Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392144

The Bulletin

Vol. 29 No. 1 1979

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

Member of the World Federation of Hemophilia
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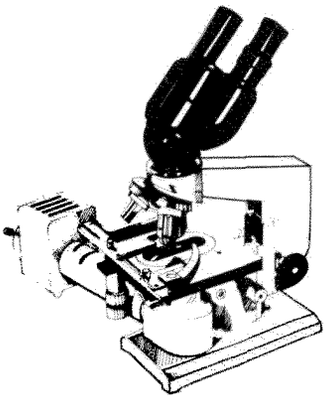
Assistance Act 1948 and the Charities Act 1960 (230034)

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

£250,000 RESEARCH APPEAL



During the past year or so it has been noticeable that the number of approaches made to the Society by hospitals have increased, not only in number, but also in variety. This is partly due to the cutbacks in expenditure made by some of the Health Authorities but it is also a consequence of the expansion in the scope and responsibilities demanded of Haemophilia Centres.

Because of these increasing demands the Council of the Society decided at its last meeting to launch a Research Appeal with a target of £250,000. It is essential that all members give their support, either through their local Groups, or as individuals.

Naturally many people resent the fact that money still needs to be produced from charitable sources for items which should be forthcoming from the National Health Service. There is a good deal of talk these days of people getting their fair "slice of the N.H.S. cake" and much of the work of the Society is to ensure that haemophiliacs and their families are not left with only the crumbs.

It is important, however, that we demonstrate our faith in those hospitals and doctors who are working to solve our problems. They do not expect "cake" from us but "bread"; the basic staff of life. We, therefore, hope that all, who can, will help to ensure the success of this Appeal.

News will be given in future Bulletins, together with information on fund raising and the projects we will be supporting so, please, "watch and help"!

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Annual Subscriptions

Membership renewals are now due and we ask all members to send their £1 subscriptions as soon as possible. Also, at this time, donations will be particularly appreciated.

It is as important now, as it has ever been, that all haemophiliacs should support the Society. It is a matter of some concern to us that there are many haemophiliacs, and parents of young haemophiliacs, who are not members and who do not feel that the Society is necessary or that it holds any advantages for them.

Perhaps the tremendous strides that have been made in recent years in the development and provision of treatment are responsible for this attitude, but those of us working within the Society know that however rosy things may appear, if haemophilia is in the family then problems of one sort or another eventually arise. It is then that the Society is asked for help.

This is not a pessimistic attitude, rather it is a realistic one. Haemophiliacs are probably among the most optimistic and philosophical people in the community (for reasons which we hope are obvious!) and it is because we are always seeking a better future that the Society exists.

If you know of any haemophiliac who is not a member, perhaps at the hospital you attend, please exercise a little gentle persuation (no arm twisting please) and try to recruit them!

By joining the Society they help themselves and, more important, others, perhaps less fortunate.

K. R. Polton, M.B.E.
Honorary Secretary

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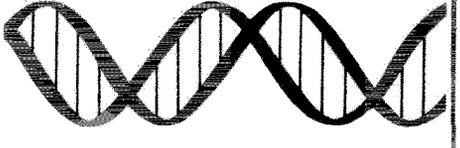

THE INHERITANCE OF HAEMOPHILIA

By Prof. G. I. C. Ingram

Haemophilia is inherited because wrong instructions for synthesising factor VIII are included in the haemophiliac's genetic package. The relevant information is carried by a gene on the X chromosome. The reason why haemophilia is almost exclusively a male disorder is because men have only one X chromosome. All the other chromosomes are paired; so if one of these is faulty, the normal member of the pair can often make up for the defect. Women do have two X chromosomes, and this is why women who are "carriers" seldom have bleeding symptoms: the normal X chromosome usually makes enough normal factor VIII for the woman's needs. The man's single X is 'paired' with a different sort of chromosome called a Y which does not carry the same genes.

At conception, a child receives a copy of one member of each pair of chromosomes from each parent, so that the right number is maintained. This is why a son (4,6 – see diagram) cannot inherit his father's (1) haemophilia because, to be a boy, he must have a copy of his father's Y chromosome, and he obtains his X as a

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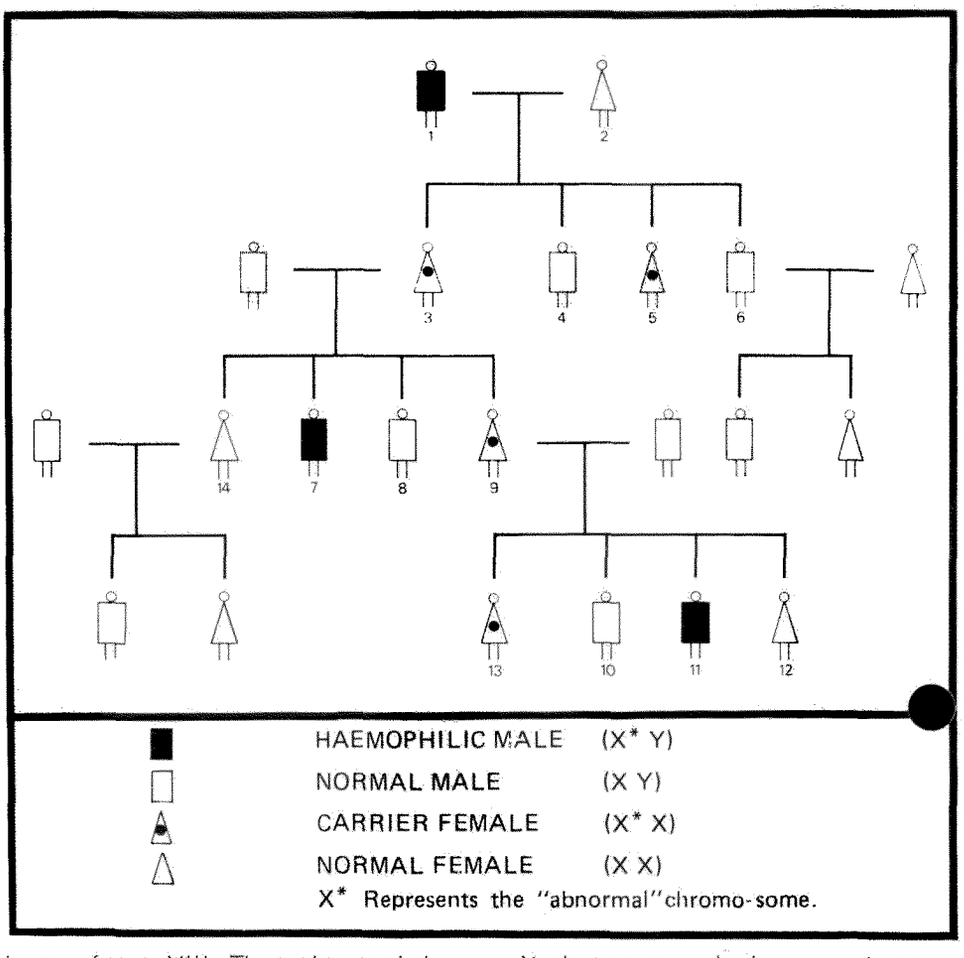
copy of one of his normal mother's (2) pair. It also explains why, ***on average,*** only half the boys in haemophilic families are affected (haemophiliacs 7, 11; non-haemophiliacs 8,10), because with each pregnancy there is an equal chance of the abnormal or the normal X chromosome being passed on from the carrier mother (3,9). For the same reason, ***on average,*** half the sisters of haemophiliacs (or girls in haemophilic families) are carriers (carriers 9,13; normal 12,14). Of course, in any given family of a few children, the proportions may not be equal, just as in a few tosses of a coin one would not expect to get exactly half heads and half tails. It also follows that all the daughters (3,5) of haemophiliacs must be carriers, because girls must receive a copy of an X from both parents, and that means that they must have a copy of their father's "haemophilia" chromosome since he has only the one X to copy. So the three rules of inheritance in haemophilia can be simply stated: all the sons of a haemophiliac will be normal and will not transmit the disorder; all the daughters of a haemophiliac are carriers; and each pregnancy in a carrier has a 50 : 50 chance of producing a haemophiliac if the baby is a boy or producing a carrier like the mother if the baby is a girl — and of course the same chances that the boy or the girl will be normal. These chances are the same with each succeeding pregnancy; and so it may happen that a woman who is a carrier does sometimes have only normal sons. This pattern of inheritance is illustrated in the diagram, which is similar to that which appears in the centre pages of the little green booklet issued with Haemophilia Cards. If we look at it from the point of view of the daughters, one can put it this way: the daughter of a haemophiliac knows that she is a carrier; but the sister of a haemophiliac doesn't know whether she is or not, she only knows that she has a 1 in 2 chance.

When we come to real families we can sometimes go a little further. Suppose the sister of a haemophiliac has a daughter herself but no haemophilic sons. This daughter has only a 1 in 4 chance of being a carrier, because probabilities multiply together (½ x ½). Again, if no haemophilic boys appear in that generation either, ***her*** daughter's chances fall to 1 in 8; and so on. If normal boys are born in either of these two generations, the grand-daughter's or great-grand-daughter's chances fall a little further still; but as soon as a haemophilic boy appears, his mother is thus shown to be a carrier, and the chances of the other women concerned have to be adjusted accordingly. The exact probability of being a carrier can be calculated for any given woman from her relationship to the haemophiliac nearest to her in the family and from the number of normal boys born to the relevant women who may be carriers.

There is another way in which a woman's probability of carriership may also be calculated. It happens, in haemophilia, that although the factor VIII does not work properly in the clotting mechanism, it still reacts with an antibody made by a rabbit injected with normal human factor VIII. These characteristics provide two ways of measuring factor VIII: a clotting assay and an estimation with rabbit antibody. In haemophilia, therefore, the clotting assay records low but the "rabbit" test gives a normal result. Now a carrier woman synthesises a mixture of the two sorts of factor VIII — the normal kind directed by her normal X chromosomes, and the haemophilic kind directed by her abnormal Xs. This test for carriership therefore consists in measuring the woman's factor VIII by both methods and seeing, first, if the clotting assay reads rather low, and second, if the rabbit measurement is higher than the clotting assay. This gives important additional evidence on carriership, but the interpretation of the results is complicated by two things.



The first problem is that the actual level of factor VIII in a given individual is affected by other genes besides the one on the X chromosome. This produces a wide range of values in normal people, a difference of about 4-fold between the lowest and the highest. Carrier women similarly show a wide range about their average value of 50% of the normal mean, so that half of all carriers will be expected to have factor VIII levels which overlap the normal range, and thus only the other half will be detectable on the criteria of factor VIII level alone. However, even carriers within the normal factor VIII range can show the discrepancy between the two methods of measurement, so that this criterion can still be applied. Unfortunately there is a further difficulty; and to understand this one, one more piece of background information is needed. The point is that, although women have two X chromosomes, both men and women are constructed to operate with only one active; so that women have to inactivate one of their pair in each cell of the body. The decision on which to inactivate seems to be taken at random by each of the small group of cells forming the very early embryo, and the proportions then established are subsequently maintained. In the normal woman it does not matter what the proportions are; but in the carrier it could result in a high proportion of her cells using the normal X, and so the clotting and rabbit measurements would give nearly the same result and her carriership would be difficult to detect. Since any proportion between the two Xs may occur in different carriers, the best way of handling the situation is to calculate the probability of carriership from the level of the clotting activity of VIII and from the proportion between the results of the clotting and the rabbit results, taken together. This probability may then be combined with the probability obtained from the family relationship to give the best estimate of the chance that a given woman is a carrier.

When the chances have been calculated, three points must be made. The first is that these manoeuvres can never give more than a probability; although it happens that a result strongly suggesting that a woman is a carrier is rather better founded than one suggesting the opposite, an absolute "yes" or "no" cannot be given. The second point is that the calculated chances must be put into perspective against the possibility of ***any*** pregnancy producing an abnormal child, which is somewhere between, say, 1 in 50 and 1 in 100 depending on parental age

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and other circumstances. If a woman related to a haemophiliac is told that the chances of being a carrier are of this order she may feel that she would be prepared to take a risk similar to that which is faced by any woman who conceives a child. The third point is that the risk must also be put into perspective against the severity of haemophilia in the particular family. If a haemophiliac son ***is*** born to the woman in question, his factor VIII level will be likely to be about the same as the levels found in his affected relations.

A word should be said about how female haemophiliacs may arise. First, there will be a small proportion of carriers who happen to be operating on nearly all their abnormal Xs, and so will produce very little normal factor VIII. Secondly, if a haemophiliac happens to marry a carrier, their daughters will be either carriers or "true" female haemophiliacs who have both Xs carrying the abnormality; this has happened with cousin marriages in haemophilic families. Thirdly, there are [redacted] ways in which the chromosomes may [redacted]huddled up in forming the germ cells, and these events may occasionally produce a true haemophilic daughter when only one parent carries the defect. Briefly, what is the situation in the other inherited clotting disorders? The family pattern of Christmas Disease is exactly like that of haemophilia, so that the chances of carriership can be calculated from the family relationships in the same way. However, in different families there are different kinds of abnormality in the factor IX, so that no one laboratory test will do for them all. The situation is still being worked out and the efficiency of the various carrier tests which may be required is not yet known. In von Willebrand's disease, which also affects factor VIII, both sexes are equally affected so the mutation is not on the X chromosomes but on some other pair. The picture of inheritance is more complicated [redacted] we used to think, because there is [redacted]ably more than one variety of the condition. In one sort, it seems that there are no symptoms if only one chromosome of the relevant pair is affected, but severe symptoms occur if the abnormality is received from both parents so that both chromosomes in the pair are affected. In these families the parents will be apparently normal and some of the children affected. In another form, mild or moderate symptoms occur if one of the pair of chromosomes is affected; and here the disorder will pass down the family only through persons who are themselves affected. The severity of symptoms may however vary from one affected member to another, so that the mildest will be difficult to detect and so it is difficult to say who ***cannot*** pass it on. The rarer clotting defects, affecting other factors, are inherited in one or other of the pattern just described for von Willebrand's disease. In some families following the second pattern it is possible to detect carriers of either sex even though they may have only very mild symptoms. Generally speaking, a severe disorder is only likely if the same genetic abnormality is inherited from both parents; but all these other disorders are so rare that this is very unlikely to happen unless the parents are related.

Anyone wanting help in understanding their own position in a family with a bleeding disorder, especially if they are wondering whether or not they are a carrier, should arrange to see the director of Haemophilia Centre to which the affected person is attached, to discuss their own situation and to have tests done if appropriate.

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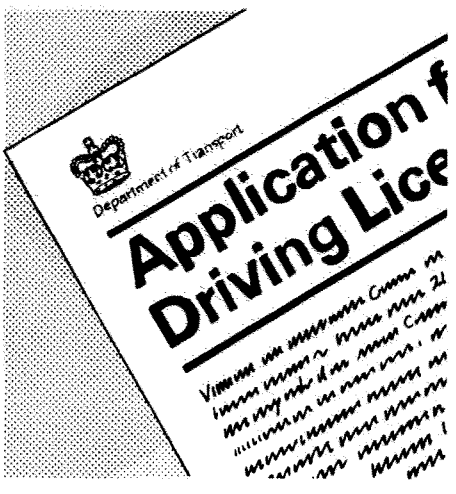
HAEMOPHILIACS – THE QUESTION OF DRIVING LICENCES AND MOTOR CAR INSURANCE



In order to obtain a considered legal opinion, the Society has taken advice from a barrister through a firm of instructing solicitors.

1. DRIVING LICENCES

Road Traffic Acts require a driving licence applicant to state whether he is suffering from a "disability" (including "disease") which could fall into either one of two categories:—

(a) A "relevant disability" would be one where the driver's disability is likely to be an immediate source of danger to the public. The barrister says that in all but the most minor cases the applicant should ask his doctor's opinion in deciding whether he has a "relevant disability".

(b) A "prospective disability". This is where, at the time of application, the haemophiliac does not have a "relevant disability" but could have such a disability in the course of time. An example would be where a haemophiliac suffered repeated knee bleeds which reduced the joint's efficiency.

Again, the barrister states doctor's advice should be taken. In the case of "prospective disability", the licence would be granted for a limited period so that the position could be subsequently reviewed but the application would not otherwise be affected.

In normal circumstances the £5 driving licence fee covers the applicant up to the age of 70 years but if the licence is only granted for a limited period (which is usually 3 years) no further fee is payable when the next application is made.

Licence holders must inform the Secretary of State (through the licensing authorities) if they have a new disability or there is a change in degree of disability at any time.

The barrister appreciates that it could be difficult for a haemophiliac to disclose his disease if he has not done so previously. Unless there has been a gross misrepresentation, he feels that the licensing authorities would be very slow to take any action in connection with previous non-disclosure.

Finally, the barrister advises that a doctor's letter should accompany the application in all cases where it is necessary to disclose the disease (which would apply to most haemophiliacs unless they are extremely mild).

If a haemophiliac has any specific queries regarding driving licence applications, please write to the Society's Office marking the envelope "Driving Licences/MJR".

2. MOTOR CAR INSURANCE

In applying for motor car insurance, a haemophiliac needs to be even more careful. If details of a disability are not told to prospective insurers on a proposal form, the company (on the grounds of non-disclosure of a material fact) could repudiate liability following a claim.

A proposal should always be accompanied by a doctor's letter preferably from the Haemophilia Centre attended by the proposer. In most cases, for new insurance applications, the doctor's letter is likely to state that he thinks the haemophiliac is fit to drive a car. This assumes he is fairly young and will have been properly treated for the last 10 or more years. Normally, no great difficulties occur and arrangements have been made with one particular insurance company via the Society's insurance advisers.

In case of difficulty or anyone requiring advice, please write to Mr. David Rosenblatt, c/o Brookdale Brealey (Insurance Brokers), 60 Bartholomew Court, High Street, Waltham Cross, Herts. Telephone No. Waltham Cross 31971. Mr. Rosenblatt is a member of the Society's Executive Committee. He has helped in obtaining this information for members, as well as advising members of the Society on a whole range of insurance matters.

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"Haemophilia is expensive, very expensive, but it is more costly not to treat the patients. How do we assess the expenditure for disability and disorder?"

With acknowledgement to the Editor of the WFH Bulletin.

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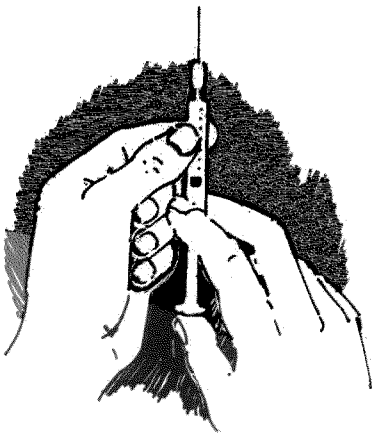
BOXFILE

FREEZE-DRIED FACTOR VIII CONCENTRATES AND THE N.H.S.



Bleeding in classical haemophilia (haemophilia A) is due to a deficiency of factor VIII coagulant activity, and its treatment consists in giving intravenous injections of material rich in this factor. Human factor VIII is best, but in patients who have antibodies to factor VIII animal factor VIII may also be of value.

At present human factor VIII is available in Britain in the form of cryoprecipitate prepared by the National Blood Transfusion Service or as a freeze-dried protein concentrate prepared by the NHS fractionation laboratories in London, Edinburgh, and Oxford. The introduction of cryoprecipitate as a source of factor VIII in 1964 was an important step forward in the management of haemophilia and did much to improve the lot of haemophiliacs, but it is difficult material to handle, is variable in potency from bag to bag, and needs to be stored at temperatures below −20°C. In contrast, the freeze-dried factor VIII concentrates have the advantages of known potency, stability at +4°C, ease of reconstitution before transfusion, and a low risk of allergic reactions. These advantages are of particular importance now that home treatment is being used increasingly in the management of haemophilia, and haemophilia centre directors generally agree that most if not all of the material used to treat haemophilia in Britain should be freeze-dried concentrate, preferably made within the NHS.

Unfortunately, the amount of factor VIII concentrates made by the NHS fractionation laboratories still falls far short of the needs of haemophiliacs. The most recent published figures, for the year 1975, showed that there were some 3000 known haemophiliacs in Britain, two-thirds of whom required replacement treatment with factor VIII at frequent intervals. These patients had received about 25 million units of factor VIII in that year. Of the material used, 65% was in the form of cryoprecipitate; 12% freeze-dried NHS concentrate; and 20% commercial factor VIII. In 1977 there is every indication that nearly 40m units of factor VIII were used for the treatment of haemophilia: 36% was in the form of commercial concentrates; 29% NHS freeze-dried concentrate; and 35% cryoprecipitate. Commercial concentrates cost about 10 pence per unit of factor VIII activity, so that this use of commercial material represents a cost to the NHS of about £1½m per annum. This is money that many experts think would be better spent in promoting the manufacture of factor VIII and other important plasma fractions within the NHS.

Besides the problem of cost there is also growing concern about the increased risk of transmitting hepatitis with commercial factor VIII concentrates prepared from large pools of plasma. Blood collected from paid donors (the source of most commercial concentrates) is 10 times more likely to contain hepatitis B virus than is blood collected from unpaid donors by national blood transfusion services. Craske ***et al*** have recently published the results of a retrospective survey of transfusion hepatitis associated with certain brands of commercial factor VIII.

The shortage of factor VIII in Britain has been widely publicised in the past few years. In 1975 the Government claimed in the House of Commons that Britain would be self-sufficient in factor VIII by July 1977, and to this end a grant of £0.5m was given to the Blood Transfusion Service. Now, three years later, we are still not self-sufficient, and one-third of all the factor VIII used has to be purchased from commercial firms. Why is this? It is not lack of skill, since some of the most able and experienced plasma fractionators in the world work in Britain. It is not lack of fractionation facilities: there are three fractionation centres in the country, none of which is working at full capacity, though to meet the target of 40m units of freeze-dried factor VIII per annum there will almost certainly be a need for extension of facilities in both blood transfusion and fractionation centres. Shortage of plasma is probably not an important reason, though the supply of plasma available for fractionation is still limited by the resistance of some physicians and surgeons to the use of red cell concentrates instead of whole blood.

The explanation of the shortage probably lies in the fact that even with adequate financial support it is difficult to switch from relatively small-scale to very large-scale production in under five years. Major changes are needed in blood transfusion practice, plasma transport, plasma processing, and distribution of products. The outlook is not all pessimism, however. We may not have reached the rather optimistic target set by the Department of Health in 1975, but there is already evidence of a substantial increase in the amount of factor VIII produced within the NHS, with production in 1977 twice that in 1976. All the factor VIII needed in Britain could be provided by the NHS laboratories in the form of freeze-dried concentrates provided that the DHSS invests enough money in blood transfusion centres and fractionation centres and has clear plans for the transition to self-sufficiency.

Reproduced from the
British Medical Journal, 25.11.78
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The Northern Ireland Committee for the Handicapped has opened an information service for disabled people in Northern Ireland. It was opened in January after six months of collection and classifying the information bank.

The information is disseminated through a subscription service to professionals and voluntary organisations, and it is hoped that both professionals and disabled people and their families will use the files and the library.

Further information from Rosemary Whalley, Information Officer, Northern Ireland Committee for the Handicapped, 2 Annadale Avenue, Belfast BT7 3JH: Tel. Belfast 64001.

from: Social Work Today, 16.1.79

WORLDWIDE

W.F.H. News

XIII INTERNATIONAL CONGRESS OF THE WORLD FEDERATION OF HEMOPHILIA

Tel Aviv, Israel, July 8th — 13th, 1979

The XIII International Congress of the World Federation of Hemophilia will be held in Israel. The Congresses of the World Federation of Hemophilia have become well known as outstanding events for all those interested in the care and wellbeing of Haemophiliacs, and the Organising Committee for the forthcoming Congress have made every effort to ensure that this Congress maintains the same high standard.

The first day of the Congress will be devoted to a guided tour of Jerusalem and Bethlehem, and will enable the delegates to meet old friends and to make new ones, whilst enjoying the magnificent sights of the area. The opening ceremony will take place that evening, and the following four days will be occupied by a one day General Assembly of the World Federation of Hemophilia, three days of

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Scientific Sessions, Symposia, Workshops and Conferences. The matters to be covered vary widely and will include The Mechanisms of Blood Coagulation: Current Understanding; Molecular and Genetic Aspects of Factor IX; Hemophilic Arthropathy: An Unresolved Problem; Hepatitis in Hemophilia; Factor VIII and Factor IX Inhibitors; Prenatal Diagnosis; Laser Surgery in Hemophilia; Everyday Problems of Young Hemophiliacs: A Patient's Point of View and Psychological Aspects. There are special social events organised for accompanying persons and for the evenings. It may also be possible to arrange for further time to be spent in Israel after the Congress.

There is a unique feature to this Congress as there will be a Youth Camp held between 10th and 12th July. The Programme includes Swimming, with a special competition; Parties, Special Sightseeing, Discussion Sessions and Seminars. Medical personnel and Concentrates will be available at all times. The number of Youth Camp places is limited to 60, so prompt booking is essential.

This Congress is attracting a lot of interest from people who are anxious to participate in its unique blend of up-to-the-moment information on Haemophilia, historical setting, Youth Camp and 24 hour care of any bleeding problems that may arise during the Congress and Camp. The Haemophilia Society is organising a Group to travel to the Congress so that doctors, scientists and members of the Society can benefit from the price reductions that this will bring. The prices vary, depending on the grade of hotel chosen, and whether the room is shared or not, but it is estimated to be between £293 and £429. This will cover the flight to Tel Aviv by Scheduled Flight, bed and breakfast at the hotel of the class chosen, and a day sightseeing. The Registration fees payable for the Congress vary from £33 for a haemophilic youth to £76 for a delegate, who is not a member of a Haemophilia Society. All the registration fees will go up £5 to £10 if registration is made after March 1979, and are here quoted at the current rate of exchange, payment being in dollars. The registration fee covers participation in scientific sessions, social events (except optional events), tour of Jerusalem and Bethlehem, and Full board and lodging for the Youth Camp participants (the rate quoted above for Group Travel would be corrspondingly reduced).

Any readers of the Bulletin who would like more details of the Congress and the Group Travel arrangements should write to John Prothero, European Liaison Officer, at the Society's offices, P.O. Box 9, 16 Trinity Street, London SE1 1DE.

MISCELLANY

RATING (DISABLED PERSONS) ACT 1978

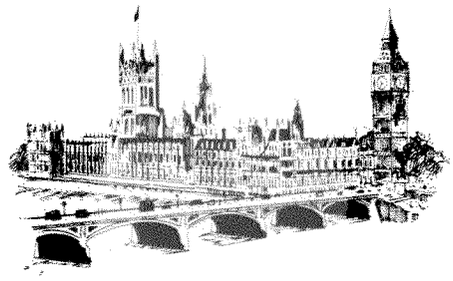
New laws governing the payment of rate relief to the disabled have been given Royal Assent.

The Rating (Disabled Persons) Act 1978 clarifies the circumstances in which rate relief on property is available; it provides for relief to be given in the form of a rate rebate; it specifies for certain facilities the amount of relief to be paid, and extends the type of institutions which are eligible.

The Act specifies that in England and Wales, standard amounts to be rebated from rate bills for certain facilities required for meeting the needs of a disabled person. Standard deductions include, for the use of each room, a sum equal to the rates that would be chargeable on a rateable value of £30, on a bathroom £20, on a lavatory £10, on floorspace for the use of a wheelchair £30, on a garage £25 or as assessed, on a carport £15, and on land for parking a vehicle £5. Deductions for heating appliances and other facilities will be subject to individual assessment by District Valuers.

The Act, which comes into force on 1 April 1979, originated as a Private Members Bill introduced by Mr. Robert Hughes MP (Aberdeen North) and had full Government support. The Department of the Environment will be issuing advice about the administrative arrangements for the new scheme and the way in which relief should be applied for.

from: Dept. of Environment
Press Release, July 1978



Mr. Edwin Wainwright, the Member of Parliament for Dearne Valley, who won 7th place in the Ballot for Private Member's Bills, today, 15th December 1978, announced the aims of his Bill to give further help to the chronically sick and disabled.

Mr. Wainwright said:

"The Chronically Sick and Disabled Persons Act, which Alf Morris piloted through Parliament in 1970, was a milestone in our social legislation.

"First, my Bill will give the disabled person a right to go to Court if a local authority fails in its duty. Under Section 2 of the 1970 Act an authority must provide a service when it is satisfied that the disabled person needs it. While enormous general progress has been made in improving services, some bad authorities still try to dodge their responsibilities. My Bill will, therefore, allow the disabled person to apply to the County Court for an order compelling the authority to do its duty.

"My Bill will also strengthen the law on access for disabled people to public and social buildings. At the moment, if a developer says it is unreasonable or impracticable for him to make a proposed new building accessible to the disabled, there is very little that can be done. My Bill will place on the developer the responsibility for **proving** that it is unreasonable and impracticable. This will give disabled people the opportunity to challenge any developer who refuses to accept that the disabled have as much right as anyone else to enter public and social buildings.

"Other provisions of my Bill will seek to affirm the rights of disabled people and strengthen their representation on committees set up to advise public authorities on social policy."

Summing up, Mr. Wainwright said:

"My Bill is intended to underline the importance of the most humane Act of Parliament on the Statute Book." (i.e. The Chronically Sick & Disabled Persons Act 1970.)

from: A House of Commons
Press Release, 15th December 1978

Errata in Edition 28 No. 4 1978, p. 6, para. 3, line 7 of Scheme Success: "grants of £30 per week for six months in a trial period of employment" is incorrect. The grant is payable for six weeks only, with the possibility of extensions up to thirteen weeks in special cases.

"House Hunting Made Difficult"

Article by Sue Tester, Research Officer at L.S.E.

The complexity of administrattive processes for assessing and meeting the housing needs of disabled people is high-

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lighted in Housing Services for Disabled People (HD Occasional Paper 3/78 DoE. £1.10) the report published last month by the Department of the Environment.

An application to the housing department for priority rehousing on grounds of disability is assessed mainly on medical criteria by a medical officer such as the district community physician who awards priority categories or medical points. In many boroughs top priority for immediate rehousing can be awarded even if a disabled person has few points for other housing need factors. This means little, however, unless enough suitable housing is available for allocation.

The medical officer's decision is based on the applicant's details of how his ability is aggravated by housing conditions, and on reports requested from G.P.s, environmental health officers, social workers or health visitors. Occupational therapists, skilled in assessing mobility and housing needs, are however rarely consulted.

Allocation officers rarely have enough information on the housing features needed, the nature of the disability and the urgency of the need, to make appropriate allocations. Nor are they given adequate details of suitable units available or nearing completion.

Since the joint circular, Adaptations of Housing for People who are Physically handicapped, the housing department or housing association should now be taking responsibility through government subsidies under the Housing Acts, for structural adaptations to their property. In the private sector the adaptation may be financed by the SSD but the client may be assessed to pay part or all of the cost: it may be advantageous to apply for an improvement grant. Before adaptations are made permission must usually be obtained from the property's owner and building regulations must be satisfied.

The long delays experienced by disabled people waiting for priority rehousing or adaptations are caused by the shortages of suitable housing and of staff, particularly OTs, the complexity of the administrative process and the apparent lack of cooperation and communication between departments.

As the handicaps produced by different housing circumstances for people with different disabilities vary so much there is a limit to the possible standardisation of procedure. Careful consideration to individual solutions will always be necessary, but the present situation, when special pleading is needed to produce results in many cases, is clearly unsatisfactory.

Field workers and voluntary organisations must continue to press for urgent cases and keep attention focused on the difficulties faced by clients and those who help them.

Community Care, 11.1.79

YOUR PROBLEMS

your letters answered by Vicki Stopford

N.B. Unless otherwise stated, letters or part of letters for this page will be written to allow anonymity and correspondence will continue to be treated with due respect to confidentiality.

Dear Vicki,

I will be leaving school this summer and want to start work at Michelin. The Careers Officer who comes to our school didn't seem to know whether this would be possible as I have Christmas Disease.

GRO-A

Dear GRO-A

Many thanks for your letter.

It may be that your Careers Officer is not familiar with Haemophilia or Christmas Disease and, therefore, did not know how to advise you. I enclose some general literature including a booklet written for the Careers Service which I hope you will be able to pass on to her.

Obviously, a lot depends on the nature of the work which you intend to do at Michelin, but perhaps you could discuss this with the staff at your Haemophilia Centre. Your Centre could also clarify your medical condition and individual limitations concerning manual work with your school and the Careers Officer involved, should they feel particularly uncertain about this.

It is sometimes useful if your Careers Officer clarifies any doubts about employing someone with Haemophilia with your prospective employer. There will shortly be a leaflet for employers available from both Haemophilia Centres and Job Centres.

I wish you every success.

Dear Vicki,

We have two boys both with severe haemophilia. GRO-A is 11 years old and GRO-A is 12 years. Because of my husband's job, we rarely get away on a family holiday. Do you know of anywhere the children could go on their own? They are on home treatment but GRO-A ankles have been bad over the last two years now and he still has to go to the hospital pretty regularly and sometimes he needs a wheelchair at school. We have heard from our Local Group of some exchange to France.

Mr. & Mrs. GRO-A

Dear Mr. & Mrs. GRO-A

Thank you for your recent letter concerning a holiday for your two sons.

It may be possible to arrange an exchange with boys of similar age from a French family and if you would like to consider this further I could pass on your enquiry to the World Federation of Hemophilia. However, in France, there is a school similar to the Lord Mayor Treloar College who have a holiday scheme for a month in the summer. I enclose initial details. The School will of course be able to provide adequate medical care and liaise with your sons' own Haemophlia Centre.

There are a number of projects in this country for children with a physical handicap. One example is 'Break' which arranges holidays throughout the year for the able-bodied, physically and mentally handicapped children. (Accompanying adults or holiday groups are welcome too.) Further information of their scheme can be obtained from their Director, 'Break', 20 Hooks Hill Road, Sheringham, Norfolk N26 8NL. Tel. Sheringham (0263) 823170/823025.

It would be useful to discuss your holiday plans with your own Haemophilia Centre so that they can advise or make suitable arrangements for treatment.

If I can help further, please do not hesitate to let me know.

Dear Vicki,

Can you help me with my problem? My wife left 6 months ago and I live on my own with my 3 year old son who has haemophilia. I believe it is only mild but he had attended the hospital for treatment. Let me make my position clear, I do not want to give up my job, which I have had for twenty years, and is a good one. My mother-in-law has had GRO-A up till now but she is too old to manage any longer.

My wife and I became members of the Society last year.

Mr. GRO-A

Dear Mr. GRO-A

Thank you for your letter and I was sorry to learn of your difficult circumstances at this time.

I think you may find it helpful to discuss alternative arrangements for the care of your son with your local Social Services Department. One possibility would be to leave your little boy with a child-minder during your working hours. The Social Services Department will have a list of registered child-minders in your area. It may be useful to ask the Director of your Haemophilia Centre to clarify, with the child-minder and the Social Services Department, the nature of your son's condition. If he needs hospital treatment only infrequently, suitable arrangements for transport to the hospital,

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when at the child-minder's, could probably be made with little inconvenience to all. There will of course be a Social Work Department at the hospital who would be only too pleased to assist you, should you prefer to contact them. I enclose some general literature on haemophilia for you to pass on to the Social Services Department and a 'Notes for Parents' leaflet.

For your information there is a National Federation of Clubs for the Divorced and Separated. The address is:— 13 High Street, Little Shelford, Cambridge. Tel: Shelford (02204) 2544.

As you are members, I wondered if you are in touch with the Society's Scottish Group. I enclose details, as it is possible that a local member may be able to help further.

All good wishes.

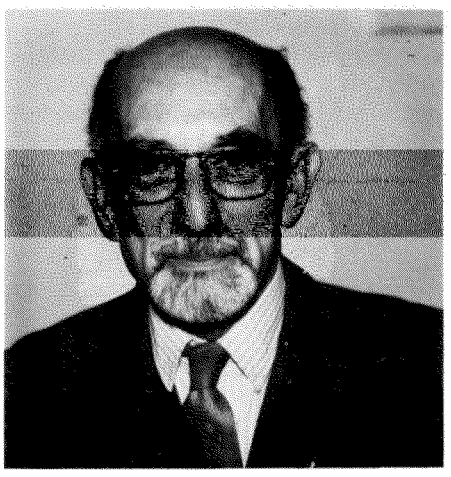
GRASS ROOTS

"YOU AND YOUR GROUP"

For some time now I have felt that the members of some Groups are not taking part in Group events to the extent that one could expect. This has been made abundantly clear at our Group representatives' meetings when the same view was expressed by various members. Often, when visiting and addressing a Group, I should have liked to express my thoughts on this matter in strong terms, but I always felt that it would be unfair to those who attend the meetings because they are not the ones who need a good telling-off. In this edition of the Bulletin I can reach all our membership and, perhaps, those of our friends who are not playing their part in the life of the Society, or in the activities of their Groups.

The Groups do not run themselves. All of them are kept alive by members who have the welfare of others at heart and who want to see improvements in treatment, and better prospects at schools and work for all haemophiliacs. Your Society is run, almost entirely, by these unpaid helpers. Why leave it all to them to do? Why not help? Without the commitment of its members the Society could not have helped to achieve present standards of treatment, and remember, there is yet more to be done! The Society's 24 Groups need your help and time and I appeal to you to do your share. Moreover, the Society and its Groups are helping to shape **your future**, so that in your own interest, you should participate. A large and active membership is needed to give the officers of the Society the backing they need to fight your battles.

The individual Groups which need your help and support are of vital importance. Three times a year the Groups send representatives to meetings, where everybody can, and does, express his, or her, Group's opinions and ideas and puts forward suggestions, which are often used as guidelines for future policy. **You** select these representatives of your Groups and your Group officers. They need you to encourage them, to back them and to make them feel that they are doing well for you. Four Council meetings a year, attended by your representatives, also give the Groups a chance to make their presence felt. Few decisions are taken, in Council, without the Group's support. The part your representatives play is such, that without them, the Society would lose much of its strength and influence in the world. At the risk of repeating myself, I again want to point out to you that your representatives **must** know that you are behind them, giving them your support and that they really are representing your views and reflecting your problems. If you want your views to be heard and known to your representatives then your best course is to participate in your Group's activities and help those in the Group to help you. Remember they need you just as you need them. Please do not fail them. If you try to fight your own battles you will soon find out how little you can achieve without the strength of your Society behind you. Without your active participation there will be **no Groups, no representatives, no Society!** It is as simple as that.



I have not found it easy to write to you so forcefully, but you all know me, or have heard of me, so I hope you will believe that I have said what had to be said. With your help, we shall grow in size and strength and we shall finally achieve our aim — a full life for all haemophiliacs.

Dr. L. Kuttner
Group Liaison Officer

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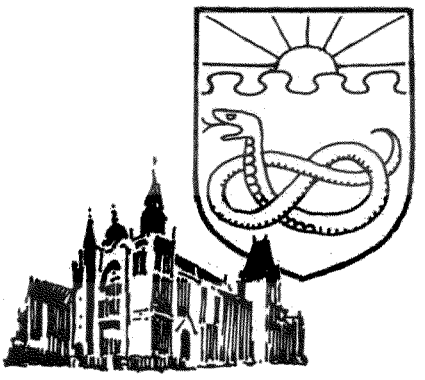
With acknowledgement to the Editor of the WFH Bulletin.

*"Reflect, also, that national or individual **self-sufficiency is an illusion. Unless we work together, locally and internationally, through haemophilia organisations, we** could become expendable in a world beset with decreasing resources and increasing shocks to its system".*
"Vigilance, you are condemned to eternal vigilance. If the haemophiliacs or the doctors relax in their efforts, whether material or mental, betrayal will ensue, from within and from without".

ANNUAL GENERAL MEETING



The Society's Annual General Meeting will be held on Saturday, 28th April 1979, at 11.30 a.m., in Lecture Theatre LG12 in the Faculty of Arts Building, Manchester University.

This will be a short meeting to conduct the formal business etc., and will be followed by a buffet lunch. In the afternoon there will be guest speakers and a panel discussion, during which members will have the opportunity to ask question on the subject of "Psychological problems relating to Haemophilia".

A formal notice of the meeting will be sent to all members in due course but, meanwhile, we would be grateful if anyone intending to go to the meeting would let us know if they will require the lunch.

Our North West Group is very kindly acting as host at the meeting and can advise you about suitable overnight accommodation, if required.

★★★★★★

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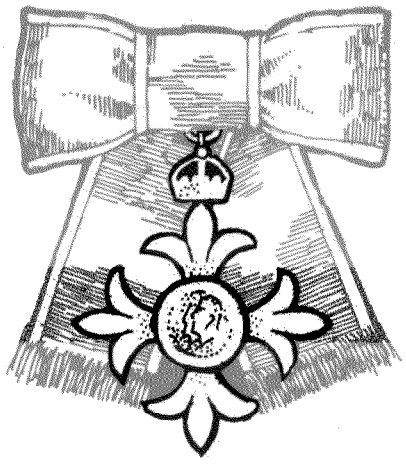

HONOURED

Sister Lillian June McElnea of the Hospital for Sick Children, Great Ormond Street, was made an M.B.E. in the New Year Honours List.

BALL PENS

We still have some of our Ball Pens available at the price of 10 for £1, or a display drum containing 50 for £5.

The pens, in red and white, are retractable, and are inscribed "Haemophilia Research".

All proceeds go to our Research Fund.

Please send for a quantity now!

STAMP CLUB

Many thanks to members of our Merseyside Group, who for the past year have been collecting stamps, which have been sold for £23. Remaining stamps will now be used for Stamp Club members.

If you are interested in joining the Club, or can donate any foreign stamps, please write to:—

Bob McClenaghan,

GRO-C

GRO-C Lancs **GRO-C**

W. BRANDIS & CO. LTD.

(Specialists in Bakery Products)

are delighted to contribute towards the cost of this Bulletin.

LYON ROAD, MERTON, SW19 2SF.

COMPETITION —
compiled by Ken Milne

We are offering two prizes, each of £5.00, for the most correct answers to the questions below. One prize is for competitors under 15 years of age, the other is for competitors of age 15 or more. Send your answers to:—

Ken Milne (Bulletin Competition),
The Haemophilia Society,
P.O. Box 9,
16 Trinity Street,
London SE1 1DE.

Closing date for receipt of entries will be 20th April 1979, and the names of the winners, and the correct answers, will be given in the next issue of the Bulletin. In the event of a tie, the winner will be chosen by lottery.

Don't be discouraged from entering because you don't know ALL the answers — you may still know more than the other entrants.

ENTRY FORM

Name .....

Address .....

.....

.....

Date of birth (if under 15) .....

1. Why is Christmas Disease so named?.....

.....

2. Which blood group is:—

(a) Least common? .....

(b) Second most common?.....

3. Which breed of dog is believed to have been introduced into Britain by the Normans, after 1066?

.....

4. (a) By whom was Cryoprecipitate first prepared?

.....

(b) In what year? .....

5. Which is the bigger needle — 19 or 21 gauge?.....

6. By what other names can Christmas Disease be described?

.....

7. Who tried to steal King Charles II's crown jewels?

.....

8. Which Haemophilia Centre (according to the DHSS) is:—

(a) The furthest East in Great Britain?.....

(b) The furthest West in Great Britain?.....

(c) The furthest West out of Liverpool, Sheffield and Edinburgh? .....

9. Which 18th Century American Lawyer studied the genetics of haemophilia?.....

10. Alexis, last Czarevitch of Russia, was a haemophiliac:—

(a) What relation was he to Queen Victoria?.....

(b) How many of his four sisters would, **most probably,** have been carriers? .....

(c) Who wrote the book "Nicholas and Alexandra"?

.....

(d) Who played Alexandra in the film "Nicholas and Alexandra"? .....

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