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The Bulletin

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

Member of the World Federation of Hemophilia
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THE HAEMOPHILIA SOCIETY
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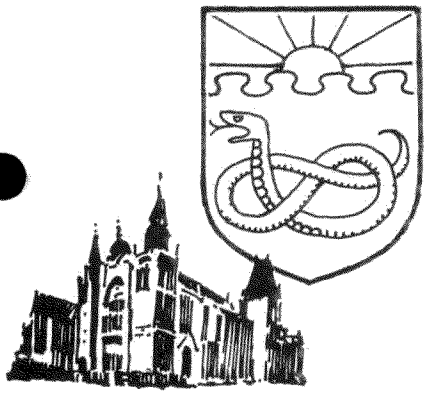
ANNUAL GENERAL MEETING



"A fellowship for sufferers from haemophilia and allied conditions, their families, and those concerned with their health and welfare."

These words, extracted from the Society's aims and objects, were never more evident than at the Annual General Meeting, held in Manchester on Saturday, 28th April 1979.

Members of our North West Group were hosts and their provision of a first-class buffet lunch, the excellent facilities provided by courtesy of the University of Manchester, and a stimulating discussion by the distinguished panel on "Psychological Problems Relating to Haemophilia" combined to make it a day which will long be remembered by the 120 people who were present.

The Annual Report (reproduced below) was unanimously adopted and the Honorary Officers and Executive Committee were elected as follows:—

Chairman:	Rev. A. Tanner MA
Vice-Chairman:	J. R. Hunter BSc
Treasurer:	H. N. Abrahams FCA
Secretary:	K. R. Polton MBE
Committee:	Mrs. M. I. Britten
	C. Knight
	Dr. L. Kuttner
	K. Milne
	J. Prothero
	J. Ritchie
	D. Rosenblatt

The £250,000 Research Appeal was formally launched by the Rev. Alan Tanner, and Mr. Howard Abrahams, our Honorary Treasurer, very generously made a personal donation of £20 to mark the event. This was followed by the presentation by Mrs. I. Clinton of a cheque for £500 from our North East Group (based in Leeds and Bradford). Thanks were expressed to all those who made this donation possible.

A full report on the panel discussion will appear in a future Bulletin. The members of the panel were Dr. Ivana Markova from the Department of Psychology, University of Stirling, Dr. Elizabeth Mayne, Consultant Haematologist at the Royal Victoria Hospital, Belfast, Mrs. Jean Lovie, Medical Social Worker at the Newcastle Haemophilia Centre, Royal Victoria Infirmary, and Dr. Gerald Beales, Research Fellow at the University of Manchester. Our sincere thanks go to them all for giving us their valuable time and for their advice and words of wisdom.

Very many thanks also go to the Committee and friends of our North West Group, whose hard work ensured the success of what many described as one of the most memorable and happy meetings in the history of the Society.

Contents

ANNUAL REPORT 1978

Mention of the 'Annual Report' tends to bring to mind pictures of the Chairman of the Company presenting to the Annual Meeting of Shareholders a review of the last year's progress (with a few caustic remarks about interference from the Government!) finishing with a triumphant declaration of the dividend to be paid out of the profits.

Our own Annual Report is different, not least because the dividend is measured not in monetary terms, but according to our success in helping members of the Society become better informed about the facilities and benefits available to them and the progress being made in the management of Haemophilia, both here at home and throughout the world.

In all aspects of our work we are able to report substantial progress and particularly in improving communication between the Council and individual Members of the Society. For instance, the new format of the Bulletin has been regarded widely as marking a new phase in our work and we are proud that the Editor has produced a publication which keeps Members up to date in such practical matters as the Mobility Allowance, Insurance, the supply of concentrates and so on. At the same time, the Bulletin keeps us informed about activities in other countries with which we are joined in the World Federation of Hemophilia. Technically, the Bulletin is one of the finest produced by any National Society and we are indebted to the Editor for the high standard of its content and presentation.

The year was marked by the publication of the Wolfenden Report on the future of voluntary organisations, from which it is clear that the Government now recognises the essential part which voluntary bodies are to play in social concerns. The Wolfenden recommendations may have profound implications for the future of organisations such as the Society as we develop our relationships with the statutory services and continue to press for improved facilities to be made available.

THE GROUPS

We are pleased to record that most of the Groups continued to flourish and we

give special mention to the Northern Group which, in the course of the year, raised over £35,000 for its local Haemophilia Centre.

As in previous years, the Group Liaison Officer travelled extensively throughout the country visiting Groups in Bristol, Norwich, Cambridge, Oxford, Cardiff, Canterbury, Birmingham, Great Ormond Street and so on.

In the course of his visits he discussed ways in which interest might be revived in those Groups where some stimulus was required, so the Society is now in the happy position of being supported energetically by 24 Groups which provide personal, local contact for their Members.

As each year passes, we are increasingly aware of the influence of the Groups working in this way, and particularly when their representatives come together for their meetings with the Council of the Society.

FINANCE

The general financial affairs of the Society were in a healthy condition during 1978, even though the normal running expenses showed an excess of expenditure over income, due not only to rising costs all round, but also to there being less donations and income from Deeds of Covenant and Legacies during the year. However, we were able to allocate £13,000 to fifteen new projects, this amount being equal to the sums raised by Groups and central fund-raising activities for this purpose.

WORLD FEDERATION OF HEMOPHILIA

The affairs of the World Federation were as dominant as usual, even though there were no Congresses. Indeed, this gave us an opportunity for reflection and a breathing space to consider topics raised at previous Congresses.

The Society was delighted to act as host at a meeting held in London in April, of the European Advisory Board of the World Federation, at which much valuable groundwork was put in for future co-operation within Europe.The unanimous election of our then Honorary Secretary, Mr. John L. Prothero, as Chairman of the EAB was noted with pleasure, and we trust that this will further the work of the Board. It is hoped that tangible results of the work of the Board will start to be seen in the forthcoming year, in many of the areas of haemophiliacs' lives.

Similarly, we were pleased to welcome the Council of the World Federation of Hemophilia later in the year, and to discuss with the members many of the problems that the Society has been dealing with recently. Their advice was greatly appreciated and we trust that they found the interchange of ideas as beneficial as we did.

THE RESEARCH SOCIAL WORKER

In accordance with the recommendations made by the Research Social Worker's June 1977 report, the co-ordinating role continued to develop. The greater emphasis on linking up families with the appropriate local agency nevertheless required, in the majority of cases, a re-assessment by the Social Worker of problem areas which needed special attention on initial referral. In 1978, the Social Worker was involved with a further 90 new cases and other contacts, whilst continuing with many of the families referred to her in previous years. Information and guidance were continually sought by Social Work Departments and other agencies, and this was much aided by the availability of the 'Introduction to Haemophilia' booklet. 'Notes for Health Visitors' and 'Notes for Teachers' were added to the series and a 'Notes for Occupational Therapists' is currently being drafted. These booklets were usually written in conjunction with representatives from the respective professions.

The organisation of Seminars for Social Workers and other Professional Groups became a major development. An Autumn Seminar entitled 'Haemophilia Today — An Interdisciplinary Approach' held in Manchester was heavily over-subscribed. A Special Interest Group which was held at the same place, entitled 'Employment problems in Haemophilia' occasioned support for an information leaflet for employers, which the Manpower Services Commission is considering as part of a series of leaflets already produced and distributed by them. At the same time, initial discussion developed on the possibility of setting up a Special Interest Group aided by the British Association for Social Workers, which would offer a meeting point for Social Workers from all Haemophilia Centres, thus leaving the Research Social Worker free to organise Seminars geared at a more local level catering for, and providing basic information to, Social Workers, Career Officers, Health Visitors, Employment Officers, Nursing Staff, GPs and so on. These Seminars could thus be held more frequently each year in different parts of the country. The success of the Seminars in previous years suggests a greater focus on this part of the Social Worker's role

In the middle of the year, the Research Social Worker moved to live in the Newcastle upon Tyne area. In view of the overall involvement of the Newcastle Haemophilia Centre in the field of Haemophilia on a local, national and international level, the geographic position of the Social Worker's office did not prove remote and co-ordination with the Executive Committee and the office staff in London was maintained. The Research Social Worker's post is a national one within the framework of the Haemophilia Society, itself a national organisation. Contact with and support from the Society's Groups continued to be an important part of the Research Social Worker's role.

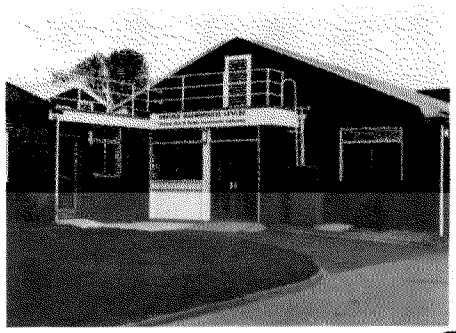
THE FUTURE

All our efforts in the course of the last year have helped us to realise that Members of the Society, as a result of the progress in treatment facilities, are now becoming increasingly free to travel throughout the world — no longer are they tied to living in such close proximity to their Haemophilia Centre.

One of our primary aims must now be to see that this sense of liberation and wellbeing is made widely available, so that others may come to share in these benefits and begin to live a full, satisfying life.

£250,000 HAEMOPHILIA RESEARCH APPEAL

The Research Appeal was formally launched at the Annual General Meeting on 28th April 1979, although some of our Groups had already started fund raising activities and had fixed their own targets, as part of our aim of £250,000.



Oxford and District Group has fixed figure of £30,000 of which £25,000 will be used to support projects at the Oxford Haemophilia Centre. On 1st April 1979 an Open Day was held and nearly 300 visitors were shown around the world famous Centre by members of the staff. Displays and photographs explaining all aspects of haemophilia and treatment; laboratory demonstrations; a continuous video film, based upon various television programmes; all combined to provide an informative, illuminating afternoon.

An information sheet was given to all visitors and this is reproduced in this Bulletin, with grateful acknowledgements to Dr. Charles Rizza and the staff of the Oxford Haemophilia Centre. We hope all members will use this information when seeking support for the Appeal and that they will write to their local newspapers and approach local organisations such as: branches of the Ladies Circle, Women's Institute, Townswomen's Guild, Rotary Clubs, Inner Wheels, Youth Clubs, and similar organisations.

The press release made to the large national, regional daily and weekly newspapers is reprinted below.

At the Annual General Meeting of The Haemophilia Society, held in Manchester on 28th April 1979, the Honorary Chairman, The Reverend Alan Tanner, M.A., announced the formal launching of a £250,000 Haemophilia Research Appeal.

The official launching date of 1st May reflects that this is a "MAYDAY" appeal, *an urgent call for help* by The Haemophilia Society, on behalf of all haemophiliacs.

Money is urgently required to support those hospitals specialising in haemophilia and allied bleeding disorders. There are projects already under way investigating the anti-haemophilia factor (Factor VIII) in blood. Where in the body is it made?

More investigation is needed into carrier detection and into pre-natal diagnosis.

What are the long term effects of regular Factor VIII replacement therapy?

Why do some haemophiliacs develop antibodies to Factor VIII? Can anything be done to rectify this?

Such research into these and other problems can relate and bring benefits to sufferers from other blood disorders in the field of haemostasis.

As a comparatively small group we sometimes feel that our needs are overlooked in the overall scope of health care and research and we therefore hope you will be interested enough in our problem to help us achieve our target by publicising the appeal.

For further information please contact:—

Kenneth Polton, MBE (Honorary Secretary),

Tel: GRO-C (office) or (home).

MY DAY

Pat Armin, Sister, Haemophilia Unit, St. Thomas' Hospital

My typical working day starts with my alarm clock. I then have a twenty minute bicycle ride to St. Thomas' in most weathers. As I am inside the hospital all day, I enjoy the air (fresh, apart from petrol fumes) in Hyde Park, at present busy with joggers of all shapes, ages and sizes. I know some of our haemophiliacs are jogging too.

Our haemophilia unit remains on the first floor of the South Wing, now the oldest part of the hospital. The treatment room and waiting area are festooned with PCs from your various holidays. I always feel it is a pity to receive correspondence only to throw it away or put it in a drawer to be forgotten. A psychiatrist will pin a label on that remark!

I clean up and restock the treatment room before going into the lab to collect patients' notes and checking with Prof. whether there are any additions to the day's programme. I then visit and, if indicated, treat our inpatients on the Wards. This may take until mid morning if we have arranged to take an assay (a test on a blood sample to determine a response to a given treatment), assuming a technician is available. Although we plan appointments and consultations during the day, any number of patients may visit or telephone with enquiries. Telephoning occupies quite a large part of my schedule whether it be answering queries from patients, ordering materials, arranging appointments or liaison with other departments.

The nurse's role within the unit has changed radically over the past few years. The changes are due to availability of factor VIII freeze-dried concentrates, thus making a home treatment schedule available and also due to the fact that St. Thomas' is the Haemophilia Reference Centre for the SE and SW Thames Regions. We have a Supraregional Haemophilia Nurse whom I work with in close collaboration. The Centre provides a seven day week, twenty four hour service to all our patients. I am available in the hospital either in the treatment room or by bleep, from 9 – 5.45 Monday to Friday; the evenings being covered by the medical H.P. I hand over the keys of our drug cupboard before I go each day, with any other relevant information regarding patients or treatments for that evening. The rota is compiled each week, but runs to a pattern so that we all know when we are likely to be involved. My role, I feel, is to liaise and generally be available to treat and advise patients, either in person or by phone. There are usually a few inpatients who need visiting daily on the Wards for assessment and/or treatment. I also undertake shopping,

After the morning round I then turn to the desk work. This involves recording all treatment and advice given in individual patients' notes, and on a computer record sheet. We have our own computer terminal in the department, and now that we have been using the system for several years, we are consolidating some useful statistics and information about all our 'bleeding' patients, which we hope leads to a better and a more efficient service. For instance, a haemophiliac telephones in to say that he has a painful right knee joint which, although responding to factor VIII treatment is bleeding frequently. We can then obtain from the computer the number of bleeds in that joint within the preceeding months and assess whether a prophylactic course of treatment is indicated, or a consultation with the Rheumatologist, Physiotherapist or Orthopaedic Department for advice.

Many departments within the hospital offer us their advice and support, namely the Dental, Orthopaedic, Rheumatology, ENT, Physiotherapy, DDU, and at times, the Medical and Surgical Firms. We undertake surgery, mainly dental, involving extractions, orthopaedic to correct or fix joints, and more recently the formation of arterior venous fistulas to improve venepuncture for individual patients who otherwise are unable to treat themselves. We want all our registered 'bleeding' patients to be as independent and self sufficient as possible, but to realise which problems they must bring to the Centre. These include difficulty with venepuncture, reaction to treatment, poor response to treatment, persistent problems with a joint, abdominal or cranial bleeds, persistent nose bleeds or persistent haematuria. There may also be a need for analgeisa assessment.

I order and pack up home treatment supplies when requested, and send them to the appropriate destination. Together with our Supraregional nurse, we are trying to organise a better system with the Blood Transfusion and Associate Centres so that individual patients can pick up factor VIII supplies at their nearest hospital. This should save both time and energy for the patient, and postage and expense.

Lunch is a moveable feast as I like to be available if and when a patient wants to come up in his lunch hour for treatment or advice.

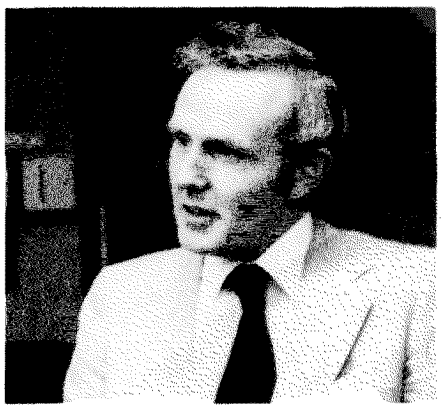
I like to feel that my role within the Centre is expanding to meet the needs of the haemophiliac within the community. My working day ends (several coffees later) with contacting the doctor on call for the night, and handing over

I enjoy my job and life in London very much. The interest and opportunity for me as a nurse and as an individual working in the Haematology Department in a large teaching hospital, brings me into contact with many different people. I never cease to admire the constant courage and cheerfulness shown by my patients as they trip (Oh no!) through the treatment room door.

At home, my day ends by checking that my alarm is on for the following morning!

HOME THERAPY

Dr. P. Jones.



The term 'home therapy' is used to distinguish intravenous injections of factor VIII or IX given outside the hospital setting. Although the first injections were literally given 'at home', the term now includes injections given at work or on holiday, as well as injections given by a patient to himself ('self-infusion') or by a trained relative or friend, or by a parent to a haemophilic child. It also includes both 'on-demand' and 'prophylactic' therapy.

When discussing haemophilia treatment all this terminology can be confusing — the really important point about the concept of home therapy is that the person with haemophilia and his family need no longer be totally dependent on a hospital for day-to-day care. Bleeds may be treated early without fuss, or loss of school or work, or play, and this early treatment should help in the prevention of disability in later life.

Much has been written about the cost of home therapy and some bureaucrats — none of them, so far as I am aware, with haemophilia in their families! — and others in the unenviable position of having to spread health budgets thinly in order to provide cover for many patients and many diseases, have suggested that this sort of treatment is an expensive luxury for the benefit of a small minority of people in need. "Why," they say, "can't haemophiliacs learn to live within the bounds of their disorder?"

One has only to think back 20 years to the misery of severely affected haemophiliacs who **did** live within the bounds of

their disorder (and who were confined to bed nursing bleeds, most of which had occurred spontaneously, for weeks at a time) to provide the answer. It is part of haemophilia folklore to imagine that sport and exercise expose a haemophiliac to an increased risk of haemorrhage. Nobody is suggesting that everyone rushes out to take up hang-gliding, but observations by families, and by professional workers at camps and sports meetings for haemophiliacs do suggest that only about one injury in 15 produces a bleed, and every severely affected man knows how inactivity predisposes to runs of bleeding episodes. **Home therapy means rapid therapy and provides a foundation on which to build healthy, muscular adults with stable joints.** It follows that the haemophiliac given the opportunity to practice home therapy has the responsibility not only to use it properly but also to keep himself fit and active.

And the true cost? The average annual cost of on-demand therapy for a United Kingdom patient is £2000. This sum would buy a month in bed in an NHS provincial teaching hospital, or ambulance travel for a patient living 40 miles from his Centre and requiring 34 treatments in the year – the average for a severely affected haemophiliac. If one considers the 90 per cent reduction in hospital admissions that follows the introduction of home therapy, it could be argued that our administrators had a bargain – without even taking into account savings in time previously lost from work by haemophiliacs and their relatives.

Why not, then, put everyone on home therapy, close most of the Haemophilia Centres and declare the doctors redundant!? The first reason is that most families are not emotionally ready for treating their affected children before the age of about six years. Before this age parents are still learning which symptoms to treat and which to leave alone, children are beginning to recognise that feeling ("aura") which heralds the very start of a bleeding episode – the key to successful home therapy – and veins may be difficult to enter regularly. It is in these early years that training for home therapy really starts; calm, unhurried and repeated consultation precedes that final day or two of technical training.

The second reason is that home therapy does not solve every problem of bleeding. Our results show that whilst about 80 per cent of bleeds are stopped with one treatment at home, 11 per cent of bleeds experienced by those on low-dose on-demand therapy still require a visit to hospital for more intensive treatment or specialised splinting. Nor does home therapy solve problems for people with factor antibodies (inhibitors).

Thirdly, everyone is aware that all medicines, including blood products, have side-effects. Haemophilia Centre Staff are trained to watch for evidence of these; careful and regular follow-up provides the necessary "early-warning system". This is why the detailed recording of every treatment given is so important. It is also why doctors in this country are reluctant to suggest that everyone with clinically severe haemophilia is prescribed prophylactic therapy – that is regularly spaced treatments which prevent bleeds. The majority of severely affected haemophilia A patients require much less factor VIII whilst using on-demand therapy at the beginning of a bleeding episode than they would inject if they were on prophylaxis. And in any case when a run of bleeds occurs into a particular site there is often an alternative method of treatment to factor replacement. The cost of prophylaxis is also high – about £5,000 for a patient in a year.

In this short article I have not tried to set out a detailed account of home therapy; people on this form of treatment should already have the United Kingdom Haemophilia Centre Director's Handbook (if they have not received a copy they should ask their Centre Director for one). It would, however, be worthwhile repeating the three golden rules of home therapy, rules on which so much of the success of modern haemophilia treatment depends:

- ***The earlier the better!*** (Early treatment prevents later damage).
- ***If in doubt, treat!*** (Trust the feeling that a bleed has started and treat it).
- ***A shot in time saves VIII – or IX!*** (Early treatment saves blood product).

Every year the Directors of Haemophilia Centres collect together figures on the number of haemophiliacs in the United Kingdom, and on the type and effects of the treatment they receive. Since 1975 figures relating to the practice of home therapy have been obtained for haemophilia A and these have shown a steady, if not unexpected, rise. By 1977 an estimated 60 per cent of people with haemophilia A* who, by generally accepted standards, should have been treating themselves or their children were receiving home therapy.

In comparison with most other countries, including America, this is pretty good going – especially when one considers all the difficulties there have been in obtaining sufficient factor VIII concentrate for National Health Service use. Before long we hope that everyone who wants to be on home therapy, who would benefit from it, and who is capable of performing the techniques involved safely will be treating themselves or their children at home.

Peter Jones

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Footnote:
*Comparable figures for haemophilia B – Christmas disease – will not be available for some months as they were not collected until this year.

WORLDWIDE

W.F.H. News

XIII INTERNATIONAL CONGRESS, WORLD FEDERATION OF HEMOPHILIA, ISRAEL, JULY 1979

There are still a few places left for people who would like to go to this Congress which was described in detail in the last issue of the Bulletin.

The Congresses of the World Federation of Hemophilia provide a forum for the world's leading experts on haemophilia and related diseases at which to expound on the latest developments in haemophilia care and to exchange ideas.

Any member, who has not already asked for details, but who would like to receive them, is invited to contact the Society's office without delay.

WIDER HORIZONS FOR HAEMOPHILIACS

Whilst there have always been haemophiliacs and their families, who have taken continental holidays, there have always been a large number who have felt that the risks of a bleeding episode, starting far away from home and their own familiar treatment Centre, was not worth the benefit that travel might bring.

The increase in Home Treatment has meant that there are now many more haemophiliacs travelling abroad; secure in the knowledge that they can now treat themselves; thereby freeing themselves and their families from many of their former anxieties. Many haemophiliacs are being given concentrates by their Centres, to carry with them for administration by a local doctor, although the problems of this are obvious.

Many haemophiliacs have had the feeling that, if only they could find out what the treatment in an area was like, before they went, then they would feel happier. We know that this especially applies to young haemophiliacs, many of whom have not been able to join in school trips abroad, and who have not been able to share in those exchange holidays with continental boys, that some of their friends have enjoyed. However, the Society is receiving an increasing number of requests, from the families of haemophiliacs in Europe, for pen-pals for their sons and for contacts with families in this country, who would like to arrange exchange holidays for haemophiliacs.

This is an ideal chance for young haemophiliacs to broaden their horizons and to travel abroad. Normally, of course, the British and continental families correspond first, so that each can satisfy

themselves that good haemophiliac care will be available to their son, and then details of the exchange can be properly worked out. Many pen friendships have developed and resulted in exchange visits.

If you, or your son, would be interested in taking advantage of any such opportunities, or would be interested in travelling to one of the special camps for haemophiliacs, that are often organised in the summer months, to give haemophiliacs the chance of a holiday in different surroundings, then you should let John Prothero, our European Liaison Officer, know through the Society's office.

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SOME FACTS ABOUT HAEMOPHILIA

The most important of the inherited bleeding diseases. Only men affected. It is uncommon.

There are about 72 haemophiliacs per million of the population in the UK, i.e. approximately 4,000 haemophiliacs in the UK.

Occurs throughout the world.

Known to occur in dogs and horses.

Excessive bleeding caused by lack of an important substance in the blood needed for normal clotting – factor VIII or antihaemophilic factor.

Deficiency of another substance, factor IX, produces a similar but less common bleeding disorder called Christmas disease.

Present at birth and can be diagnosed on a sample of blood taken from the umbilical cord when the baby is born.

Inheritance

All daughters of a haemophiliac are carriers but all his sons are normal. The sons of carriers have a 50:50 chance of being haemophilic. The daughters of a carrier have a 50:50 chance of being carriers.

In a quarter to a third of cases a family history of haemophilia is not known.

The degree of severity of the condition usually runs true in the family.

Severe haemophilia – the man with no factor VIII in his blood (0%) bleeds for little or no apparent reason. Life disrupted and tendency to become crippled unless bleeds are treated early.

IN SEVERE HAEMOPHILIA BLEEDING AFFECTS MAINLY JOINTS AND MUSCLES (APPROX. 95% OF ALL BLEEDS.)

Less severe haemophilia – more than 1 or 2% factor VIII in the blood. May lead normal, or near normal, lives unless injured or subjected to surgery, when they may bleed very badly and should be managed as severe haemophiliacs. Do not usually suffer crippling.

Superficial cuts and scratches are usually not troublesome. In babies and toddlers bleeding from the tongue or lip is fairly common. Haemophiliacs probably bleed more commonly into joints because the blood vessels in the lining of the joint are very liable to be damaged against the hard surface of adjacent bone. When the joint is damaged or inflamed as a result of previous bleeding further 'spontaneous' bleeds may occur for no apparent reason.

Treatment of haemophilia

Factor VIII is present in normal blood and factor concentrates are prepared from blood collected at blood donor sessions. The treatment of haemophilic bleeding is to give sufficient factor to completely prevent bleeding for as long as may be required for healing to occur.

A single small dose may be enough to arrest an early bleed from a small injury. This makes home treatment of minor bleeds possible, providing a suitable treatment material is available.

On the other hand large doses given every 12 hours over many days may be needed in the case of accidental injury or for surgery.

The cost of factor VIII for treatment may be great – £25 for a single small dose or perhaps many thousands of pounds to cover a major operation. A year's supply of home treatment could, therefore, cost £2,000 to £3,000. A single major operation could cost £2,000 to £6,000.

The cost of **not** treating haemophilia in terms of pain, disability, hospitalisation, disruption of family life, education, work and leisure is incomparably greater.

With advances in treatment there has been a great improvement in life expectation, e.g.

1840 – 88% died before age 21 (no treatment)
1940 – 66% died before age 21 (Blood transfusion only)
1979 – near normal expectation? (factor VIII Concentrate)

Diagnosis of carriers of haemophilia

May have a family history of the condition.

May have a lower than normal antihaemophilic factor level.

May bleed more than normally expected after injury, operations, childbirth, etc., and may even require a little antihaemophilic treatment to avoid excessive bleeding.

They can be diagnosed in 60–70% of cases.

The unborn baby in a known carrier can be sexed early in pregnancy and shortly it may also become possible to diagnose haemophilia in the baby before birth.

Reproduced by kind permission of Dr. Charles Rizza.

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The Royal Association for Disability and Rehabilitation (Radar) AGM will be on September 12th 1979. Venue to be arranged.

The Naidex Conference will be held from 20th–22nd November 1979, at the Wembley Conference Centre, London.

We are sure that all members are pleased to know that our Patron, Her Royal Highness, The Duchess of Kent, is now GRO-C GRO-C A letter expressing good wishes from members of the Society was recently sent to Her Royal Highness and the following reply, received from Mrs. Jane Napier, Lady-in-Waiting, was read at the Annual General Meeting.

"Thank you so much for your very nice letter with the message from your members. This has been passed on to the Duchess of Kent who was most grateful for their kind enquiries. Would you please tell all those concerned that Her Royal Highness was immensely touched by their thoughtfulness.

"Thank you for giving the date of your Annual General Meeting. The Duchess particularly asked me to send her very best wishes to you all and she hopes you will have an enjoyable and successful meeting."

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Points of View

Items in this column do not necessarily reflect the views of the Society.

From our member Mrs. GRO-A of Croydon, Surrey . . .

"I am writing to you on a matter of great happiness for me and my family, and I hope of interest to other haemophiliacs. My son, GRO-A aged 11, suffers from haemophilia, joined a stage school on Saturdays, from there he had the opportunity of auditioning for a part in Fagins Gang in the West End musical "Oliver". I am pleased to say he has got the part and has now joined the company. He is enjoying it very much. You will appreciate there are a lot of things that boys with haemophilia cannot do and therefore at times it becomes very hard for them. I therefore think this is a great encouragement for other haemophiliacs to know. The part includes singing and a little acting which is not strenuous. I have, however, discussed this with his doctors who are very pleased and support him. I hope this is of interest and, as I stress, of great encouragement to others, as it is very hard to find outside interests at this age, which they can enter and enjoy."

From the Ontario Chapter of the Canadian Hemophilia Society . . .

"Thank you for sending your Bulletin which we find informative, constructive, and alive with information."

From a doctor in Mid-Wales . . . **"I found your last Bulletin very interesting especially as regards the articles on inheritance and on driving licences. The latter raised points of law of which I was not aware and will be of help to me in my practice. Why not ask the British Medical Journal to re-publish?**

As regards inheritance — it has long been my feeling that not enough attention has been paid to the sisters of haemophiliacs and the problems they face."

From the Director of a Haemophilia Centre . . .

"Recently one of our severe grade haemophiliacs was locally examined for a mobility allowance, for which he had applied, and the request was declined. The refusal was reviewed by the appropriate Board who sent me a pro-forma to complete on the patient's behalf. In my completion of the form it was my ability to quote from the extract from Hansard which you quoted on the front page of edition 28 of the Bulletin which probably made the difference. The Medical Officer reviewing the refusal reversed the decision and the patient has now been granted the allowance."

MISCELLANY

"The Future for Voluntary Organisations" Nicholas Hinton, Director, The National Council of Social Service. The debate on the Wolfenden Report about the future of voluntary organisations has provided a backcloth to the work of many voluntary organisations in 1979. If only one thing could be accomplished in 1979, it ought to be gaining the acceptance of Central and Local Government of four principles to be applied in their dealings with the voluntary sector.

The first principle is, the ability of volunteers and voluntary organisations to increase significantly the resources available to meet demands. The second principle implies recognition of the fact that, some services are qualitatively better, if they are supplied by the voluntary sector and that, wherever appropriate, professional workers should act as consultants supporting the supporters. The third encourages organisations to act as critics of the status quo and to be innovators. The fourth principle recognises that involvement in voluntary services provides an opportunity for people to contribute to the services which impinge on them and their communities.

Ref: *Social Work Today, Volume 10, No. 18 2179:*

GRASS ROOTS

A new Group of the Society has been formed, based in Dundee, and will be known as the "TAYSIDE GROUP". The Group will work in close liaison with our Scottish Group and has already raised over £2,000, a large proportion of which will be used to support the work of the Haemophilia Centre at Ninewells Hospital, Dundee.

Will any member wishing to participate in the Group's activities please write to Mr. D. D. Edward (Chairman), "Glenora", Lochlands Drive, Arbroath.

Text of talks given to the Council of the Haemophilia Society on 17th March 1979 by Sister Gill Davies, lately of the North East Thames Regional Blood Transfusion Centre, and Sister Sheila Dykes of the Haemophilia Reference Centre, St. Thomas' Hospital.

Sister Davies

This job started in 1974 when, in our Region, the working party on haemophilia from the Regional Association of Haematologists was very keen to expand its Home Treatment Programme and to organise haemophilia care in the Region. The working party members were very aware that they needed to link up hospital and community care in the Region, so they put their heads together and decided that one of the best ways of dealing with the problem was to appoint a State Registered Nurse to co-ordinate everything for them. They approached the Haemophilia Society and asked if it would fund the post for one year and then hopefully, they would be able to get the National Health Service to take the post over. This is what happened and Cheryl Astor, who had worked as the Sister at the Royal Free Hospital Haemophilia Centre for a couple of years, was very keen to start the job off, although she was only able to do the job for 9 months before she emigrated to Australia. She was based at the Blood Transfusion Centre at Brentwood, which is in the middle of the North East Thames Region. This is where I came in, as I was working there as a Staff Nurse and I used the 9 months to get some haemophilia experience myself and then took over from her when she left. As I mentioned, the Association of Haematologists thought it would be best to have this job based on the Blood Transfusion Centre. It was slap bang in the centre of the Region which was handy and they thought that, if the sister wasn't biased towards any of the Haemophilia Centres, it might work slightly better from that point of view. I am not sure if that was the case or not, but I do think it was a wise choice to use the Blood Transfusion Centre as a base.

I would like to tell you a bit about our role. The first thing we did was to identify all the haemophiliacs in the Region. There was a lot of donkey work in the beginning which involved visiting every hospital which had a haematology department in the Region, getting all the Notes out and finding where all the haemophiliacs were and, of course, it meant visiting the 8 Haemophilia Centres. From all this information we compiled a Regional Register, which was one of the things the haematologists wanted. We ended with a list of 'Who's Who', their Factor VIII levels and other informati and found we had 520 patients, whi staggered everyone! The Regional Register is kept at Brentwood and gives all the information about all the patients so that the doctors at all the 8 Haemophilia Centres have the information readily available. This was quite handy, because it gave me the opportunity to assess the facilities available at all the Centres. I could see which was operating a Home Treatment Programme, which had facilities for surgery, which gave orthopaedic care, rheumatological care, which gave genetic counselling, which could do dental care and which of them gave a 24-hour service.

Once we had got this groundwork done, each Centre was keen to expand their Home Treatment Programme, or to get a Home Treatment Programme started, if they had not had one previously — of our 520 patients, only 25 were on Home Treatment. So together with the Directo of each of the Haemophilia Centres, we selected the patients we thought were suitable for going onto Home Treatment. I did a Home Visit to each patient we thought suitable, checked the home environment, saw who in the family was going to do the venepuncture, whether it was the patient himself, or a relative, checked whether they had a telephone, whether they had a fridge or a freezer so we could determine whether they would be using Cryoprecipitate concentrate and then, finally, I visited each patient's GP to put them in the picture and to see whether they were keen, as the haematologists thought this was very important.

Once all this work was done, we had another meeting with all the Centre Directors. If we still thought the patient was suitable, we went ahead and started their training. That was either done by myself, if they lived near to Brentwood, or to where I lived, or if they lived nearer to a Haemophilia Centre, they found it easier to go there, but one way or another, we got them trained. Once they were

established, we let them go home with their supplies and I visited them about once a month to carry on their supervision and to make sure they were managing OK, and I also ran a delivery service. You know yourselves the problem of picking up Cryo with the cold boxes and what have you, so I ran a 'Cryo on Wheels' service to a lot of them. This was useful because I could bring back all the dirty syringes and needles and dispose of them at Brentwood. I had about 7 patients who were quite housebound, so they did really rely on me to take the supplies out to them. After the 2 years we have 60 patients on Home Treatment, so we did well, I think.

As you can imagine, the Home Treatment Programme did take up about 90% of my time, especially as the Region was so big which means much time travelling around. But there was, of course, a lot of other work to do. I attended many of the Clinics that each of the Centres held. They were either the Clinics for the Home Treatment patients, where they come up regularly every 3 months for a thorough check to see how they were going, or the regular clinics at the hospitals held to see if anyone else was suitable to go onto Home Treatment. I also visited a lot of the inhibitor patients. I could not do very much for them, except offer them advice, but even that took up a lot of time. I also went to see many dentists to see if they would undertake any of the routine care of some of the patients, to save them traipsing up to their Haemophilia Centre all the time, and I managed to persuade quite a few dentists that their patients were not going to dissolve into pools of blood in the surgery and so managed to get some to undertake routine care.

I had quite a lot of contact with Social Workers and Health Visitors. We held joint meetings and solved quite a few of the haemophiliacs' problems in that way.

The Haemophilia Working Party still met quite regularly. The Haemophilia Centre Directors also got together from time to time and I attended these meetings to discuss how the haemophiliacs were getting on in the Regions.

Keeping the Register up to date took quite a lot of time and I used to ensure that the Centres kept giving me details of the new patients so that I could add them to the Register. We used to find quite a few new patients cropping up. When I went to see GPs to discuss Home Treatment with them, they would often suddenly say "Do you know about such and such a patient down the road?" I would take their names and addresses and then find out they weren't on the Register at all. We managed to find about 20–40 patients in this way who were haemophiliacs, but who weren't registered at any Centre. I arranged to go and visit them and tell them about the Centres, get them up and registered. 3 or 4 of these patients ended up on Home Treatment. When going to see haemophiliacs, they would tell you of a distant cousin or uncle, and it was amazing how many cases we picked up in that way and subsequently managed to help.

Being based at the Blood Transfusion Centre helped me quite a lot, because I had a check on the supplies of treatment material. We have a stock of concentrate there which I kept up, so that each of the hospitals knew that, in an emergency, there was a reserve of concentrate there. If any of the doctors wanted to undertake planned surgery they knew they could telephone me and I could tell them what state the reserve stocks were in and they could go ahead and plan the surgery.

I think that is a quick résumé of my work.

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Sister Dykes

My post came into being in May 1978 and I was given the splendid title of Supra-Regional Nurse Coordinator for Haemophilia, which I think really covers a lot of things! It was envisaged that my role would be to help with case finding throughout the Supra Region covered by St. Thomas' Hospital, to assist in liaison on the provision of Home Treatment and to teach people in order to ensure that the most suitable care and management should be available to all haemophiliacs. My working relationships were to be with medical, nursing, technical and administrative staff, patients and the general public. My first task was to become familiar with the Supra Region which is made up of the South-West and South-East Thames Regions which cover Surrey, Sussex, Kent and South London, so it is quite a large area. It includes the Haemophilia Reference Centre, 7 full Haemophilia Centres, 15 Associate Centres and 2 other hospitals where local haemophiliacs can receive treatment. I think that one must remember that, with the Associate Centres in particular, some of them are more than willing to help with the immediate crisis, but were only too happy to get you off the premises soon after, whereas others are delighted to do as much as possible, including minor surgery. So there is a very wide range when you turn up on the doorstep as to what exactly is available. I visited all these hospitals and met all the Directors and Haematologists concerned and have very much appreciated their willingness to help and cooperate. I took the opportunity on these visits to compile a Register of patients, but I am slightly concerned as to how accurate it is and I would not like to depend on it entirely. It contains the names of 600 patients suffering from haemophilia and related disorders, although the latter are not fully recorded and I know some have since moved out of the Region. I kept the information down to a minimum and I use it really as a basis for my own work. If any enquiry comes in to me then I can put the enquirer on to the Centre Director concerned so that he can deal with it. I have only discovered one family, with a history of Christmas Disease, that was not aware that a treatment was now available, and when I got in touch with the mother I got the rather sad reply that I was "25 years too late." Apart from that, my case finding really has been more an exercise to ensure that all haemophiliacs are formally registered and attached to a recognised Centre.

Much of my work at some of the Centres has been to implement Home Treatment Programmes. These programmes had not previously been started because of shortage of staff for teaching purposes, an unawareness of the benefits of Home Treatment and sometimes through a shortage of Factor VIII supplies. I have been able to assist by being available to give instruction on Home Therapy, to discuss with Directors who would be suitable candidates and potentially benefit the most from Home Treatment and when a shortfall of Factor VIII supplies has been a serious problem, a reallocation of the existing NHS supplies has been arranged to ease, although I am afraid never to exactly solve, the problem. I think it would be fair to add that the reallocation of the supplies has only been possible by the larger, more favoured Centres in the past, relinquishing some of their supplies in order to support the smaller Centres, and the larger Centres now have the burden of purchasing supplies in order to maintain the standards they have set.

At Centres where people were already on Home Treatment, I have tried to give ideas based on past experience as to what changes might be practical to improve the general care and management of the haemophiliac.

As well as visiting the Centres, I have also been able to make home visits and again I very much appreciate the kind reception that I have had from everyone that I have visited. The visits have been made for a variety of reasons, including instruction on Home Therapy, supervising treatment within the home situation and to help teach a haemophiliac to do his own venepuncture where previously it had been done by a parent. I have also made visits to people who were already well established on Home Treatment, as much to get ideas and suggestions as to what improvements and changes they would like to see in existing arrangements as for me to assess how they were getting along on Home Treatment.

Home Treatment isn't the answer for everyone, especially those only needing infrequent treatments, but these families, I think, have welcomed visits to discuss problems that they have had, and also to

be taught how to give care and when to give it, so that they can learn to carry their own supplies when travelling, especially abroad. I think it is a help when faced with a non-English speaking foreign doctor, that you at least know which way up the syringe is going and that at least everything is going satisfactorily and this has given them freedom and more confidence. Beside personal visits and the inevitable telephone communications, another valuable source of contact for me has been through local Groups of the Haemophilia Society, who have been very friendly and kind towards me.

Unlike Gill, I have been based at St. Thomas' Hospital and I found it most helpful to have this close connection with the Supra Regional Reference Centre. I think perhaps I might also add that I was working there for 3 years previously, so I already had very close connections. I did find that through working there I had a knowledge of the area and I have been able to answer queries coming in from and about, the Region, and I could also keep the Reference Centre Director in touch with the news of the Region. Through helping at the Centre, I have been able to keep in touch with current treatments and new developments in management.

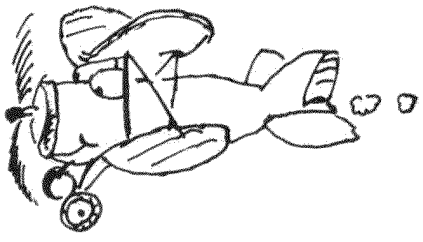
I have assisted at follow-up clinics at the Centre for those on Home Treatment and this is something that I would like to see more widespread within the Region. Meanwhile, the staff at St. Thomas' have been willing to see and help assess other haemophiliacs from within the Region at the request of their Centre Directors. St. Thomas' has a computer system, to record the bleeding episodes, the material given to each individual, etc. which I think the Society already knows about, as it has helped with the funding. It is hoped that it will soon be possible to extend this system within the Region, and having already worked with the existing system, I would be ready to help implement it.

At the end of an exercise I believe one should review one's original aims and objectives and assess what one has achieved. I find this very difficult and I hope the answer is going to come from you. But changes there have certainly been and progress made and I would like to think I have had a hand in these changes, but nothing would be possible without the concern and interest of the medical staff of each of the Centres and the determination and indomitable spirit of the haemophiliac himself and his family. I personally am much indebted to my Reference Centre Director, Professor Ingram, for his continuing encouragement, help, support and interest and to the Haemophilia Society for their generous financial support in funding this work and thus making it possible at all.

In answer to questions, Sister Dykes and Sister Davies made the following points:—

The South-East and South-West Thames Regions have each got about the same general population, but there are more haemophiliacs recorded in the South-East Thames Region, although it is not known why.

TRAVEL INSURANCE, INCLUDING MEDICAL EXPENSES COVER, FOR HAEMOPHILIACS



The Society is pleased to announce that a breakthrough has been made in the field of travel insurance for haemophiliacs. Messrs. Burgoyne Alford & Co. Ltd. and Brookdale Brealey (Insurance Brokers), via Lloyds of London, in conjunction with Lloyds Brokers, have arranged a travel policy so that a person having haemophilia, or an allied disorder, can go abroad, secure in the knowledge that he will be properly covered on the medical expenses section of the policy, as well as all other sections.

There will be certain warranties and requirements but these are no more than any prudent Society member would expect. For instance, he will be required to have a letter from his doctor saying that he is fit to travel. Furthermore, he should take with him sufficient concentrate to be treated, either by himself, or by someone else, should the occasion arise. Full details of these and other requirements are shown on the proposal form, which may be obtained solely from Mr. D. Rosenblatt of Brookdale Brealey (Insurance Brokers) of 60 Bartholomew Court, High Street, Waltham Cross, Herts. Telephone No. Waltham Cross 31971.

It cannot be emphasised too strongly, that the long term success of this new scheme will largely depend on our members' not abusing it and their making absolutely certain that they make every effort to see that avoidable claims do not arise. There is no philanthropic figure in the background with an inexhaustible fund of money, who will be happily making payment of medical expenses for those haemophiliacs who have failed to make proper provision for themselves, before going abroad.

Claims paid out to members will come from a pool of money which is provided from the premiums paid by our members and their friends when taking out this new policy. The fate of this opportunity is, consequently, in our own hands.

So that the fund may be made as large as possible, members are urged to ask their families and friends, i.e. non-haemophiliacs, to effect normal travel insurance, again with Lloyds, via Mr. Rosenblatt at the firm's name and address given above. The standard Lloyds policy is competitive and has good cover. In this way the new scheme, which is of great importance to all members, will have every chance of continuing to provide insurance for haemophiliacs against unfortunate and unforeseeable illness or accidents whilst abroad.

Mr. Rosenblatt will be happy to answer any queries members may have.

The new cases found in the North-East Thames Region were split about half and half between severely affected and less severely affected, but they had had no contact with a Centre and were just sitting at home like hermits, and even their GPs did not know of Centres and Cryo. They were so glad to go to Centres and be registered and find out what treatment was available for them now. Often some of the cases with a family history of haemophilia were the worst. Because nothing could be done for Grandfather they hadn't got round to checking if anything could be done for the present generation! Many of these had been living well away from a Centre and yet now some were on Home Treatment and their lives had been revolutionised, and for the first time in 20 years they are getting out and about. This does show the average GP who probably has no haemophiliacs 'on his books' often does not himself know of the present position with haemophilia treatment. Those that did, were often relieved to learn of the Home Treatment programme because they had been worried as to what they could do if they had been telephoned with a problem. Some patients were found to have been registered at a Cen[redacted] for some years, but had not attended [redacted] treatment as they had not previously been made aware of the availability of modern treatment.

If a Social Worker is involved who really knows haemophilia and is interested, they can be invaluable, but so often they do not know what is involved and it can take months to explain matters and what is needed, so that frequently Centre Staff tend to deal with the problems of their patients themselves.

It was found that if a visit was made to schools when a haemophiliac was applying to enter, but before he started, it was possible to smooth the ground, let them know what it would be like having a haemophiliac in the school, advise them about what sports they could play and what activities they could undertake. It often helped them decide to accept a haemophiliac, when they might not otherwise have done. The schools w[redacted] usually very pleased and very grateful to have the information, but it was more difficult if the child was already there, when sometimes a school would ring up in a panic and need problems sorting out straight away.

In the North-East Thames Region the Register of Patients is kept at Brentwood and is available on a 24-hour basis, so that if a patient ended up at a Centre, the Director could ring up Brentwood where the Register has quite a bit more information than that on the patient's 'Green Card' and this has been used quite a few times and has been found to be very valuable.

In the South-East and South-West Thames Regions they do not keep the Register on the computer and there are strong feelings in one of the Centres that the information should not be freely available, so their Register is very much for use by Sister Dykes for her own purposes and she is rather more inclined to refer enquiries back to the patient's Centre.