir Weldon and to his work. The gap left by his death will be difficult to fill.

All members will, we know, wish to be associated with the messages of sympathy which the Society has sent to Lady Dalrymple-Champneys.

Highness, The Duchess of Kent, on 22nd May 1980, to formally open the new extension to the Newcastle Haemophilia Centre at the Royal Victoria Infirmary. Almost £40,000 was raised by our local Northern Branch through a special appeal, which included among its supporters Mrs. Catherine Cookson and Mr. Brendan Foster. Both were introduced to Her Royal Highness, together with many members of the staff and our local Branch, during a tour of the Centre conducted by the Director, Dr. Peter Jones.

On 2nd December 1980, the Duchess was shown over the premises of Travenol Laboratories Ltd., as part of a visit to Thetford, Norfolk, in connection with local community projects. The Society was represented by Mr. John Prothero and Mr. Ken Polton and during a tour of the plant, conducted by the Managing Director, Mr. Alan Barrell, the Duchess showed great interest in the production of the various items made by Travenol that are especially relevant to haemophilia, i.e. equipment for blood collection and the administration of blood products. Travenol supply a high proportion of such items to the Blood Transfusion Service and the National Health Service.

Oxford Hostel

The lease of the Hostel expired in December 1980 and this coincided with the realisation that the need for such an establishment had declined to such an extent that it was no longer required.

When it was opened in 1968 many haemophiliacs were moving to the Oxford area to obtain the benefits of the treatment provided at the world-famous Oxford Haemophilia Centre. Since those days treatment of a high standard, which is now available throughout the United Kingdom, and the development of home treatment has meant that no new applications have been received for some time for the temporary accommodation provided to cover the period while a permanent place to live was being sought. The Hostel was also used for overnight stays by the relatives of haemophiliacs who were transferred to Oxford from other hospitals. This need, also, now appears to be no longer required.

It has been decided, therefore, to proceed with the closure of the Hostel, a move which, in itself, is a clear indication of how the lives and well-being of haemophiliacs have improved during the past 15 or so years.

World Federation of Hemophilia

The Society's support of the World Federation of Hemophilia had an added dimension this year, for in addition to the active role that some of our officers and members have as officers of the WFH, the year saw a very enthusiastic participation by some of our younger members in the 1st International Haemophilia Conference held in Bonn, West Germany, in October. The role that the haemophiliac has to play in his own care, and in the organisation of his own life, was demonstrated by the efforts made by the Conference organisers to ensure the active participation of at least one haemophiliac from each of the member organisations of the WFH. The result must have been the largest number of haemophiliacs ever participating in a WFH meeting. Our Society was well represented by no less than 10 members who had been sponsored by their local groups with added financial support from one of the commercial suppliers of Factor VIII concentrates. The younger members played a prominent role in the extension of the organisation of the World Haemophilia Youth movement and were prominent in the poster and discussion sessions. The benefits that the Society obtains from its membership of the WFH and the participation in its meetings was thereby greatly increased, and it is hoped that the exchange of experiences and ideas enabled our representatives to contribute to the well-being of other haemophiliacs from less fortunate countries.

FINANCIAL REPORT FOR THE YEAR ENDED 31st DECEMBER 1980

Subject to audit, the Society's accounts for the year ended 31st December 1980 reflect a financially secure and sound situation.

After two successive years of incurring net operating deficits the General Fund income and expenditure account for 1980 shows a net surplus for the year of almost £4,000. This is extremely pleasing, especially in view of the fact that the economic recession which the country has suffered during the past year could well have contributed to restrictions in donations and rising administrative costs. For comparison purposes, it would be useful to set out below in tabulated form brief extracts from our accounts for the past five years:

	1976	1977	1978	1979	1980 (Unaudited)
	£	£	£	£	£
Research Fund Donations	31,741	7,787	12,928	22,814	60,707
Other Donations	17,237	19,641	9,981	13,537	13,181
Deposit Interest Received	3,577	3,498	2,333	2,350	8,083
Annual Draw (Net)	1,352	1,514	1,771	2,509	2,529
Total Costs and Running Expenses of Society	18,586	18,301	18,544	21,094	21,516
Net Surplus	1,101	7,558	–	–	3,764
(Deficiency)	–	–	(3,304)	(1,643)	–
Benefit Grants made to Members	439	811	411	238	462

It can be seen from the above that a record sum has been raised for the research fund and a large proportion of that amount has come from a total of 22 of the local groups who have raised amongst them for the year ended 31st December 1980, in excess of £44,000. In addition, 10 of the local groups contributed a total of in excess of £7,200 for other donations to the General Fund. We have, of course, had the benefit of earning high interest rates on our bank deposits for the past year, and this is reflected in the large amount of interest earned for the period of in excess of £8,000. Without the benefit of such high interest rates, it is perhaps worth noting that not such a satisfactory surplus situation would have resulted for the year and we should, therefore, not lose sight of the fact that a reasonably substantial element of our donations is still required for the General Fund. Our administrative expenses, however, have only slightly increased compared to the previous year and this is despite the fact of high inflation partly contributed to by an increased VAT rate, compared to previous years, of 15%. With regard to VAT it is unfortunate that charities such as our own continue to bear the brunt of VAT on expenditure despite the fact that such expenses are financed by voluntary contributions on which there is no VAT. If charities were exempt from VAT on all expenditure it is perhaps worth noting that for the year ended 31st December 1980 we would have saved approximately £500 which would have been added to our surplus for the year.

At the time of writing the £250,000 research fund appeal has raised approximately £87,000 since its official launch at the beginning of 1979. We have obviously a long way to go before reaching our target, but it is however extremely satisfying to have raised such a large sum of money in such a relatively short period of time. The research fund balance as at 31st December 1980 is in excess of £51,000. This is after making research fund grants for the year in excess of £31,000. A total number of nine grants are shown in the research fund as being paid and payable for the year, and in addition there is a sum of £14,500 relating to 4 other grants, which, although approved, have not been charged in the accounts for the year ended 31st December 1980. These will be reflected in the following year, as soon as the Society has received all financial documentation relating to them.

Referring to a point raised at the April 1980 Annual General Meeting concerning an administrative charge to the Research Fund from the General Fund, it should be pointed out that for the year ended 31st December 1980, no such charge has been made, partly because the General Fund had a surplus for the year and partly because all interest received has been credited to the General Fund. This situation is closely monitored and if it appears necessary for such a charge to be made then it shall be done.

In conclusion, it must be stressed that at present the Society's financial position is extremely healthy, but none of us must lose sight of the fact that research fund grant applications continue to be received, and administrative costs are always increasing. All the Groups and others associated with the Society made tremendous and successful efforts during the year ending December 1980. Let us hope that continued efforts achieve at least equal results at the end of this current financial year.

CONCLUSION

It should be clear from this report that the Society continues both to be active and to be in the midst of a process of adaptation. Times change, and with them priorities, and so also must our organisation to deal with altered circumstances. It is, perhaps, easy to forget that ours is a small organisation, representing a small number of people, relative to the general population. In the past this may have led to the Society spreading its resources too thinly in an attempt to respond positively to almost every request.

It has become increasingly clear to the Executive that this will be less and less possible in the future. The Society must become much more selective, in particular, about which research projects to support. However optimistic one may be about future fund-raising prospects, it is clear that there is a limit to what can be raised but almost none on what scientists can spend. As a consequence of this, the Society must improve its methods of project selection and develop or extend its contacts with the caring professions; hence the involvement with the Centre Directors organisation, the British Association of Social Workers Special Interest Group for Haemophilia and Haemostatic Disorders, the Haemophilia Nurses Association, and, of course, our own Medical Advisory Panel. In the future our relationship with these bodies is likely to be vital to our effective development. With this in mind, 1980 augurs well for the future.

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WORLDWIDE

W.F.H. News

THE WORLD HEMOPHILIA YOUTH CONFERENCE

The World Hemophilia Youth Conference was held at the General Assembly of the World Federation of Hemophilia in Bonn. It was the first such meeting at which the aims for Hemophilia Youth were set out. Delegates were asked that on their return home they should try to stimulate the interest of young haemophiliacs. The first meeting in this country was held in London on the 22nd November, as a consequence of the Bonn initiative. The response of Groups was very disappointing. Only some three Groups sent representatives between the ages of 16 and 30 but, even with this low attendance, there was a lively discussion on the form that Hemophilia Youth should take in this country.

In the afternoon a report was given to the Council asking for the Society's support. Group representatives were asked for the names and addresses of young members of their Groups. There was some discussion about the lack of interest taken by young haemophiliacs in the Society's affairs but it was hoped that Hemophilia Youth could fill this gap. The Council was told that the aims of Hemophilia Youth were to stimulate and utilise the ideas and abilities of the younger members of the Society and to aid them through the exchange of experiences related to haemophilia. To carry out this work Hemophilia Youth must have the support of the Society's younger members.

Any haemophiliacs between the ages of 16 and 30 who are interested in World Hemophilia Youth should either contact their local Society representatives or write to: GRO-D GRO-C GRO-C

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"YOU'VE BEEN WHERE?"

Slung astride a canvas approximation of a breeches-buoy, I was being carried down four flights of extremely narrow French steps. But my lifters were GRO-D and GRO-D, four strong men and true — so what was the problem? Well, no problem really, except that it was six a.m., the staircase boasted no windows, the lights had fused, and it was pitch black.

GRO-A

Al fresco fix at Ostia; helped by Kathy (nurse), using a rather old table . . .
Picture: B. Sloggett

Actually, we did have one source of light, a torch, so I felt safe enough — until halfway down, when someone offered the following 'thrilling' advice:

"Tell you what GRO-D give GRO-A the torch, so you can hold on to him properly." I'm GRO-A, and I don't think I'll ever forget the implications of the word "properly", used in the context of the previous two flights . . . But I survived, dear reader, and I didn't faint . . .

It had been the tour's last night we had spent in St. Quentin, at the friendly little hotel I shall always recall as the place of the Black Dawn Abyss. We were making an early start for Boulogne and the ferry. In the bus, I banished from my thoughts the daybreak dice by finishing off the Chianti, and proceeding to play Phil's recorder, rather badly . . .

Did I tell you about the Chianti? Oh, it was just that there was this three-litre bottle on sale in a service station near Turin, with such a pretty label (all right, it was also cheap). Anyway, I bought it to help me over the Alps: I don't like heights, you see (heh, heh).

Did I tell you about the Alps? Oh, wow, you must admit, they're really high; I mean, when you're in a valley looking up, they LOOK high — but when you're up there looking down, they really ARE high. Lovely though, REALLY.

I remember a triangular cleft, filled with delicate mist, isolated in the sun, far down; and the precise villages, lower still; and the swathes of conifers above the pasture, then the rock, and the glisten of water. Up there, at the height of the St. Gotthard pass, there is just the unlikely audacity of the road, and the scattered tiny lakes, and thin air. But I survived, dear reader, and I didn't faint . . . Unhappily, I was unable to record Switzerland, having used my last film at the Pantheon, in Rome. So hang in there, memory, don't forget the Alps . . .

Did I tell you about the Pantheon? Oh, that was only the most perfect manmade sight my twenty-six years have yet shown me. Quite ordinary, even dowdy, from the back; but get round in front, and then inside, especially inside, and you'll see something that only genius in authority could make happen. Good old Hadrian, I mused, all that Empire to run, and he still found time to personally design the Pantheon, just in case, by some strange twist of fate, I should ever get a chance to go to Rome.

Did I tell you how I got to Rome? Well, it wasn't easy, I can tell you. First I had to become an Open University student, and slog away at that for a couple of years; then I had to notice a tiny advert., tucked away in "Sesame", the O.U. paper, for "M.P.A. Study Tours". "M.P.A." means "Mixed Physical Ability"; so the tours are made up of types with sundry physical handicaps, and super-type helpers, including a tutor, and a nurse. Well, I got on a proposed tour, and saved up like a good 'un — two weeks in Rome and Florence, flying there and back. Unfortunately, the tour was to be partly subsidised by the Open University Students Association, and just then their budget was cut when Sir G. Howe started playing "Chancellors"; the tour was cancalled. Curses . . .

That was summer '79, and it took only months to discover that there is more than one way to bankrupt a Haemo., fortunately. The same organiser, a kind lady of infinite resource named Valerie, pulled together another tour, this time under the estimable umbrella of the Midlands Council for the Preparation and Training of the Disabled. Money was short, because time was short; so mini-buses (two) would replace 'planes, and we would have to miss Florence, driving via France down to Rome over three or four days, and returning after a week by a more easterly route, including Strasbourg, where we were promised a seminar at the Council of Europe, and a luncheon reception arranged by my M.E.P., Mr. Derek Enwright. "It's a pioneering trip," said Valerie; she's such a kidder, with her penchant for euphemism. But, though we pioneered, and though we tripped, it all happened, and I must thank all concerned, mentioned above or unmentioned, for I survived, dear reader, and I didn't faint . . .

Our Special Issue (January 1981) of the Bulletin on the Prenatal Diagnosis of Haemophilia has provoked a good deal of interest and a number of requests for extra copies.

If any haemophiliac would like a copy to be sent to his female relatives, who are possible carriers, please inform our office.

Now look, I've used nearly all my space, and I still have so much unrelated: the day at the most sublime Ostia Antica (the ancient Roman port); the Roman Forum, from where the world was ruled, and where Julius Caesar was praised, but not buried; the hole-in-the-ground toilets where you have to make like a wicket-keeper; the midnight encounter with the two ladies from Dallas, Texas; my first greengages; the disbelief at speeding through Bourgogne and Champagne, without stopping to buy one; the silky mist over the Med. at Monaco as we looked down on the idle rich on their yachts; the little boy in Rome who limped on alternate legs, because he was still only learning his trade as a beggar; the German school choir's entrancing waterside impromptu, at the country estate of Hadrian (yes, him again); Rheims Cathedral (stained glass to blow your mind); my defeat of the head-waiter at Strasbourg; etc., etc. — and all courtesy of Factor VIII, which I consumed in hotel room, mini-bus, and Roman ruins.

Yes folks, us Haemos are mobile now, all right. If I can survive five countries in fifteen days (France, Monaco, Italy, Switzerland and Germany), then so can you lot. Get to it, you guys . . .

GRO-A
Leeds, W. Yorkshire

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GRASS ROOTS

SUSSEX GROUP 1980

Our first meeting of the year was held in March when we showed the N.B.T.S. film "A Little Goes A Long Way". This was an interesting account of blood collection, plasmapheresis and the use of blood products including factors VIII and IX.

In May we invited John Prothero down to talk on "Haemophilia in Europe". The turnout was a little disappointing for a good speaker with an important up to date subject. Later in May we had a stall at the local Lions Carnival which provided publicity and some boost for the Research Appeal Fund.

The July meeting took the form of a sponsored walk in aid of the Research Fund, it was held over a 5 km. stretch of the South Downs Way and despite the terrible weather a reasonable team turned out to support us.

Our September meeting combined the visit of the Travenol rep and the showing of the film "JOEY". In a short talk after the film we were told of the latest developments and research carried out by Travenol.

In November we held our annual Wine and Cheese party at which we had hoped to have the local Careers Officer for the Handicapped but unfortunately she could not attend so John Ritchie agreed to give his impressions of the European Congress held in Bonn in October. We also had the pleasure of opening and counting out the contents of a large collecting box from the shop of Mrs. GRO-D the mother of our Publicity Officer. This turned out to hold

COLCHESTER & DISTRICT GROUP

FOR HIRE: HIGHFIELD CARAVAN PARK, 3 miles CLACTON (off main London Road, buses to town)

6 BERTH CARAVAN — 2 END BED-ROOMS — TOILET — SHOWER — GAS COOKER — FRIDGE (electric) fully equipped. RAMP PLUS WHEELCHAIR for narrow door access.

HIGHFIELD has entertainment, swimming pool, hire shop, hairdressers, fish & chip shop, take-away, pool room, sand pit, children's playground, supermarket, news-agents etc., launderette, 2 bars, betting shop, amusement arcade.

For further details:

P. A. FROST (Hon. Treasurer)

GRO-C

GRO-A

GRO-A

Sponsored Walk July 1980. Group at Clacton.

nearly £95 in silver, a welcome boost to our funds.

December brought us round to our annual Christmas Party when the younger members, and some not so young, enjoyed plenty of food and fun.

We take the opportunity to wish all other Groups a Happy and Prosperous 1981 with lots of support from members!

To the end of February 1981 the Research Appeal has reached
£89,215

MISCELLANY

RED CROSS URGE DISABLED PEOPLE TO LEARN FIRST AID

The British Red Cross is urging disabled people to learn the basics of first aid because "they might be the only people available to save a life in an emergency."

The move comes as part of the International Year of Disabled People which is designed to encourage handicapped people to take as full a part as possible in everyday life.

Chief Medical Adviser of the British Red Cross, General Gray, said: "Most disabled people would be able to do something if they were among the first on the scene of an accident or if one of their relatives had an accident in the home.

"Basic training in first aid procedures could be invaluable. Some disabled people may not, for example, be able to give the "kiss of life" but there are many things most of them could do. It is important that each individual disabled person learns what those things are."

General Gray added that even if handicapped people were not themselves able to carry out first aid procedures, they might be able to tell others at the scene of an accident what to do.

He also stressed that it was particularly important for disabled parents to learn how to cope in an emergency involving their own children.

Disabled people or their helpers who are interested in knowing more should contact their local Red Cross Branch by looking under 'B' for British or 'R' for Red Cross in their local telephone directory.

NEWCASTLE HAEMOPHILIA CENTRE: DAY CONFERENCE

In response to a number of enquiries from Disablement Resettlement Officers at the Department of Employment and staff in schools, a Day Conference was held in Newcastle Haemophilia Centre last September (1980). Invitations to attend were sent to Health Visitors attached to each family practice known to the Centre, all heads of schools, the staff in local Careers Offices, Department of Employment Offices, school medical services and Social Services Departments. The aim was to include any professional staff who might in the course of their day's work be in touch with a family attending the Haemophilia Centre for treatment.

The response was positive. Over 150 people turned up! Each member of the Haemophilia Centre staff spoke briefly about their work and the afternoon session was given over to discussing in more depth the problems of those with haemophilia who are unemployed and seek work.

School staff were able to ask about exercise programmes and behaviour problems in school. It was possible to dispel anxieties about bleeding episodes and inform the audience about the Home Therapy Programme, and availability of treatment.

Families have reported back since the meeting an increase in confidence in their school staff when responding to haemophilia.

Careers Office staff and Department of Employment colleagues are now contacting the Centre more readily to seek support when approaching firms.

Staff in the Centre were able to learn first hand of difficulties. Staff changes suggest that this Conference may need to be repeated in due course.

J. Lovie (Mrs)
Medical Social Worker

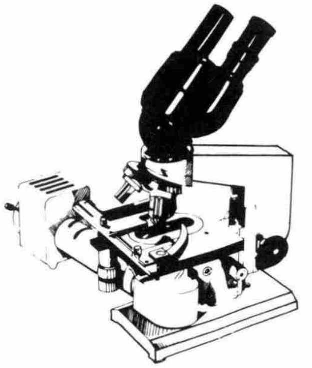
If you would like a quantity of Collecting Stockings for display in clubs, pubs, canteens etc., your request will be dealt with immediately.

BR CHAIRMAN ANNOUNCES RAILCARD FOR DISABLED PEOPLE

British Rail is to introduce a half-rate travel railcard for nearly ¾m severely disabled people — the registered blind and those in receipt of mobility or attendance allowances — BR Chairman Sir Peter Parker announced recently. The card is expected to cost £10 and to be available during the late summer or early autumn this year.

He gave the news while addressing an International Year of Disabled People's conference ('Transport without Handicap', sponsored by the Department of Transport) on the role of public and private transport operators in meeting the needs of the disabled. Sir Peter stressed the importance of all transport systems removing barriers to mobility and helping disabled people to live more active lives.

£250,000 Research Appeal



The following are among the grants approved by the Council of the Society during the past six months.

£4,500 to St. Thomas' Hospital, London, for equipment needed in connection with a study of the carrier state in haemophilia. This is being carried out in co-operation with the Hospital for Sick Children, Great Ormond Street, The London Hospital, and the Royal Free Hospital.

£1,300 for equipment for the Royal Victoria Hospital, Belfast (provided by our Northern Ireland Group), and **£1,138** for the Liverpool Haemophilia Centre (provided by our Merseyside Group).

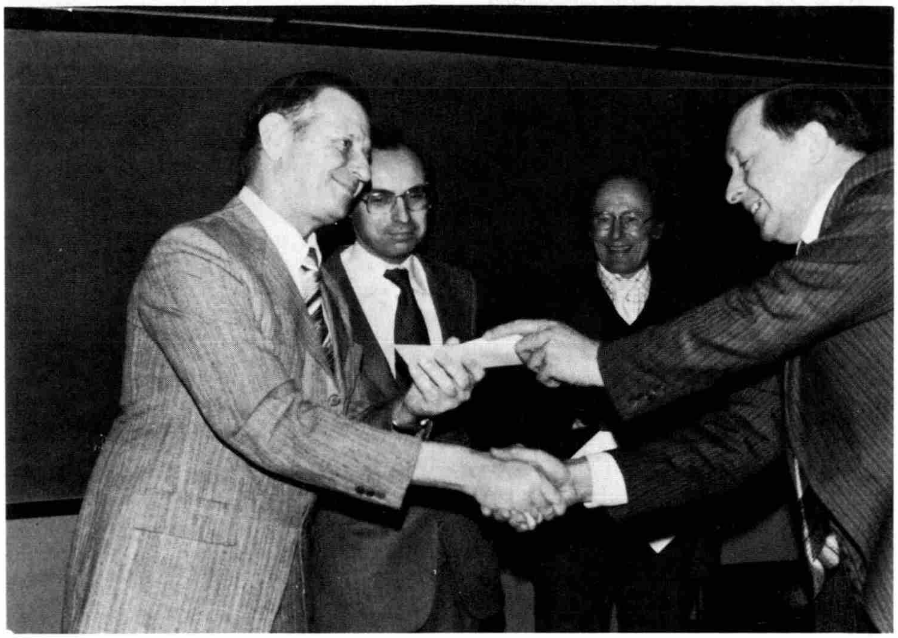
£2,350 to St. James's Hospital, Leeds, towards the cost of a research assistant and equipment in connection with an investigation into chronic joint damage.

£500 to Addenbrooke's Hospital, Cambridge, towards the cost of investigations into joint damage following chronic bleeding (paid for by our Cambridge Group).

£3,500 to the Isle of Thanet Hospital, Margate, for equipment for the Haemophilia Centre.

£4,000 to the Department of Biochemistry, University of Oxford, and **£5,000** to the Sheffield Haemophilia Centre, towards the cost of investigations into the possible synthesis of Factor VIII. (This is the subject under discussion at the Annual General Meeting on 25th April 1981).

Earlier last year grants of **£10,000** to the Cardiff Haemophilia Centre, University of Wales, **£12,606** to King's College Hospital, London, and **£3,500** to Lewisham Hospital, London, were made.



L to R: Dr. Reuben Mibashan, Director of the King's College Hospital Haemophilia Centre receiving a donation of £5000 from the Society, at the 1980 AGM. The Honorary Secretary Mr. Ken Polton is handing over the money, watched by Mr. Charles Rodeck, Consultant Obstetrician and Gynaecologist and our Chairman, The Rev. Alan Tanner.

The response to the letters that continually leave our office asking businesses, trusts and all kinds of commercial firms for their support, has been exceptional considering the effects of the recession. But only the magnificent support given by our Groups has made the making of these grants possible. Some have also made generous donations towards the general running of the Society, also very necessary. We would particularly mention the following amounts received during the past few months, which we acknowledge with gratitude:—

Northern (Newcastle) £2,500; Sussex (Brighton) £500; Jersey £1,200; Tayside (Dundee) £510; Southern (Bournemouth) £600; East Kent £350; North West (Manchester) £1,030; Birmingham & Midland £400; Lewisham £2,250; Oxford £1,000; Lincoln £100; Merseyside £1,500; Sheffield £1,000; South Wales £1,500; Great Ormond Street £630; Scottish £3,929.

During the year ended 30th September 1980 our Northern Ireland Group raised a fantastic £14,644 by means of Darts Tournaments, Car Raffle, Flag Days, a Fashion Show, and a variety of outdoor and indoor events. In addition to providing the money for the purchase of much needed items at the Belfast Haemophilia Centre, they have generously contributed £11,000 to Society funds. Future plans include the purchase of a holiday caravan.

Individual members have also given marvellous support and although we obviously cannot list here all those concerned we would particularly mention the following, again with grateful thanks:—

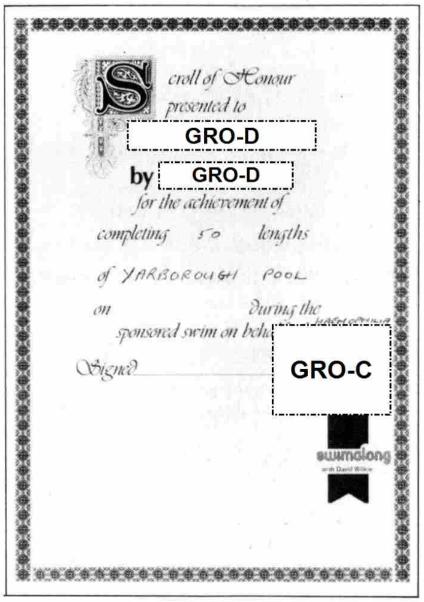
Mr. & Mrs. GRO-D and friends at the Queen Anne public house, Walworth, London, who raised £400; Mr. & Mrs. GRO-D and friends at the Double Century public house, GRO-D, near GRO-C, £500; Mrs. GRO-D of Doncaster, £200 from a Coffee Morning; Mrs GRO-D and the Inner Wheel Club of Jersey, £200.

Mrs. GRO-D and her friends of GRO-C raised £3529.30 by means of Snowball Lunches. Mrs. GRO-D specifically asked that our Scottish Group should send this money to the Research Appeal and this has been done. This is the largest single sum ever raised by an individual member and congratulations and thanks go to all concerned.

GRO-A, aged 22, a member of our Merseyside Group, has completed a sponsored cycle ride from Land's End to John O'Groats, a total of nearly 900 miles. With his friend GRO-A of Bristol, a fellow student at Lancaster University, the aim was to raise £700 but the final figure raised was £1,414.09! Many thanks to GRO-A and GRO-A for a marvellous achievement.

Executive Committee member David Rosenblatt collected a magnificent cheque for £500 on the evening of Wednesday, 28th January, 1981 at the Double Century Public House, George Green, near Slough, Bucks.

Mine hosts Mr. & Mrs. GRO-D last year collected £1,000 in nine weeks for a guide dog for a blind person. Since then the Society have been fortunate in being beneficiaries. Mrs. GRO-D started with a pile of 2p pieces, collected from pub customers. Mr. John Fisher went on a sponsored walk in the Dales and Pennines



Scroll of Honour
presented to
GRO-D
by GRO-D
for the achievement of
completing 50 lengths
of YARBOROUGH POOL
on during the
sponsored swim on beh GRO-C
Signed

GRO-D with GRO-D, who presented a scroll of honour to him for his sponsored swim at Yarborough Pool.

GRO-D

covering 190 miles and received about £200 for his efforts. He asserts that his main difficulty was being sunburnt on the backs of his knees! That was last June and must have been between 2 and 4 pm on a Wednesday, since no one remembers the sun in 1980.

Mr. & Mrs. Cowdrey's customers and friends include a local couple who have an eleven year old haemophilic son.

The Society thanks all Double Century's generous customers.

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ANNUAL SUBSCRIPTIONS

A form for the renewal of your membership was enclosed with our last Bulletin. If you have not already done so, we hope you will forward your subscription, which was due on the 1st January, as soon as possible.

If it is possible for you to send something over and above the basic £1 to help with the ever increasing expenses, such as postage, printing of the Bulletin, and the other costs involved in the running of the Society, it will be most helpful and very much appreciated.

Donations to the Research Appeal are also urgently needed to help pay for projects at various hospitals, as detailed elsewhere in this Bulletin. Please be as generous as possible.

To save on postage please indicate if you **do** require a receipt.

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British Association of Social Workers and Haemophilia Society

HAEMOPHILIA AND RELATED HAEMOSTATIC DISORDERS SPECIAL INTEREST GROUP

During 1979 discussions were held between Social Workers, the Haemophilia Society and BASW regarding the formation of a Special Interest Group for Social Workers and others involved in the care of haemophiliacs.

A Social Worker may often be the one social work specialist in this area in their authority, and can therefore be quite isolated. This emerged clearly during a number of seminars arranged over several years by Vicki Stopford, formerly Research Social Worker for the Haemophiliac Society. These were attended by a number of disciplines: including doctors and nurses as well as social workers.

A preliminary meeting was held in November 1979. Social Workers and other staff in Haemophilia Centres were also asked to indicate whether they would like to participate in such a group. An ad hoc committee was set up in November 1979 and met again in April 1980. BASW formally recognised the group in September 1980. A particular feature of this group is that it is co-sponsored by the Haemophilia Society and BASW. The committee comprises members of the Haemophilia Society, a nurse and social workers. Members of the group include social workers, nurses, doctors and members of the Haemophilia Society. This mix is seen as a positive beginning offering a potentially broad-base for exchanging experiences and ideas.

On December 5th, 1980 the Royal Free Hospital, London was the venue for the first full committee meeting and half day conference of the Special Interest Group at which the topic was genetic counselling. The conference was preceded by the committee meeting at which, among other matters, future plans for the Special Interest Group were discussed. It was decided to hold twice yearly meetings at which such subjects as unemployment, careers advice, family support and genetic counselling may be examined. Our newsletter has already been produced and ideas for the format and content of future editions were drawn up.

The conference itself was attended by 60 people — more than our current membership. It aroused a great deal of interest and provoked some lively discussion. Dr. Ted Tuddenham, Co-Director of the Haemophilia Centre at the Royal Free Hospital, chaired the session. He opened with an overview of the subject and gave an introduction to the Royal Free Haemophilia Centre.

Mrs. Patricia Wilkie from Edinburgh University gave an account of the research being carried out into socio-cultural attitudes towards genetic counselling and family planning in the West of Scotland.

Mrs. Cath Evans, Social Worker in the MRC Genetics Unit at Great Ormond Street Hospital, spoke of the social work contribution in that Unit. Dr. Ruben Mibasham, Haemotologist at King's College Hospital, spoke with great wit and sympathy of the advances being made in pre-natal diagnosis. He showed a remarkable film he made with colleagues of an 18 week foetus being tested for various haemostatic disorders.

The final speaker was Dr. Connie Miller from the Haemophilia Programme at Cornell University Medical Centre in New York who spoke of her dual role as a Geneticist and Genetic Counsellor but gave particular emphasis to the latter. She spoke of the importance of well planned genetic counselling timed to suit individual needs and involving all members of the family. Dr. Miller's visit was sponsored by Armour Pharmaceuticals. She was also able to visit several Haemophilia Centres around the country where she made further presentations and took part in various discussions.

Participants then broke into small groups to discuss several related topics. This was followed by a plenary session at which group leaders reported back revealing a very lively interest in the issues raised during the afternoon.

The next meeting of the Special Interest Group will be at Manchester Royal Infirmary on Thursday May 7th, 1981. The topic will be: "Entitlement to Benefit — the contribution of the Centre and the Social Worker".

There will be workshops on:

1. The impact of receiving benefit — the haemophiliac's perspective.
2. Ethical dilemmas?
3. Practical difficulties in the entitlement, e.g. Mobility Allowances and Motability.
4. Genetic Counselling with families — a follow up from the previous meeting.

SUMMER CAMP AT CHEPSTOW

Dr. Tuddenham will again be able to take some haemophlic boys to a summer camp this year. The camp will be from Thursday, 13th August to Saturday, 22nd August 1981. It is taking place at St. John's on the Hill, Chepstow, at a site overlooking the Wye Valley with plenty of room for good walks, canoeing and famous attractions nearby — the Severn Bridge, Tintern Abbey, Chepstow Castle and the Forest of Dean — a lovely area to explore.

Would parents of haemophilic boys aged 9 to 11 write to Dr. Tuddenham at the Katharine Dormandy Haemophilia Centre, Royal Free Hospital, Pond Street, London NW3 2QG, for further details. This is a camp run under the auspices of the Church of England Youth Organisers CYFA Pathfinder Ventures.

Dr. Tuddenham would also like to hear from any nurse or doctor involved in haemophilia care who would consider helping at this camp or would be interested in setting up similar ventures.

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SUMMER CAMP 1982

Our Scottish Group is considering the possibility of organising a Summer Camp for haemophilic boys and their families and enquiries are being made within the Society to assess the demand for such a Camp.

It would be held in the summer of 1982 with the possible venue in Stirling. The objective of the Camp would be to educate the haemophiliac and his family to realise the full potential of the haemophiliac in society.

During the week of the camp, talks would be given on topics such as: dental care, genetics, schooling, employment and insurance. The boys would have the opportunity to take part in a number of sports, hobbies, and other activities.

An essential element of the Camp would be the experience of living together and learning from other haemophiliacs with past experience of coping with and overcoming their problems. Individual counselling would be available from a wide variety of professional advisers and full medical treatmentwould be constantly on hand.

Similar Camps have been organised with great success by haemophilia societies in other countries in Europe.

To make the project viable it is estimated that a minimum of 120 people should attend. The approximate cost per person, per week is estimated at £70.

If you are interested please let the Trinity Street Office know.