Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392145

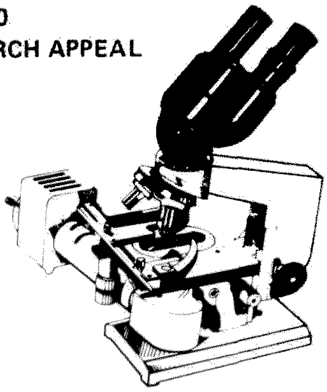
The Bulletin

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

Member of the World Federation of Hemophilia
Registered in accordance with the National
Assistance Act 1948 and the Charities Act 1960 (230034)

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

£250,000 RESEARCH APPEAL



On the 1st May 1979 our £250,000 Research Appeal was officially launched as a "MAYDAY" appeal and, although getting off to a slow start impetus has increased so that in under one year over £40,000 has been raised.

About 75% of this sum has come from our Groups so ably led by their local committees, whose hard work and enthusiasm are a marvellous example to us all. The variety of events organised and sums raised are almost unbelievable!

Most Groups have made substantial donations and we would especially mention Northern Ireland £10,000 – Merseyside £2,700 – Jersey £1,900 – Great Ormond Street £2,200 – Northampton £2,000 – North West (Manchester) £2,500 – South Wales £2,500 – Northern (Newcastle) £2,700. Other Groups, some quite recently established, have played their part and details are given in this Bulletin.

Individual members have also sent generous contributions and organised fund raising functions and a stream of letters regularly leaves our office addressed to companies, trusts etc., seeking help and support.

Grateful thanks go to all those concerned in raising the largest amount ever achieved by the Society in such a short time. This money has been raised by people not only for hospitals, which they themselves attend, but also for hospitals in other areas, where, in the judgement of the Society's Council and Medical Advisory Panel, the projects being undertaken will be of most benefit and value to haemophiliacs and their families.

One such project is that on "Pre-natal Diagnosis of Haemophilia" being carried on jointly by Professor Arthur Bloom and Dr. Ian Peake (who have been awarded the French Haemophilia Association's International Prize for their work on a new assay method for Factor VIII) at the University of Wales, Cardiff, and Dr. Reuben Mibashan and Mr. Charles Rodeck of King's College Hospital, London.

In the past some women, who were likely to be carriers, when told that their unborn child was male, chose to have their pregnancy terminated, rather than risk the birth of a haemophiliac son. This, of course, meant that some normal babies were being aborted.

Now, thanks to new techniques developed in co-operation by the two hospitals mentioned, it is possible to determine whether or not a male foetus has haemophilia.

This is a tremendous step forward and can fairly be described as "life saving" work. It is an advance which could transform the lives of many carriers, some of whom have refrained from having children, or even from marrying, because of the possibility of having a haemophilic son. It will obviously be of interest to all haemophiliacs with a daughter, a sister, a cousin, or other female relative, who may be a carrier.

Because of the importance of this work the Society has responded in a positive way to requests for financial help from the two hospitals concerned. £10,000 has been granted to the University Hospital of Wales to pay for a Research Technician for 2 years and £12,606 to King's College Hospital for Research Staff and new Coagulometer Instruments.

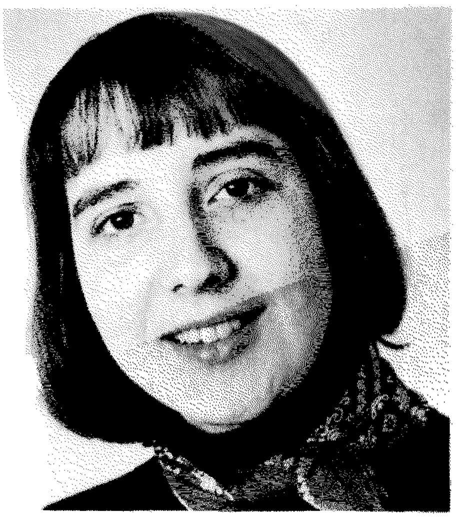
In our Bulletin No. 3 in 1979 we anticipated that "further calls will probably be made upon the Society's Research Fund in the future to finance projects in this comparatively new and exciting field".

These calls may have arrived more quickly than expected but we feel sure that all in the Society will agree that the grants made are fully justified and will bring the day nearer, when there is a national pre-natal diagnosis service available to all who need it.

We hope that you will continue to give your support, in every way possible, to our Research Appeal.

CONTENTS

VICKI STOPFORD



Readers of the Bulletin will be familiar with the features of Mrs. Victoria Stopford, the Society's Research Social Worker, for her photograph appeared regularly to mark her column, "Your Problems".

In her replies to letters from members, Vicki revealed a wide-ranging acquaintance with all aspects of haemophilia and the needs of our members. She dealt with the severely practical matters such as caravan holidays and the benefits available from various agencies but she was equally well-informed about the social and emotional factors which are so evident in families which have a child with haemophilia.

We became so used to having Vicki as the Society's Research Social Worker that we do well to remember how much time was spent by the Executive Committee in preparing for the appointment of a full-time member of the staff. Even after careful study of similar appointments in other organisations it was clear that our own appointment would be in the nature of an experiment.

So it was that Vicki came to us in 1974. Her previous experience as a Social Worker, after she qualified in 1968, had largely been with Local Authorities, with a special responsibility for Mental Health, but she quickly settled into her new environment and mastered the language of haemophilia with remarkable ease.

As we look back on her five years with the Society, we can see how Vicki approached this pioneer work with enthusiasm, skill and patience. One of the most valuable aspects of her work has been in arranging a series of Seminars in various parts of the country, when Social Workers have been given the opportunity to share their concerns with a view to improving the facilities available at their Centres.

From these Seminars, and as a result of her own research, Vicki gradually produced a comprehensive set of booklets providing essential information for people with haemophilia and those involved in caring for them professionally. The "Introduction to Haemophilia" series covers notes for Social Workers, the Employment Services, Careers Officers, Teachers and, of course, for Parents! More than twenty booklets and specialist pamphlets were written by Vicki for Social Work Agencies and other Professional Groups so, had she stayed with us much longer, we would have found ourselves in difficulty due to shortage of library space!

During her time with us, Vicki added to her family by the arrival of Benjamin and then Elizabeth and she took in her stride the move to Newcastle when her husband Martin became Deputy Director of Corporate Planning at British Shipbuilders. By some means or other she also found time to finish her reading in Social Sciences and proceeded to her degree as a Bachelor of Arts of the Open University.

After five years with the Society, Vicki, and those who advised her, felt it was time to move on to other work and it is an indication of her standing among her peers that she was invited to become a lecturer in Sociology at the North Tyneside Polytechnic.

Vicki is well suited for such a demanding appointment and her pupils will be fortunate in having a tutor who, apart from being a specialist in her subject, has the compassion and sensitivity to help people in coping with their problems.

We have good cause to be grateful that Vicki stayed with us for so long and we bid God-speed to her, Martin, Benjamin and Elizabeth as she takes up the next phase of her work. **A.T.**

GRASS ROOTS

The activities of the Society's Groups, particularly during the past year, have reached a peak of achievement of which we can all be proud and grateful. Thanks to the funds raised we are able to finance projects which a few years ago we could not have even considered supporting.

The brunt of the work naturally falls upon Group Committees who give their time unstintingly. For example, our Birmingham/West Midlands Group Committee either organised or were present at 24 events between June and November 1979 to raise funds. A marvellous effort!

But Committees cannot do it alone. They rely upon the support of all members in their area if they are to succeed. If you are not in touch with the Group in the area in which you live please write to the name and address given in this Bulletin.

You will then be kept informed of the social and other activities being organised from which so many members obtain a great deal of enjoyment, support, and of course knowledge of what is going on locally with regard to haemophilia and its problems.

Pressure of work, home commitments etc., very often prevent members from participating as fully as they would wish but even if you cannot become actively involved your attendance at a meeting, a jumble sale, or a carnival, or just selling raffle tickets indicates support which is very much appreciated and encouraging.

So, if you are not already in touch please write to your local Group NOW!

Addresses are given in the following brief account of Group activities.

BIRMINGHAM/WEST MIDLANDS

A total of over £1,600 was raised last year, most of which is for the Research Fund and to support the holiday caravan. A variety of events, ranging from stalls at markets, fairs and carnivals to darts contests were held regularly throughout the year. A recent Newsletter stressed the importance of haemophiliacs attending the six monthly clinics at their Haemophilia Centre. Excellent advice – especially for those on home treatment.

Birmingham and Midland Group
Mrs. J. R. Owen, GRO-C
GRO-C

BRISTOL

Illness and other difficulties have prevented the Group from being very active during the past year. Plans are in hand to organise a meeting – can you help?

Bristol & South West Group
Mr. W. C. Payne, GRO-C
[redacted]

CAMBRIDGE

£1,300 was raised to purchase equipment for the local Haemophilia Centre, mainly from a Spring Draw, a Jumble Sale and a Dance. A target of £2,000 has been set in support of the Research Appeal.

Cambridge & District Group
Mrs. L. Duncan, GRO-C
[redacted]

COLCHESTER

A Children's Physiotherapist was guest speaker at a recent meeting and since then efforts have been concentrated on publicity – talks to Women's Institutes etc. Unfortunately, because of lack of support, an outing to Kilverstone Wild Life Park had to be cancelled.

The holiday caravan at Clacton, which is shared with a local physically handicapped group, was well used during the summer.

£1,000 is the Group's target for the Research Appeal, of which £250 has already been donated.

Colchester & District Group
Mrs. P. Bridges, GRO-C
GRO-C

EAST KENT

At a general meeting the guest speaker was Mrs. Riva Miller, Social Worker at the Royal Free Hospital. Later in the year 18 members were shown around the Pathology Laboratory at Canterbury.

Future plans include a talk to be given by Dr. Savidge, the newly appointed Director of the St. Thomas' Hospital Haemophilia Centre.

£700 has been given to the Research Appeal as part of the target of £2,000

East Kent Group
Mr. C. J. Scott, GRO-C
GRO-C

GREAT ORMOND STREET

Although relying upon very few members it has been possible to send £2,200 to the Research Appeal and £38 to the general funds. A sponsored walk organised by Tollington Park Catholic Youth Club raised £760 and a batch of 100 appeal letters to firms has raised £260.

Great Ormond Street Group
Mr. D. Campbell, GRO-C
GRO-C

JERSEY (Affiliated Group)

Although competing with other much larger charities which are extremely active in Jersey, there is a very busy fund raising programme. £1,800 has been donated to the Research Appeal plus £200 to the general funds since the start of last year. This was raised in many ways, a "Chicken and Chips" supper, a Barbecue Brunch, a Rummage Sale/Bazaar, a Dinner and Dance, etc. A pile of pennies has been started in the Jersey Airport bar so if you are there on holiday don't forget to contribute! A "100 Club" is being organised and a collecting bottle in the Arden Hotel raised £194.02. The collection of stamps raised £200 last year.

Jersey Haemophilia Group
Mrs. B. Picot, GRO-C
GRO-C

LEICESTER

Plans are in hand to revive the Group and it is hoped to circularise details of a meeting in the near future.

Leicester & Leicestershire Group
Mr. R. Bodicoat, GRO-C
GRO-C

LEWISHAM

Various events such as stalls at the Blackheath Fayre and the Mayor's Michaelmas Market have combined to enable the Group to raise about £1,000 during the year. This will go towards the £3,000 recently granted to the Lewisham Haemophilia Centre by the Society. Because of the particular problems associated with the Area Health Authority it is important that support is given to ensure that the standard of treatment for haemophiliacs is maintained and not affected by "cuts in budget".

Lewisham Group
Mrs. H. Hodgkinson, GRO-C
GRO-C

LINCOLN

In the first few months since the formation of the group £120 was received in donations from local shops etc. One of our younger members, Andrew Would, did a sponsored swim which raised over £400. Local Young Farmers raised £115 from carol singing.

It is hoped that by giving financial and other support the local County Hospital may be designated as a Haemophilia Centre in due course. Can you help?

Lincoln & District Group
Mr. L. G. Mumby, GRO-C

MERSEYSIDE

Extremely active fund raising has meant that £2,700 has been donated to the Research Appeal plus £100 to general funds during the past year. A charity shop raised £600 and a football match £400. At the Group's Annual General Meeting the guest speaker was Dr. Elizabeth Mayne, Director of the Belfast Haemophilia Centre.

We are especially grateful to Mr. Julian Lander for his advice and information on Mobility Allowance problems and also to Mr. GRO-C who runs the Society's Stamp Club.

Merseyside & District Group
Mr. L. Dodd, GRO-C
GRO-C

NORFOLK AND NORWICH

Although members are few, fund raising is proceeding towards the target of £500 for the Research Appeal.

At the Group's Annual General Meeting questions will be answered by Dr. Leslie and Dr. Black from the Norwich Haemophilia Centre.

Norfolk & Norwich Group
Mrs. M. Brierly, GRO-C
GRO-C

NORTHAMPTON

During the year £2,000 was donated towards an investigation into von Willebrands disease being carried out at Oxford. This was possible thanks to money raised from a Darts Night (organised by Unicorn Darts), a Cabaret Evening, Flag Days etc.

Since the Group was formed treatment facilities at the local hospital have very much improved, so that local haemophiliacs do not now have to travel, so regularly, to Oxford for treatment. Also, some are going on to home treatment.

Thanks to a donation of £120 from a Ladies Circle it was possible to send a local teenage haemophiliac to a summer camp in Norway, which was organised by the Norwegian Haemophilia Society. It is hoped to repeat this scheme in the future.

Northampton & District Group
Mr. M. C. Shaw, GRO-C
GRO-C

NORTH-EAST (Leeds)

Although there are 135 on the Group's mailing list only a disappointing 17 turned up for the Annual General Meeting. However over 70 came to the Christmas Party which is much more encouraging.

A good source of funds has been collections at various shopping precincts and large stores which have made it possible for £1,000 to be donated to the Research Appeal. But more members to help means more money raised!

North Eastern Group
Mrs. I. Clinton, GRO-C

NORTHERN IRELAND

An astounding £10,000 has been donated to the Research Appeal thanks mainly to a Grand Draw in which the first prize was a car. £1,500 was raised from a Darts Competition and a substantial donation was received from the Queen's University Student Rag Day.

At the Group's Annual General Meeting the guest speaker was Dr. Peter Jones from Newcastle.

As a result of approaches made by the Group to Standard Telephones £2,000 was given to purchase equipment at the haematology laboratory at the Royal Victoria Hospital, Belfast.

Members regularly receive the Group's magazine "CLOTT".

Northern Ireland Group
Mr. S. Graham, GRO-C
GRO-C

NORTHERN (Newcastle)

The fund for the development and purchase of equipment for the Newcastle Haemophilia Centre has now reached a total of £39,500. A fantastic achievement in only 14 months!

It is hoped that the new building will be officially opened by our Royal Patron, H.R.H. The Duchess of Kent, towards the end of May 1980.

Fund raising continues with a target of £5,000 for the Research Appeal, with such events as a Pie and Peas Supper, a sponsored Penny-Farthing Ride, Flag Days etc. Drink can rings have been sold for scrap and money raised from the sale of tee shirts, bird baths, and other items made by hospital patients. £2,700 has already been donated to the Appeal.

Help was given to enable a local haemophilic teenager to go to a Summer Camp at Pisa, organised by the Italian Haemophilia Association, with considerable beneficial results.

Northern Group
Mrs. L. Reynolds, GRO-C
GRO-C

Tony Berry presents a cheque for £742 to committee members of the North West Group — Norma Guy, Norman Johnson, Malcolm Marks, John Morrissy. The Houghton Weavers Folk Group also gave a concert in aid of the North West Group funds on 29th January.

NORTH WALES

Although having a fairly quiet year the Group has given £635 to the Research Appeal. Long distances to travel keep down attendances at meetings but those who attended the A.G.M. were most appreciative of the talk given by Dr. Frank Boulton from the Liverpool Haemophilia Centre.

North Wales Group
Mrs. C. Holliday, GRO-C
GRO-C

NORTH WEST (Manchester)

£2,500 has been given to the Research Appeal plus £260 to the general funds. Almost £4,000 was raised during 1979 from dances, stalls at fairs etc., tombolas, raffles and it is intended to donate at least 75% of all monies raised to the Appeal.

Mr. Tony Berry and the Houghton Weavers Folk Group raised £742 by means of a sponsored "No Drinking for Lent".

At the Group Annual General Meeting in October a talk was given, accompanied by a film, by Dr. Reuben Mibashan from King's College Hospital, London, on "Pre-natal Diagnosis of Haemophilia", which greatly impressed all present.

North West Group
Mrs. M. Morrissy, GRO-C
GRO-C

NOTTINGHAM/DERBY

Although it has not been possible to organise any meetings during the past year fund raising continues. If you can help with Group activities please write to:

Notts & Derby Group
Mrs. M. G. Walker, GRO-C
GRO-C

Mr. J. R. Hunter shaking hands with Dr. S. H. Davies (extreme right). From left to right: Mrs. Fay Turner, Mr. Bert Dickie, Mr. Anderson Cowe (Group Chairman), Miss Jo Donnachie, Dr. Louise Stirling.

OXFORD

Fund raising is very active and £2,000 has been raised towards the target of £30,000 of which £25,000 will be used to support the work of the Oxford Haemophilia Centre.

Professor Duthie from the Nuffield Orthopaedic Hospital spoke to the Group on "Joint Replacement" and later in the year a physiotherapist was a guest speaker.

A highly successful "Wine and Cheese" took place on 9th December, and was attended by over 100 people including doctors and staff from the Oxford Haemophilia Centre. This was the occasion for the presentation of the R. G. MacFarlane Award to Dr. Rosemary Biggs.

Oxford & District Group
Mrs. T. Britton, GRO-C
GRO-C

SCOTTISH

Successful meetings have been held during the year and attendances are improving. In October Professor Arthur Bloom from Cardiff spoke on carrier detection and diagnostic research and later in the year a "Wine and Cheese" was held to mark the retirement of Dr. S. H. Davies, Director of the Edinburgh Haemophilia Centre. This was attended by Mr. J. R. Hunter, Vice-Chairman of the Society, and Dr. L. Kuttner, Group Liaison Officer, and a scroll signed by everyone present was presented to Dr. Davies.

Mr. Hunter read a message from all in the Society saying "those of us who have been entrusted with the conduct of the Society's affairs remember the pleasure it gave us when you agreed to become a member of our Medical Advisory Panel and how greatly we have valued your wise counsel and guidance, always so willingly and helpfully given. Among your patients an friends, all that you and your work meant in their personal struggle first to survive and then to overcome their disability will be remembered with gratitude and affection."

With his usual modesty Dr. Davies refused to allow a presentation to be made from members of the Group and insisted that the money donated amounting to £196 should be given to the Research Appeal.

Progress is being made towards the Group's Research Appeal target of £5,000, nearly £3,000 raised so far. One member gave a flower vase which was sent to Sotheby's in London and raised £132!

Scottish Group
Mrs. S. Cowe, GRO-C
GRO-C

SHEFFIELD

One of our newest Groups, a very good working Committee has been formed and initial interest of local members is very encouraging.

Bad winter weather has prevented a general meeting being arranged but it is hoped to get things moving in the New Year.

Sheffield & District Group
Mrs. L. Judge, GRO-C
GRO-C

SOLENT (Southampton)

Among events organised during the year were a Book Stall and a Disco and as a result £250 has been given towards the Group's target of £500 for the Research Appeal.

Members report that the local Haemophilia Centre now has its own treatment room and that seven patients are on home treatment.

Solent Group
Mrs. A. Webster, GRO-C
GRO-C

SOUTHERN

The target of £1,000 towards the Research Appeal has almost been reached thanks to a donation of £400 from Parkstone Grammar School, £200 raised at a Steam Engine Rally, and £50 collected in a local shopping centre.

Dr. Peter Green, Director of the local Haemophilia Centre spoke at the Group's Annual General Meeting.

It is reported that a local member has had both knee joints and one ankle replaced with artificial joints and is now waiting for his other ankle to be similarly treated. Another member comments upon the tremendous value he has had from hydro-therapy following an operation.

Southern Group
Mrs. J. R. Payne, GRO-C
GRO-C

SOUTH WALES

A target of £10,000 has been set for the Research Appeal and £2,500 has been forwarded so far. A flag day raised over £350 and also obtained useful press and radio publicity. A Bonfire Night Party raised £250, despite appalling weather, and £210 was shared with the Blood Research Fund at the University Hospital raised from carol singing.

55 patients are now on home treatment and the Group has provided the funds to purchase 40 new type tourniquets. They also shared the cost, with the Leukaemia Research Fund, of long range bleepers for use in the haematology department.

South Wales Group
Mrs. D. Lewis, GRO-C
GRO-C

SUSSEX

The Group hosted the meeting for the Society's Annual Draw in October and presented a cheque for £500 as a first donation to the Research Appeal.

Appeals letters have brought in about £250 and various events including a sponsored walk and jumble sale raised over £400.

The Group News Letter "BLEEDERS DIGEST" is distributed regularly to all local members.

Sussex Group
Mr. R. Martin, GRO-C
GRO-C

TAYSIDE (Dundee)

The Group has now been formed for almost one year and tremendous progress has been made.

As a result of the many and varied activities such as potato picking, snowball lunches, £300 has been donated to the Research Appeal, £300 to the Oxford Haemophilia Centre Appeal and £500 is to be used to purchase equipment at Ninewells Hospital, Dundee. A further £1,000 has been raised with the proviso that it is used locally.

Mr. Andy Stewart, the well known entertainer, has very kindly agreed to be the Group's Honorary President.

Tayside Group
Mr. B. G. Bissett, GRO-C
GRO-C

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GROUP CARAVANS

BIRMINGHAM GROUP:
GLENDOWER CARAVAN PARK,
BERWYN STREET,
LLANGYNOG, POWYS.
Apply to:
Mrs. J. Owen, GRO-C
GRO-C

LEWISHAM GROUP:
CHURCH FARM CARAVAN SITE,
PAGHAM,
Nr. BOGNOR REGIS,
SUSSEX.
Apply to:
Mrs. J. Copping, GRO-C
GRO-C

COLCHESTER GROUP:
(shared with PHAB)
HIGHFIELD HOLIDAY PARK,
CLACTON ON SEA,
ESSEX.
Apply to:
Mr. Peter Frost GRO-C
GRO-C

NORTH WEST GROUP:
CROOK O'LUNE CARAVAN PARK,
CATON,
Nr. LANCASTER.
Apply to:
Mrs. Norma Guy, GRO-C
GRO-C

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MISCELLANY

SUMMER CAMP

A few places have been reserved for 9 to 11 year old children with Haemophilia at a camp in Felixstowe. The camp is run under the auspices of CYFA/Pathfinders, the Church of England youth organisation. Dates – Saturday August 2nd to 9th. The site used is the campus of Felixstowe College which has a fine range of buildings for indoor activities and extensive grounds for outdoor pursuits. Sports facilities include a heated swimming pool, tennis courts and putting green. Optional activities of the camp include team games, outings, boat trip, candle, kite and model making, painting, cooking and other crafts.

For further details please contact Dr. E. Tuddenham, Co-Director, Katharine Dormandy Haemophilia Centre, Royal Free Hospital, Pond Street, London NW3 2QG.

Dr. Tuddenham will be in residence at the camp as one of the leaders.

Approximate cost £30.00.

ANNUAL SUBSCRIPTIONS

Annual Subscriptions were due in January and if you have not already done so we hope you will forward your £1 as soon as possible.

If you can make a donation to the Society's Research Fund or General Funds it will be very much appreciated. The £1 subscription does not even cover the cost of despatching our Bulletin; for example, because of the recent Post Office price increases, one issue now costs £240 in postage alone!

We are sure that all members will join in sending good wishes to GRO-A GRO-A and also GRO-A both very active members of the Executive Committee.

Both have been unwell and Mrs GRO-A GRO-A To both we say 'get well soon'.

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THE TREATMENT OF HAEMOPHILIA

We have obtained a quantity of pamphlets on various aspects of "The Treatment of Haemophilia", which have been produced by the United States National Hemophilia Foundation in co-operation with the World Federation of Hemophilia.

Although it should be remembered that some of the advice and information given is mainly relevant to the situation in the United States, we suggest that the following will be of particular interest to members:–

1. "Your Child and Hemophilia" – a manual for parents.
2. "The Hemophilic Child in School" – prepared for teachers, nurses, and other school personnel.
3. "Comprehensive Care" – for the person with haemophilia.

To obtain copies please send 15p (in stamps) for each pamphlet required.

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Also in the series are the following, which are written for the guidance of doctors, nurses, and others in the medical professions. A complete set has been issued to each of our Groups and also to all Haemophilia Centres in the United Kingdom.

4. "Physical Therapy in Hemophilia".
5. "Orthopaedics".
6. "Surgery in Hemophilia".
7. "Control of Pain in Hemophilia".
8. "Dental Care in Hemophilia".
9. "Home Therapy for Hemophilia".

Any member requiring a full set of the nine pamphlets should send £1 please. This is to help to defray the high costs of the importation and delivery of the pamphlets to our office.

Appreciation is expressed to Cutter Laboratories, Berkeley, California, who made possible the preparation, publication and distribution of the pamphlets.

THE R. G. MACFARLANE AWARD – 1978

The R. G. MacFarlane Award for 1978 was presented to Dr. Rosemary Biggs at a special party at the Churchill Hospital, Oxford organised by our Oxford and District Group. The Chairman of the Group welcomed the members of staff, both past and present, of the Haemophilia Centre at Oxford, other members of staff from the Churchill Hospital, staff from other hospitals, the officers and members of the Executive Committee of the Society and representatives of other Groups of the Society, as well as members of the Oxford and District Group. He extended a very warm welcome to Dr. Rosemary Biggs and said how pleased and honoured we all were that Professor MacFarlane had travelled from the north of Scotland to be present at the meeting.

The Reverend Alan Tanner, Honorary Chairman of The Haemophilia Society expressed his pleasure at being present at what was obviously a very important day for the Society and for the Oxford Group. Important because we had managed to get together Professor MacFarlane and Dr. Biggs and her friends who had worked with her at Oxford, for the presentation of the R. G. MacFarlane Award, that being the highest honour which the Society was able to pay to any doctor, scientist or other person working in the field of haemophilia. The occasion would go down in the annals of the Society, and he felt it was good that we were able to hold it on the hallowed ground of Oxford itself, one of the places of learning which sets a standard of excellence throughout the world.

He described how the Society had decided to establish an award to recognise merit in the doctors, scientists and others who work with haemophiliacs, and said how delighted the Society had been that Professor MacFarlane had agreed to the Award standing in his name. The name of Professor MacFarlane had resounded throughout the world as being one of the leaders, not only in research, but in the whole management and concern for haemophiliacs. It was in the 1940's and 1950's that most haemophilia patients were either referred to, or had samples of their blood sent to, "Macfarlane at Oxford". Any doctor who was working in the backwoods of London, or perhaps somewhere north of the border, who wanted their first thoughts confirmed, sent their samples and sometimes their patients, to "MacFarlane at Oxford", and thus it was that in this period Oxford became synonymous with blood coagulation disorders. We wrote about Professor MacFarlane in our first News Bulletin of 1978 when we reported the establishment of the Award, and it was worth reading again — "Professor MacFarlane is known throughout the world as a man who established Oxford as the most important Centre for the treatment of haemophilia and allied blood disorders. His first paper on the subject was published in 1931 when he was a medical student, and his career commenced at St. Bartholomew's Hospital, London, in 1933, where much of his research into Russell's Viper Venom was carried out". The Reverend Tanner reminded the gathering that Russell's Viper Venom was at one time the last resort, if not the first resort, that doctors turned to in order to stem prolonged bleeding, because it was one of the few materials that had been developed. The article went on — "Together with Dr. Rosemary Biggs, Professor MacFarlane for years led the world in haemophilia. It would be difficult to find any publication on haemophilia which did not include at least one of their names as a reference. When he retired in 1967 he did so with the knowledge that his plans for a haemophilia Centre at Oxford, combining facilities for treatment, research and a fractional plant, would soon be realised. It is said of Professor MacFarlane that there is no one who has contributed more to the understanding of haemophilia and those suffering from it. Reading through his many papers, one can clearly see his logical and scientific approach to the problem, often showing the mark of genius". It is because of this that the Society was so pleased, when we came to think about the Award, that Professor MacFarlane agreed to allow us to perpetuate his name by calling it 'The R. G. MacFarlane Award'.

GRO-A


Dr. Rosemary Biggs


From left to right: Dr. J. M. Matthews, Prof. R. G. MacFarlane, Dr. Rosemary Biggs, Dr. Ethel Bidwell, Dr. Charles Rizza

The Reverend Tanner reminded the meeting that the Award took the form of a gold medal with a citation, which may be given to a doctor, a scientist or other person who had been involved in research, in the management of haemophilia, or in the more general care of those with haemophilia, or related disorders. The first Award was made in the previous year to Dr. Katharine Dormandy, and the second Award was being made to Dr. Rosemary Biggs. He pointed out that when Dr. Biggs had retired from her work at Oxford we had had the opportunity to make some comment on her work at that stage and to make a small token present at that time, a foretaste of things to come, which had now arrived.

Dr. Rosemary Biggs qualified in 1943 and later joined Professor MacFarlane at Oxford at the Medical Research Council's Blood Coagulation Research Unit. She was then the joint author of "Human Blood Coagulation and its Disorders" which was first published in 1953. She was also the adviser to the Department of Health on Blood Coagulation, especially haemophilia. When Professor MacFarlane retired, by that happy arrangement Dr. Biggs had been there ready to step in and continue the work which he had established and she was appointed Director of the Medical Research Council's Blood Coagulation Unit in Oxford. The members of the Society were particularly grateful to Dr. Biggs, who was largely responsible for organising the annual meetings of Haemophilia Centre Directors when the officers of the Society were first invited to take part in the meetings — a major step forward and a privilege for the Society as a whole.

No few remarks, he continued, do more than touch on the work that Dr. Biggs had done for the Society and for haemophiliacs in general. Throughout the world her name was coupled with that of Professor MacFarlane, for they obviously worked as a team and that was why there are so many references in medical literature about their work, and why the name of Oxford had become established in the medical and scientific field. When we come to the point of making the Award, we also wanted to register deep gratitude to Dr. Biggs for having dealt with people as individual persons. Many of those who had come into contact with her have testified to the warmth with which she received them, to the encouragement that she had given them to cope with haemophilia in their lives. It was for this that we had come together to register our thanks.

The Reverend Tanner then introduced Professor MacFarlane who said that on such an occasion it was impossible to avoid the usual set of cliches, for he really did feel it was a pleasure and it certainly was a privilege for him to be asked to present the Award to a person with whom he had worked so happily for over 25 years, and for whom he had so much admiration and a very great deal of affection. Professor MacFarlane then read out the citation, which he felt was extremely well worded — "The R. G. MacFarlane Award, 1978, presented to Rosemary Biggs by The Haemophilia Society in grateful recognition of her outstanding scientific achievements in the field of haemophilia and blood coagulation, which, together with her sympathy and concern for people with haemophilia and their families, have transformed their social and physical wellbeing". That was signed Weldon Dalrymple-Champneys and Alan Tanner, the President and Chairman of The Haemophilia Society. He felt that that described Rosemary Biggs' contribution very well and there were only a few points he wanted to underline. The first was a scientific one. Her introduction of her Thromboplastin Generation test had revolutionised not only the accurate identification of clotting defects, but also the chemical production of therapeutic materials and the measurement of the effect of treatment. In other words, it had provided a method of identification and measuring, without which no real progress could have been made. What had happened in the field of clotting disorders was comparable, in his opinion, to the introduction of antibiotics in the treatment of bacteriological diseases and it was Rosemary Biggs' work that was largely responsible.

The second point concerned Dr. Biggs' clinical work, which had been emphasised by the Reverend Tanner. She always applied her laboratory work for the benefit of her patients and that so often didn't happen in laboratory work. With the greatest devotion and determination, she had treated and kept in touch with hundreds of individual haemophilic patients in this country and all over the world. Moreover, she had attracted and trained scores of students, postgraduates and research workers, also from all over the world who came to Oxford to study with her' her laboratory methods and her methods of clinical treatment.

The last point was the matter of administration. Here Rosemary Biggs had battled for years with all the real difficulties of setting up and organising haemophilia Centres caused by the seemingly unreal bureaucratic frustrations and delays that always infuriatingly engulf any medical or scientific advance once it reaches a certain level of national importance, and it is because Rosemary Biggs had battled for so long and so effectively on all these fronts that he had so much pleasure in presenting her with the Award.

Prof. R. G. MacFarlane & Dr. Rosemary Biggs

The MacFarlane Award Medal

In accepting the Award, Dr. Biggs thanked the Haemophilia Society very much for the honour they had done her in giving her the medal and citation, Professor MacFarlane for coming down to present them to her and everyone present for the kind words that had been addressed to her about her work in the Haemophilia Centre. She thought the Haemophilia Centre in Oxford had contributed substantially to the wellbeing of haemophilic patients and it made her very happy to know that the Haemophilia Society recognised that. She thought that it was a fortunate set of circumstances that the people who worked there were there at the time that social conditions developed making possible those advances in the treatment of haemophilia. She thought that the advances that had been made at the Oxford Haemophilia Centre would have been impossible without the other people who worked there. Without Dr. Bidwell Factor VIII and IX certainly would not have been made, without Dr. Rizza and Dr. Matthews the Centre would not have developed as it had in the clinical field, and, of course, the whole thing could never have been thought of without Professor MacFarlane. Dr. Biggs added that she was very happy to have made some contribution to the work and how very grateful she was to the Haemophilia Society for making the presentation to her, and pointed out that of course none of the research on haemophilia and blood coagulation could have been made without the faith and cooperation of the many haemophilic patients who were registered at the Oxford Centre, at a time when they had very little in which to trust. It was the combined work of everybody that had made it all possible.

The formal part of the meeting ended with prolonged applause for Dr. Biggs.

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NATIONAL AWARDS FOR ACHIEVEMENT IN EDUCATION AND IN SPORT

The generosity of a number of people has made it possible for awards for those with haemophilia or another disorder of haemostasis to be established. Although primarily intended for young people, in exceptional circumstances two of the awards will be open to older age groups.

These annual awards will be for **achievement**, and we are delighted that they are personally linked with the names of Catherine Cookson and Brendan Foster, two people who, by sheer hard work, have excelled in their chosen fields.

Mrs. Catherine Cookson is the world famous authoress of many books about people, including her own autobiography 'Our Kate'. Her work has been filmed and televised and she is loved by many readers for the honest and humane way in which she writes about life in all its variety.

Mr. Brendan Foster is the athlete of international repute, and a keen exponent of 'Sport for All'. Holder of world records in both the 3,000 metres and the 2 miles, and an Olympic record in the 5,000 metres, he has helped revolutionise the athletic scene in the United Kingdom.

THE AWARDS

These will be two senior and two junior awards.

Each senior award will be in the form of a personal certificate and a cheque for £75. Each junior award will be in the form of a personal certificate and a cheque for £25.

Junior awards will be open to all children with haemophilia or another disorder of haemostasis below the age of 12 years. Senior awards will be open to those over the age of 12 years and, usually, below the age of 21 years.

Award winners will be selected annually in October, the first awards being made in 1980. The judges will be Mrs. Cookson, Mr. Foster, the Chairman of the Haemophilia Society and the Medical Director of the Newcastle Haemophilia Centre. Unless specifically requested to the contrary, the names of the winners of the awards will be announced in the Haemophilia Society Bulletin.

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HOW TO ENTER

1. The Catherine Cookson Awards for Achievement in Education

These awards (one senior and one junior) will be given for academic achievement. This need not necessarily depend on success in competitive examinations, especially in the younger age group.

In addition to the general details requested below, each entry should include the names and addresses of two referees, one a doctor with personal knowledge of the candidate's disorder and its severity, and the other a school teacher or lecturer with personal knowledge of the candidate's academic achievement.

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2. The Brendan Foster Awards for Achievement in Sport

These awards (one senior and one junior) will be given for achievement in any field of sport (indoor or outdoor). Each entry should include the names and addresses of two referees, one a doctor with personal knowledge of the candidate's disorder and its severity, and the other a sports teacher or coach with personal knowledge of the candidate's achievement in his or her chosen sport.

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General

All entries and references will remain confidential to the judges, and no names or other details of any entry will be divulged without the written permission of the candidate and/or his or her parents or guardians.

In deciding the winner of each award the judges will take into account the candidate's haemostatic disorder and its severity. Competition for the awards is limited to the United Kingdom. The decision of the judging panel will be final.

Entries for the awards should be sent to the National Haemophilia Awards for Achievement, Newcastle Haemophilia Centre, Royal Victoria Infirmary, Newcastle upon Tyne, NE1 4LP, marking your envelope 'Awards'. All entries received will be acknowledged. The closing date for entries in any one year is 31st July.

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INNOVATIONS FOR HAEMOPHILIACS

Dr. Charles Forbes is confident that improved care for difficult patients should lead to less arthropathy and analgesic misuse.

In the past 15 years there has been a dramatic improvement in the management of patients with haemophilia. This is due directly to a method of producing a simple cheap concentrate of factor VIII by the method of cryoprecipitation of human plasma.

For the first time it seemed possible that enough human material could be provided for routine and emergency use by using a high percentage of standard blood donations. The method is simple, relatively reliable and does not require sophisticated apparatus. It is therefore ideally suited for Regional Blood Transfusion Services and up to 40 per cent of all donations in many areas are used for this purpose. It is clear that this was the turning point in haemophilia care.

Many sophisticated concentrates are now being prepared with cryoprecipitate as the starting material. While they have many advantages they are extremely expensive and provision of adequate supplies remains in the political, rather than the medical, arena.

Availability of such preparations has led to more aggressive approaches to therapy, the most important of which is self-administration of the concentrate by the patient at the time of injury or at the start of a bleed (see figure). There is now little doubt of the major changes this has produced in the life-style of the severely affected patient.

An extension of this procedure is the routine administration of material to protect against bleeding. This is extremely costly, consumes large amounts of material and can only be recommended in selected patients at the moment, but should be the ideal goal for all patients.

There seems to be no evidence of serious side effects from this increased exposure to plasma products, in particular no increased incidence of factor VIII inhibitors or of hepatitis B carriers.

There can be no doubt about their benefits, with normalisation of social life, reduction in bleeding episodes and better attendance at school and work. The ultimate objective will be reduction of crippling from recurrent joint bleeds and normalisation of the life span of the patients – neither of which have been achieved as yet.

The most serious complication in the routine management of the haemophiliac is the development of an antibody to factor VIII in about 6 per cent of patients. This does not change the baseline level of the factor or increase the bleeding tendency, but does make treatment ineffective.

As yet no clear method of management is fully agreed on. Factor VIII – inhibitor bypassing activity (FEIBA) is widely used, but doubts exist about the theoretical basis as well as its place in management.

Products which contain activated factor IX may also be useful and recently concentrates of porcine factor VIII, treated to remove the platelet aggregating activity of the high molecular weight carrier protein, have been produced (Hyate) but these have not yet had sufficient clinical evaluation to assess their worth. There seems little evidence that long term immosuppression is of value.

In a small number of very mild patients with reasonably high baseline levels of factor VIII, it is posible temporarily to boost the level to one which is haemostatic by the infusion of des amino D-arginine vasopressin which probably acts by stimulating release of coagulant activity from storage sites.

This overcomes the problem of using plasma concentrates in this small group of patients who seem to have a surprisingly high incidence of serum hepatitis after such exposure – presumably a reflection of a low level of immunity to the virus due to infrequent previous exposure.

Haemophilia Centre Handbook
Notes for Doctors and Nurses
involved in the
Care of Patients with Congenital
Coagulation Disorders
by Jennifer Voke, Colin Madgwick &
Katharine Dormandy
published by Immuno Ltd.
price £3.00
available from the Royal Free Hospital
Haemophilia Centre
not available from bookshops

This inexpensive manual will prove valuable as an orderly source of facts for quick reference and as a teaching aid. It was written for the staff of the Royal Free Hospital Haemophilia Centre but is now available for anyone involved in the care of patients with inherited bleeding disorders. The book is dedicated to the memory of Dr. Katharine Dormandy who died while the manuscript was in the final stages of preparation.

Fibrinolytic inhibitors such as Aminocaproic acid (EACA) and Cyclokapron (AMCA) are of limited value and should be reserved specifically as an adjunct to concentrate in control of bleeding following dental extraction. There is no proof that they have any place in management of haemarthrosis or in patients with inhibitors.

Relief of pain from degenerative joint disease remains a problem for every patient and clinician in the haemophilia centre. One must temper humanity with the dangers of drug dependance and every centre has four or five such patients who have become addicted.

The drugs usually involved are dihydrocodeine (DF 118), dipipanone, and occasionally pethidine. These patients often have other evidence of personality disorders and are extremely difficult to manage. Hopefully with better treatment and orthopaedic care in the future we shall see less arthropathy and hence remove the trigger for analgesic misuse.

As medical treatment has improved the physical care of the haemophiliac, we have become more aware of the social and psychological stresses and strains in the patients as well as the families. These are currently under investigation and hopefully some will be amenable to counselling, both genetic and social, but this equally requires the motivation of the person involved and the will of society. Perhaps the most important force for good in the future is a powerful, motivated and active National Haemophilia Society.

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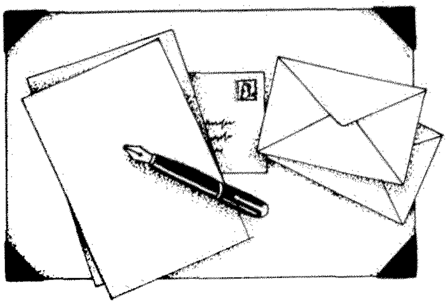
Charles Forbes is senior lecturer in medicine at the Royal Infirmary, Glasgow.

Points of View



From Mr GRO-A
GRO-A
Kent.

Dear Sir,

I am writing to ask you if you would mention this letter in your next Bulletin. My son, GRO-A went to watch Gillingham Football Club, which is quite a long way from Margate. While he was watching the match he got a severe bleed in the leg and told a Policeman, who was standing in front of him. The Policeman and his friend carried my son out of the ground, got him an ambulance and went with him to Margate Hospital (some 50 miles away) where GRO-A was treated. When they got back to Gillingham he phoned me at Margate to ask how GRO-A was. I think this was so kind, that I cannot thank the Gillingham Police enough. I hope you can print this so that I can send them a copy.

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