Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

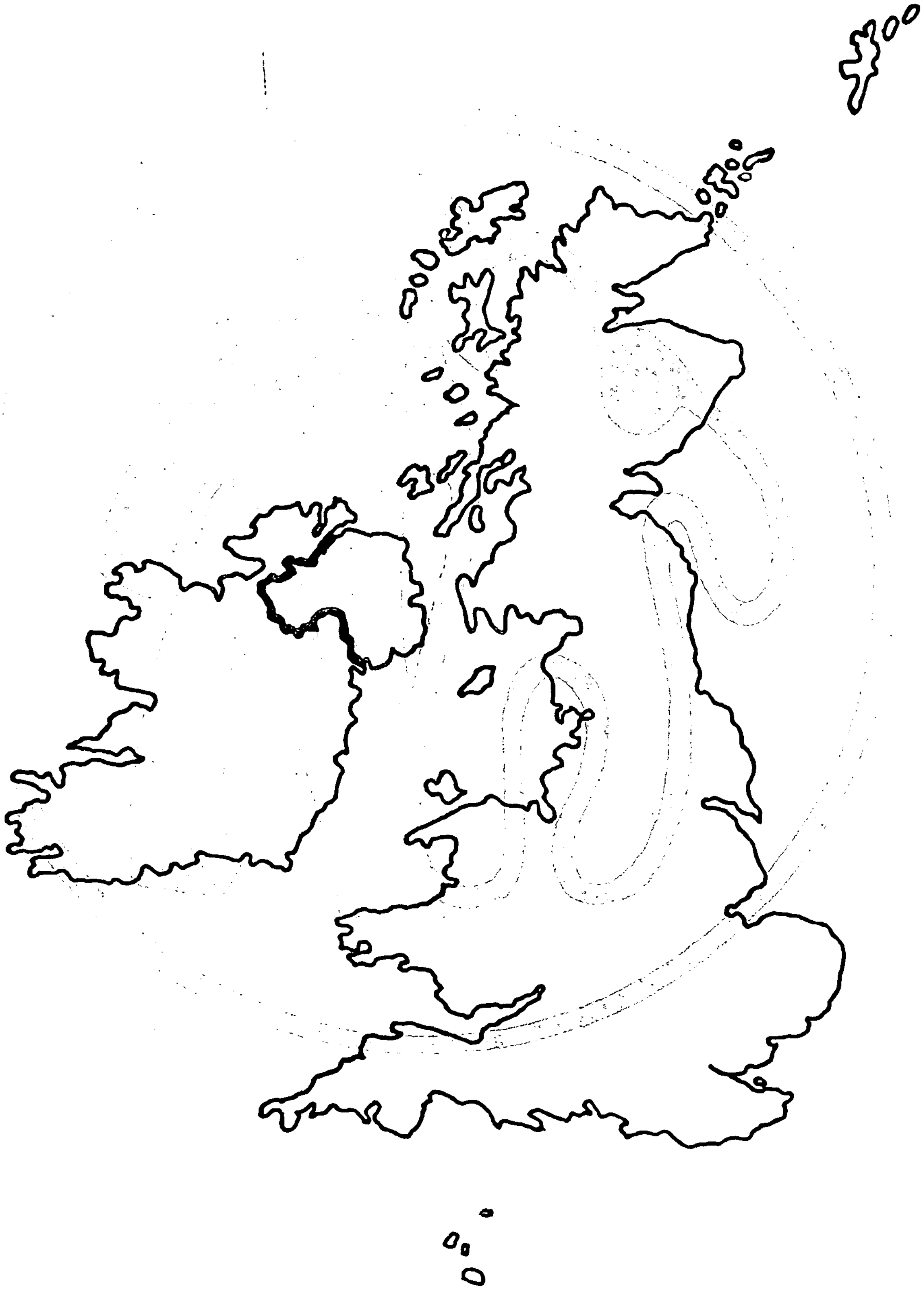
Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392032

GRO-A

1988 Annual Report



The Haemophilia Society
A review of 1988

PATRON:

H.R.H. The Duchess of Kent

OUR NEW VICE-PRESIDENTS

The Baroness Masham of Ilton

Robert Key, MP

Frank Field, MP

PATRON
H.R.H. The Duchess of Kent

President:
Mrs. Catherine Cookson, OBE, MA

Vice-Presidents
Dr. Rosemary Biggs, MA., MD., FRCP.
Dr. S. H. Davies, MB., ChB., FRCP., FRCPath.
Robert Key, MP.
Frank Field, MP.
J. F. Wilkinson, PhD., MSc., MD., FRCP., FRIC.
The Baroness Masham of Ilton

Honorary Officers:

Chairman	The Revd. A. J. Tanner, MA.
Vice-Chairman	Dr. L. Kuttner, LLD.
Vice-Chairman	Mr. K. E. Milne, BSc.
Treasurer	Mr. J. L. Prothero

Executive Committee:
Mr. K. Colthorpe
Mr. A. Cowe, BA., MBA., ACIS.
Mr. T. Fitton, BA., ATD.
Mrs. C. Hazlewood
Mrs. J. Hodgson
Mr. G. Kirman, Eng. Tech., AMSERT
Mr. C. Knight, BA.
Mr. J. D. Miller, B. Comm.

Medical Advisory Panel:
Professor A. L. Bloom, MB., ChB., MD., MRCP., FRCPath.
Dr. B. Colvin, MA., MB., MChir., MRCP., MRCPath.
Professor C. D. Forbes, DSc., MD., MB.ChB., FRCP.
Dr. P. Jones, MD., FRCP., DCH.
Dr. P. Kernoff, MD., FRCP., MRCPath.
Dr. E. E. Mayne, MD., MRCP., FRCPath.
Dr. C. R. Rizza, MD., FRCP(Edinburgh).
Dr. E. G. D. Tuddenham, MD., MB., BS., FRCP., FRCPath.
Dr. C. A. Ludlam, PhD., BSc., MB., ChB., FRCP, MRCPath. (Co-opted)

General Secretary: David G. Watters, J.P.

Office Staff:

Jean Chilemba	Receptionist/Typist until November 1988
Paul Burba	Receptionist/Typist from December 1988
Jonathan Cooper	AIDS Co-ordinator
Linda Matthews	Administration Secretary
Heather Maynard	Personal Secretary to the General Secretary
Jude McGuigan	Clerical Assistant

Volunteer: Alan Weir

Auditors: Pridie Brewster

Solicitors: Paisner & Co., London

Bankers: National Westminster Bank PLC

Registered Charity no. 288260
Company limited by guarantee (Reg. no. 1763614)
Registered office 123 Westminster Bridge Road London SE1 7HR

THE CHAIRMAN'S STATEMENT

In this report, we record the outstanding progress made by the Society during 1988 in meeting the needs of people with haemophilia. It is encouraging to know that people involved with the work of other voluntary organisations are invariably greatly impressed by the way we are able to achieve so much with comparatively slender resources. However, the opportunities for developing our work are increasing steadily and our ability to take advantage of them is limited only by the funds available.

With regard to fund-raising, we have experienced two unexpected problems. First, misunderstanding arising from the £10m made available by the Government to meet the special needs of people with haemophilia who are HIV positive, as a result of the blood products used in their treatment. It was essential that this money be kept separate from the funds of the Haemophilia Society, so the Macfarlane Trust was established for this purpose. Some of our supporters have been under the impression that the Society's financial affairs were made secure when this grant was announced. We are now seriously concerned lest this misunderstanding should affect their contributions towards our work. It cannot be emphasised too strongly that the money controlled by the Macfarlane Trust is to alleviate the particular difficulties experienced by people who are HIV positive, and for that purpose alone.

The second confusion arose from the wide publicity given to the announcement that synthesised factor VIII was being used in clinical trials, referring to this being "the cure of haemophilia"! Many of our well-wishers told us how delighted they were in hearing that many of our problems would now be solved. Alas, it will be some considerable time before the results of the clinical trials are known and then we expect there to be a further period during which the production technology will be developed before we can reap the benefits of this scientific progress.

So, while we are encouraged by this news, it will be many years before its effects are felt. meanwhile, the work of the Society goes on and our need for financial support increases steadily.

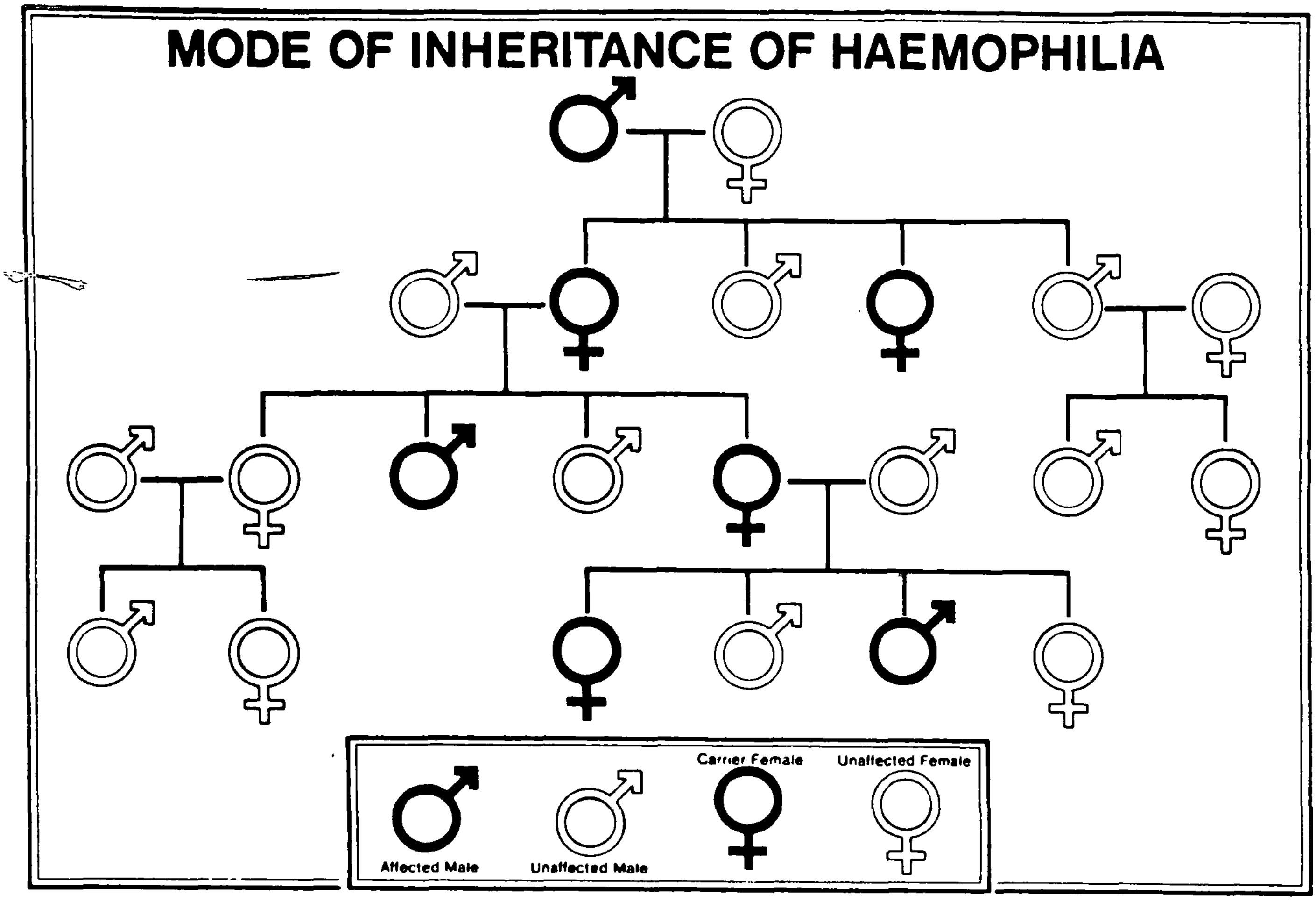
I have referred to the outstanding progress made by the Society in so many aspects of our work during the year. This would not have been possible without the indefatigable efforts of the General Secretary, David Watters, and his team. We recognise our good fortune in having the benefit of his special skills and experience at this critical time in the life of the Society.

Many of our members are coping courageously in very disturbing circumstances and we are very conscious of our responsibility to assure them that they are not alone in their struggle.

There is still much to be done.

We look to our friends for their continued support in caring for people with haemophilia and those who are close to them.

MODE OF INHERITANCE OF HAEMOPHILIA



WHAT IS HAEMOPHILIA?

Haemophilia is a blood condition in which one of the essential clotting factors is either completely or partly missing. The deficiency of either factor VIII or factor IX causes the condition.

Because of this a person with haemophilia may bleed for longer than normal.

Cuts and grazes are not great problems, but internal bleeding into joints, muscles or soft tissues is. These haemorrhages can follow even slight strains, cause acute pain and lead to disabilities.

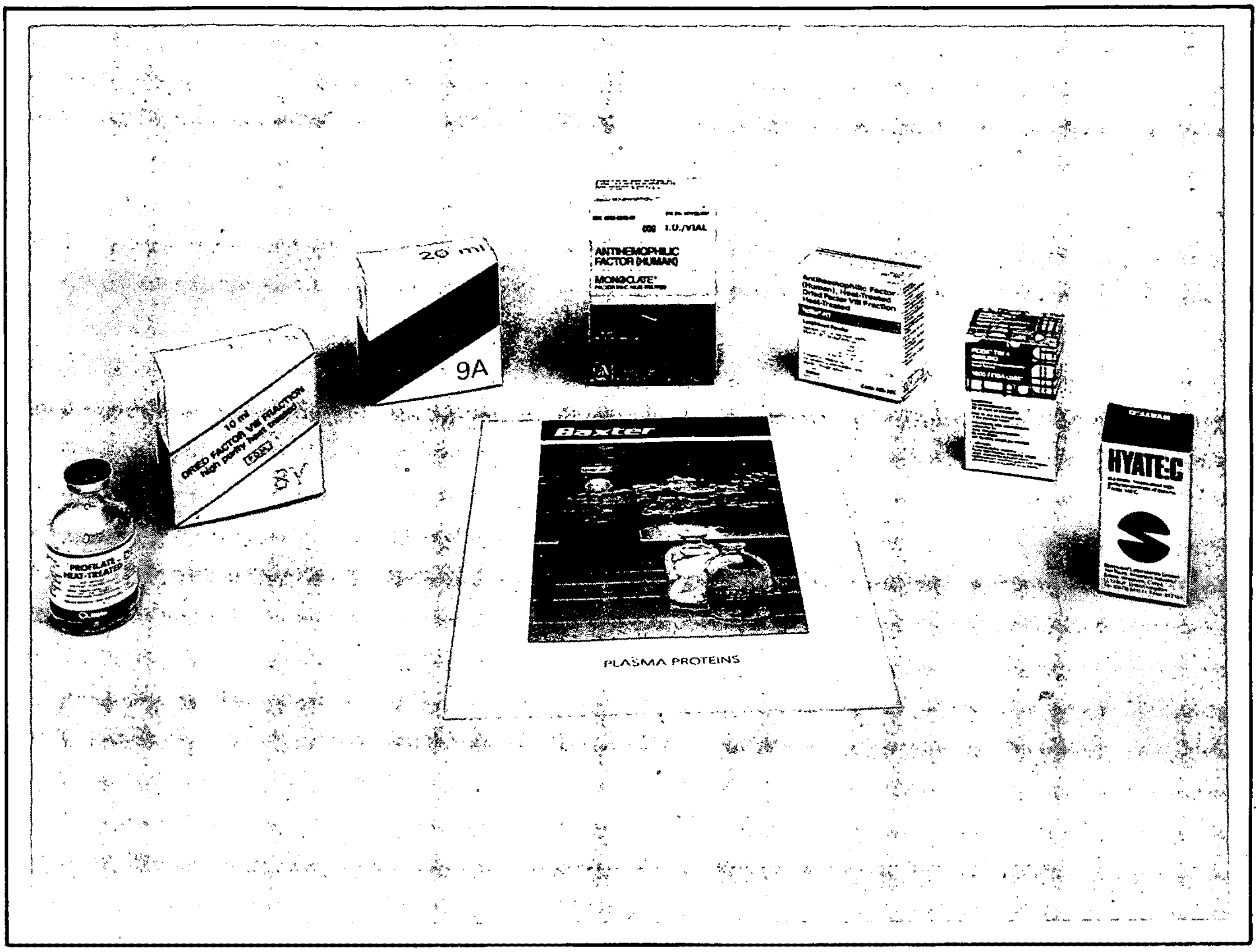
People with haemophilia often have severe arthritis because their joints were damaged in the days before treatment was available.

Young children with haemophilia must learn to avoid undue knocks and bumps, while participating in life as normal children.

Haemophilia is usually hereditary but can appear in any family. It is carried by females but generally only males are affected. There are around 7,000 people with haemophilia in the UK. Haemophilia is a lifelong condition for which there is no known cure.

However, in recent years treatment has become available in the form of intravenous injections of the missing clotting factor. This has greatly improved the lives of people with haemophilia. It is essential that each bleeding episode is treated as quickly as possible to avoid the risks of prolonged bleeding and joint damage.

There is another condition, vonWillebrand's Syndrome, in which factor VIII deficiency is combined with a platelet disorder. In some respects this condition is similar in its symptoms and treatment to haemophilia. VonWillebrands Syndrome has a different inheritance pattern and affects both men and women.



Some of the blood products used in the UK

Unfortunately, treatment with blood products can result in complications and some severe side effects. Specialised care and further research are required to deal with these problems.

People with haemophilia should attend specialised medical centres where their blood, orthopaedic, dental and general medical condition can be supervised by experts.

Many people with haemophilia are now able to keep treatment materials at home so that bleeding episodes can be treated immediately and schooling and employment need not be disrupted.

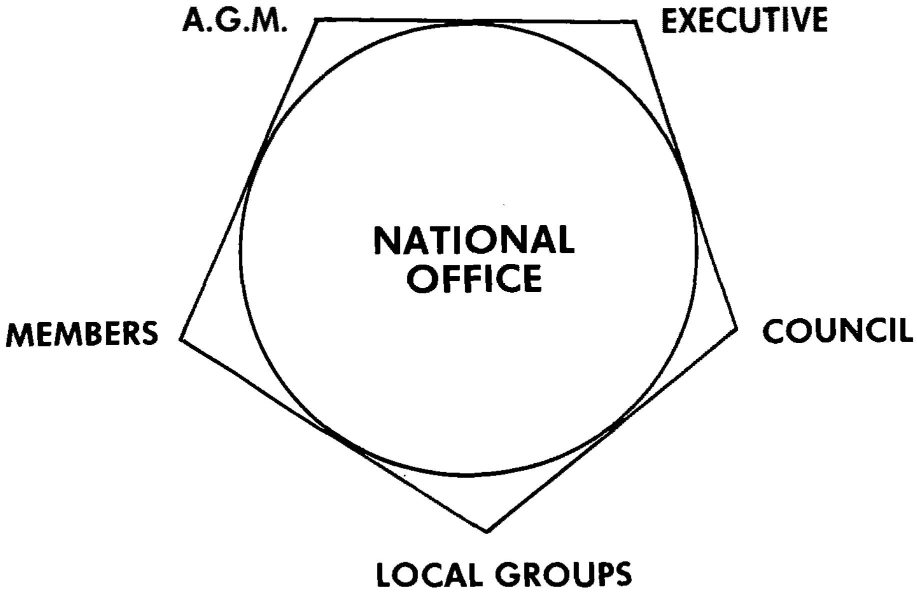
The Haemophilia Society gives help and support to people with haemophilia and their families through a network of local groups and representatives.

. . . gives financial aid in cases of hardship.

. . . publishes and distributes information useful to people with haemophilia, their families and the health care professionals concerned with their treatment and welfare.

. . . represents the interests of people with haemophilia to those politicians, civil servants and public bodies whose responsibilities affect their medical, economic and social welfare.

. . . gives some financial help to hospitals which care for people with haemophilia and to those who are conducting research into haemophilia and related disorders.



HOW DOES THE SOCIETY WORK?

Membership of the Haemophilia Society is open to anyone who has an interest in haemophilia or a related condition. Our membership includes people with haemophilia, their families, health care professionals and those who support our work but have no direct connection with the condition at all.

The Society is a national organisation and our members participate and benefit from membership in a number of ways.

At the Annual General Meeting members elect the Executive Committee. The Executive Committee represents members at the national level. This committee is legally responsible for ensuring that the Society is managed in accordance with the requirements of the Charity Commissioners and the Companies Acts.

Local Groups, of which there are thirty, allow members to have social contact and fellowship with others who share their interests. The Groups are a vital part of the Society's life as they identify local problems, work for solutions to those problems and provide immediate support to members in need of help and understanding. Different Groups operate in different ways according to local conditions. All Groups are represented on the Council of the Society. This meets four times each year and the Executive Committee are responsible to, and are advised by, Council.

Members also have direct contact with Head Office. Through correspondence and telephone calls members have access to the expert knowledge and assistance of the Society staff. By this means members can receive personal advice about any of the topics referred to in this report. Staff are also able to build up picture of problems of difficulties as they emerge at local or national level.

As the range of issues facing the Society has grown in recent years, a number of Working Parties have been set up. Comprising Executive Committee members and other members with specialist knowledge, the Working Parties study particular areas of concern to us and devise and implement appropriate responses. It is a feature of the Society that it enjoys active involvement from so many people directly affected by the condition. Thus it combines the best features of a self help organisation with those of an efficient national member organisation.

The North Wales Adventure Holiday

A number of activities and facilities are operated through some active local Groups.

Foremost among these is the Adventure Holiday for boys organised and run by the North Wales Group. This holiday allows boys with haemophilia to participate in "outward bound" activities while under the medical supervision of experts in haemophilia care. The value of this experience in boosting the confidence of these boys is inestimable.

There are five Haemophilia Society caravans in different parts of the country. Managed by local Groups, these offer cheap holidays in caravans which allow access to people with walking difficulties. In Perth there is a charity shop which raises funds for the Society. All these undertakings demonstrate the depth of commitment our Society enjoys from our Group members.

The Society holds seminars and conferences for members and health care professionals. In 1988 there was a national seminar for members held in Liverpool. The North West Group held a local seminar in Blackpool. The North East Group held a day seminar in Leeds. These events help to bring our scattered membership together in an atmosphere where problems can be shared and feelings of isolation overcome. We thank all those who have participated in the seminars and those whose generous financial support (particularly the pharmaceutical companies) have made them possible.

The Society has a vital role in a network of organisations concerned with the treatment and care of people with haemophilia. We have our own Medical Advisory Panel comprising a number of eminent doctors whose expertise is made freely available to us on a wide range of medical questions related to haemophilia. We are privileged to be invited to the Haemophilia Centre Directors' meetings. This allows us to observe and comment on national and local policies for haemophilia care. The Haemophilia Nurses Association brings together those nurses who work in haemophilia centres and who are often the main point of contact between our members and their hospitals. The social workers' Special Interest Group meets with us regularly to ensure an exchange of views on this essential service for many of our members. We record our thanks to the many busy health care professionals who so willingly support the work of the Society.

WELFARE

Many people with haemophilia have full time jobs and are able to lead economically active lives. For others, however, the joint damage caused by the condition means that they are not able to work. Almost all people with severe haemophilia have mobility problems, or are at risk of developing such problems. For those affected by HIV there are extra expenses associated with leading a healthy life.

For several years now the Society, through David Watters, the General Secretary, has played a large part in securing Mobility Allowance and Attendance Allowance for members who are entitled to these benefits. Each year David Watters travels all over the country, appearing before medical tribunals to present claims on behalf of members. A number of cases have been taken to appeal by the Social Security Commissioners, and their decisions in favour of haemophilic applicants have ensured that the way is now made easier for other applicants in the future.

During 1988, a number of major changes in the Social Security system were introduced by the government. The Society has monitored these changes constantly and has given advice and help to members about claiming the benefits for which they may qualify under the new arrangements. This has been a time-consuming and complex activity. We are grateful to Jonathan Cooper whose meticulous attention to the detail of the changes has protected our members interests in this area. Much of this effort has benefitted those our our members affected by AIDS. In particular, the Society has been able to secure benefits relating to dietary and other costs related to HIV infection.

Late in 1987 the government gave £10 million to meet the special needs of people with haemophilia and HIV infection. Early in 1988, in order to administer this charitable fund, the Macfarlane Trust was created as a separate legal entity. This is particularly important in safeguarding

Advice on Benefits from the General Secretary

the confidentiality of its work. However, during the first eight months of 1988 the administration of the Macfarlane Trust was carried out by the Society. We continue to appoint six of the ten Trustees. Now that the Macfarlane Trust has established its own identity, with its own premises and staff, the two organisations enjoy a co-operative working relationship.

Many of our members who are affected by HIV and AIDS have been pursuing legal compensation claims in 1988. The Society has played an active part in bringing together the individuals involved so that they can co-ordinate their efforts. We have provided information to groups of solicitors representing the individuals. It has also been important to maintain open channels of communication amongst all parties in the litigation, lest the close relationships which exist in the world of haemophilia be damaged. The Society has actively supported calls for "no-fault" compensation arrangements.

As we have noted elsewhere, the granting of the Macfarlane Trust money has not solved all the problems of people with haemophilia and HIV. The Society's help is still required to assist with the social and medical aspects of these conditions. The Society has been instrumental in establishing support groups and providing a forum for the exchange of information in this field.

The Society exists to serve all people with haemophilia. The majority of our members are not affected by HIV, yet their financial, practical and emotional needs must still be served. Whenever we are aware of need, the Society can help with cash grants. We are fortunate in having the co-operation of many social workers in all parts of the country who are able both to direct those in need to the Society, and to give practical help to complement our support. Our local Groups and publications programme help to support all members of the Society.

GRO-A

GRO-A *receives synthetic factor VIII*

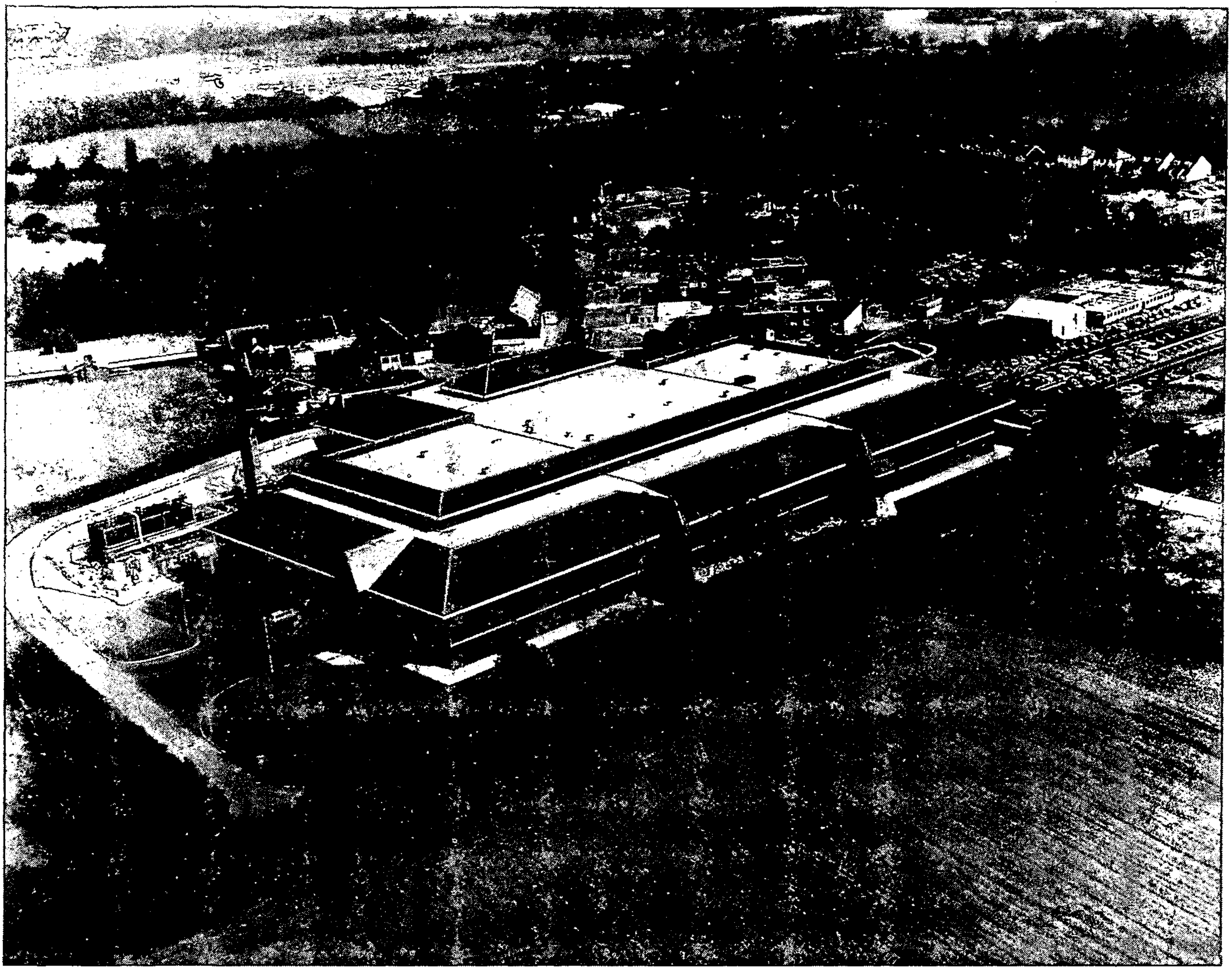
TREATMENT AND CARE

When people with haemophilia suffer a bleeding episode, they depend on prompt treatment by an infusion of the missing blood factor (in most cases factor VIII). The availability and quality of blood products is a major concern of the Society.

The most significant event in 1988 in relation to the supply of blood products was the increased output of factor VIII from the Blood Products Laboratory at Elstree. The new production facility at Elstree reached its full processing capacity during the Spring. By the end of the year NHS products constituted the majority of those used for the treatment of people with haemophilia. Unfortunately, it does not appear that it will be possible for the UK to become self-sufficient in blood products in the near future because heat treatment introduced to increase purity has resulted in lower yields from a given quantity of blood plasma. The increased supplies of blood products, for which the Society has campaigned for many years, is very welcome and we pay tribute to the skill and dedication of the staff at BPL. While the capacity of BPL may increase further in due course it is important that supplies of plasma from Regional Blood Transfusion Services be increased so that production can continue at full capacity.

During 1988 difficulties arose in Scotland and Northern Ireland which had for many years been self-sufficient in blood products. This resulted in the use of commercial factor VIII by patients who had previously only ever been treated with NHS concentrates. The Society discussed the situation with the Chief Medical Officer for Scotland and steps are being taken to improve facilities at the Protein Fractionation Centre in Edinburgh where products are manufactured for both Scotland and Northern Ireland. We hope that both countries can be restored to self-sufficiency, but the use of commercial factor VIII will continue to be necessary in 1989.

The increased output of factor VIII from BPL was particularly important as it became apparent early in the year that an acute shortage of factor VIII could be in prospect. Companies producing factor



The Blood Products Laboratory, Elstree

VIII, mostly based in the United States found that the extra treatment necessary to increase the purity has greatly reduced the yield of the concentrates. The UK is fortunate in having been cushioned from these problems, which have caused major difficulty in other countries.

A further development in 1988 was the introduction by some companies of a purification stage involving the use of monoclonal antibodies. While this produces a concentrate of much greater purity it also reduces the yield of factor VIII. Haematologists are at present uncertain as to whether these products offer any significant advantages but they are certainly useful in the treatment of patients who react badly to "traditional" products.

In 1988 considerable publicity was given to the commencement of clinical trials of synthetic factor VIII. This represented a significant development in the genetic engineering of factor VIII. It was unfortunate that parts of the media gave the impression that the transformation of haemophilia care was imminent. Over the next few years careful clinical trials will be needed to ensure that synthetic factor VIII has no unforeseen side-effects.

We are fortunate in having the continued support of those pharmaceutical companies who not only supply the commercial blood products on which our members were so heavily dependent during 1988, but also keep us informed of product developments. We are grateful for their financial assistance in enabling us to attend conferences and hold seminars referred to elsewhere in this report.

The Society has supported a number of research projects and haemophilia treatment centres during the year. Our financial support is of necessity limited, but we do attempt to encourage research which will be of direct benefit to people with haemophilia. The grants awarded during 1988 reflect the breadth of our interests, ranging from research into the immune system to specialist physiotherapy services. We have also been able to provide improvements to some treatment centres to lighten the burdens on haemophilic patients attending for treatment.

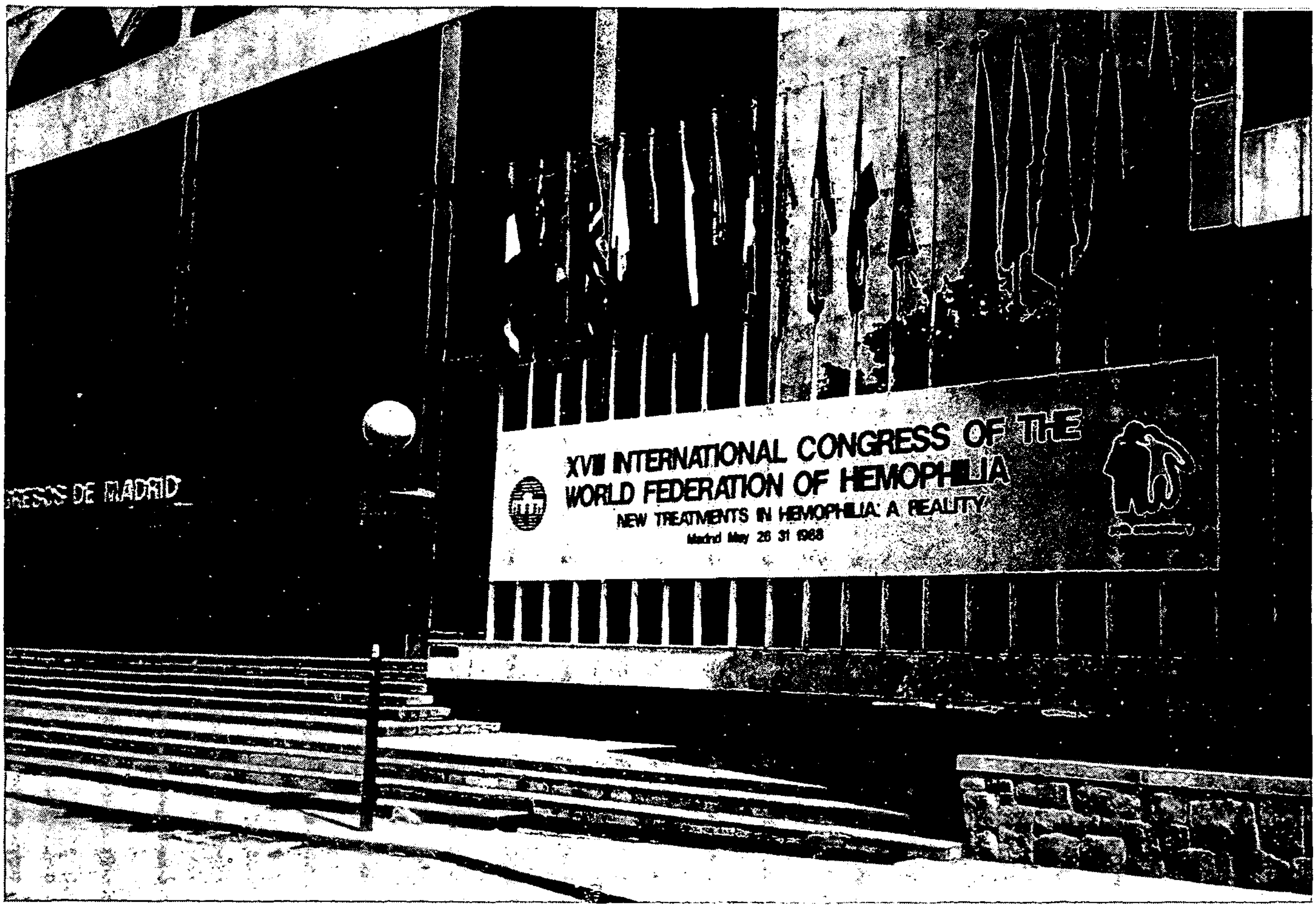
COMMUNICATIONS

The need for information about haemophilia and related issues has continued to grow in 1988. Given the widely dispersed nature of our membership, publications are a vital form of communication. The Society publishes THE BULLETIN, our official journal, four times a year, and UPDATE, a less formal newsheet, is also now produced on a quarterly basis. We have been pleased to notice an increase in the number of articles being submitted for publication, many from very eminent specialists. Some of our most interesting and moving items have come from our own members. We wish to thank all those who have sent material for publication.

Our press and media service continues to operate a 24 hour, 365 day a year service, providing a prompt response to the many requests for information and policy statements which journalists seek from the Society.

In the course of the year a number of specialist publications were produced, including a special report on the recompense campaign for distribution at the WFH conference in Madrid. A special series of briefing papers for Members of Parliament on the work of the Society was initiated. We were able to help our friends in the Canadian and Irish Haemophilia Societies by sending them much of our 1987 Recompense Campaign literature for adaptation and use. Also on an international theme, we have exchanged Bulletin articles with the National Hemophilia Foundation (USA), the Haemophilia Foundation of Australia, and the South African Haemophilia Society.

The costs associated with printing and distribution of our publications forms a substantial element in the Society's budget. However we believe that the benefits accruing from our communications represent a significant contribution to successful living with haemophilia. The information we supply to the wider public (and it is requested and supplied in surprisingly large quantities) helps to foster an environment in which the value of the work of the Society is understood and appreciated.



INTERNATIONAL

The Haemophilia Society in the UK was a founder member of the World Federation of Hemophilia (WFH), in whose work we continue to play a major part. Our Chairman is also Chairman of the WFH, and our General Secretary is Chairman of the Professional Staff Management Committee as well as serving on the International Compensation Committee.

In May 1988 the XVIIIth International Congress of WFH was held in Madrid. The UK was well represented at this Congress which was entitled "New Treatments in Haemophilia – a Reality". Much discussion and debate centred round the topic of producing purer blood products, and AIDS, hepatitis and inhibitors were also important themes. Society members, staff and health professionals participated actively in the Congress which is an important two-yearly forum for sharing information and inspiring others to achieve higher standards of treatment and care.

We welcome Charles Carman as the new President of WFH. He comes from the USA and we look forward to working with him to improve the quality of life for people with haemophilia throughout the world.

The UK Haemophilia Society has a special interest in the Indian Federation of Hemophilia, to whom we try to give special support. During 1988 we were able to send further medical equipment for use in their treatment centres in Delhi, Calcutta and Trivandrum. Our involvement with haemophilia care in India is a constant reminder of our good fortune in the UK, where, although factor VIII is a precious resource, it is, nonetheless, available.

During the year we had communications from people with haemophilia from Poland, Czechoslovakia, Kenya, Israel, South Africa and Brazil. We welcomed to our office visitors from many overseas countries and, from time to time, we were able to provide them with help during their stay in the UK. Such contacts are always valuable as we in our turn are able to advise our members about facilities and friends we can recommend in other parts of the world.

David Watters, General Secretary

Linda Matthews

Jonathan Cooper

Heather Maynard

Paul Burba

Jude McGuigan

Alan Weir

STAFF

In order that the Haemophilia Society can be effective in serving our members needs, we require the expertise and support of professional staff. We are fortunate that over recent years we have been able to build up and retain our small but exceptionally dedicated team of staff.

David Watters, the General Secretary, has continued to lead the staff during 1988 and his efforts have resulted in greater achievements for the Society, and even higher standards of service to our members. We thank him for his dedicated service to the Society, which goes beyond anything we have a right to expect.

Linda Matthews has been instrumental in developing highly efficient administrative systems in our office. Our financial reporting system is now fully computerised, as are our member records and mailing lists. This essential resource not only ensures a high standard of service to members, but is invaluable in our fund raising work.

During 1988 Jonathan Cooper, who was initially employed on the strength of a particular charitable donation, became a full time permanent member of staff. His visits to Haemophilia Centres all over Britain have resulted in an invaluable directory of treatment facilities, which we shall be able to use in securing high and consistent standards in the future. The knowledge he has acquired of the Social Security system has been of great value to our members.

Heather Maynard continues to provide the General Secretary with personal administrative support of the highest calibre. During the year under review we said farewell to Jean Chilemba and welcomed Paul Burba in the post of receptionist/typist and have valued their help in the front line of the office. Jude McGuigan, who previously worked on a voluntary basis, has become a full employee, servicing our press cutting library and supporting our sales activities.

We continue to benefit from the voluntary help given by Alan Weir who responds promptly and efficiently to the requests we receive for information and literature.

Without our staff, the Society would not be able to operate as it does, nor would it command the respect that it does from the medical profession, the government, the civil service and the many other organisations with which we come in contact.

Soldiers of R.E.M.E., Caterham; proud fundraisers

FUNDRAISING

The demands made upon the Haemophilia Society have grown very considerably in recent years. Each year we face a growing financial burden in order to meet the costs of increased provision of services to our members. The need for cost-effective and successful fundraising is constantly before us.

As the Chairman has noted in his statement, 1988 has been a particularly difficult year for fundraising. The perception of the Macfarlane Trust funds and the over-enthusiastic heralding of "the cure" of synthetic factor VIII, have caused many donors to think that the problems of haemophilia have been solved. We hope this Annual Report has played its part in giving a true picture of the continuing needs for a strong and growing Haemophilia Society.

We are deeply grateful to all the individuals, trusts, corporations, and other organisations who support our work, but we are conscious that we are forced to operate on a very tight budget with very little room for development or expansion of our services. If we are to continue to develop our work for the greater benefit of people in need, we must redouble our efforts to secure a sound financial base from which to operate.

Our fund raising takes place at all levels of the Society, from individual members, Groups and our national office. We have been fortunate in benefitting from a few very large charity events, but we are equally dependent on a miriad of smaller fund-raising programmes which are essential to our financial well-being. We are particularly grateful to the International Airlines Charity Ball Committee who have selected us again as the beneficiary of their Ball for the next three years.

Our thanks go to all those who supported our work in 1988, and especial thanks go to our Groups and people with haemophilia who gave impressive support, reflecting the high degree of commitment to the work of the Society.

DONATIONS 1988

Our thanks to all those people who made cash donations of less than £50, fundraised throughout 1988, contributed by Deed of Covenant, contributed by Give as You Earn, helped sell raffle tickets and special thanks to D A Crawford, Marion Gregory and Kevin Martin who sold a staggering number of draw tickets.

GRO-A

Pharmaceutical Companies:

Alpha, Armour, Baxter, Bayer UK, CBLA, Immuno, Speywood.

Groups:

Birmingham, Cambridge, Hampshire, Jersey, Lewisham, Merseyside, Norfolk & Norwich, North East, North Wales, Northampton, Northern, Northern Ireland, Perth, Sheffield, South Essex, South Wales, Southern, Tayside.

Sponsored Events:

Simon Berger, Corporals Giles, Groome and Griffiths, Mr Hamidi, Heather Muir, Messrs Skidmore and Dennies, E L Thomson, Anna Whitmer.

Groups, Clubs, Events Etc.:

Airlines Charity Ball, Arbury Community Centre, Sunday Tea Dances, Austrey WI Handicraft Group, Bankes, Ashton Christmas Club, Barr Hall Lunch, Braunton Comprehensive School, Bristol Cathedral School, British Aerospace, Woodford, Clwb Carmen, Dragon School, Ellen Wilkinson High School, Kirkham Grammar School, Lathmere School, Loughborough Students Rag, Maidenhead Keep Fit Class, Mar-Eli School of Dancing, Ness Gala Week, Old Time Modern and Sequence Charity Dance, Mr and Mrs Phillips, BBQ and Cabaret Nights, Pond House Pool & Darts Team, St Luke's, Woodside, Stanstead Abbotts Young Farmers Club, Street Methodist Church, Balloon Race, TI, Chesterfield, Villages of Swanaton & Northington, Wadham College SU, Mr and Mrs Watts, Barn Dance.

Livery Companies:

The Carpenters' Co, The Drapers' Fund, The Fishmongers' Co, The Haberdashers' Co, The Skinners' Co, The Worshipful Co of Bowyers, Worshipful Co of Carmen, The Worshipful Co of Glaziers & Painters, The Worshipful Co of Gold & Silver Wyre Drawers, The Worshipful Co of Pewterers.

Trusts and Companies:

3M, ABB Kent, Abbey National, Adshead Ratcliffe, The Alchemy Foundation, Aldwyns Trust, Alex M Jacob Charitable Trust, Alfred de Rothschild Charity, Alliance & Leicester, Allied Dunbar, Andrew Balint Charitable Trust, Antony Hornby Charitable Trust, APV, Aurora, Bank of England, Bank of Scotland, Barclays, Bayer UK, The Beatrice Laing Trust, The Beaverbrook Foundation, Bell, Nicholson, Henderson, The Benham Charitable Settlement, Benjamin Priest, Bernard Meyers, Birmingham Midshires, The Brand Trust, Bright Steels, Britannic Assurance, Brixton Estate, Bryan Lancaster's Trust, Brymill, BTR, Bunzl, C T Bowring (Charities) Fund, Cave & Sons, Cazenove & Co, Charity No 326296, Charter Consolidated, Child & Co, The Christopher H R Reeves Charitable Trust, The Christopher Laing Foundation, Christopher Rowbotham Charitable Trust, City of London, Clive Holbrook, Colt Car Co, Commercial Union, The Commonwealth Fund, Cornhill, The Cotton Trust, Courage, Coutts, The D W Greenwood Charitable Settlement, Dalgety, The De Clermont Charitable Co, The De La Rue Co, Delta, Denise Cohen Charitable Trust, Dobson Park Industries, The Dowty Group, Druck, E W Taylor, Eagle Star, Edward Cadbury Charitable Trust, The Esmee Fairbairn Charitable Trust, F C Pollard Charitable Trust, F J Wallis Charitable Settlement, Fairview, Fisco, The Fitton Trust, Forum Lodge No 3537, FPS, Friends Provident, G S Plaut Charitable Trust, The Gerald Bentall Charitable Trust, Gerrard & National, Glaxo (1972) Charity Trust, The Godinton Charitable Trust, Goode Durrant, Gresham, The Guardian Royal Exchange, Guinness, H L Stembridge Charitable Settlement, Hall Charitable Trust, The Harold Hyam Wingate Foundation, Harris & Sheldon, Harris Charitable Trust, The Hedley Foundation, HFC, Highland Leasing, Hill & Smith, The Hoover Foundation, The Hunting Group, IMI, International Thomson, The Inverforth Charitable Trust, J Davies (Charities) Ltd, Jaguar, The James Weir Foundation, The Jan Branford Charitable Trust, The Jane Hodge Foundation, Jeffrey Young, The Jephcott Charitable Trust, Jessie Spencer Trust, John & Celia Bonham Christie Charitable Trust, John Coates Charitable Trust, John Lewis, Johnson & Firth Brown, Johnston Management, Joseph & Mary Tiley Trust, The Joseph Lucas Charitable Trust, The Joseph Rank (1942) Trust, Joseph Strong Frazer Trust, Jubilee Trust, Kalamazoo, Land Hind Trust, Land Rover, The Laurie Nidditch Foundation, The Lewis Family Charitable Trust, Lloyds, Members of Lloyd's & Lloyd's Brokers, London & Manchester, The London Metal Exchange, Lord Ashdown Charitable Settlement, Lord Barnaby's Foundation, Masons, Matthews Wrightson Charity Trust, Maurice Wohl Charitable Trust, MB, McArthur, MEPC, Mercantile, The Michael & Anna Wix Charitable Trust, Michelin, Midland, The Midland News Association, Miss Marsh Charitable Trust, Mitchells, Moore Paragon, The Moorgate Trust Fund, Morgan Grenfell, Morrison Bowmore, The Moss Family Charitable Trust, Mowlem, Mrs Gabrielle M Sugden-Wilson's Charitable Settlement, Mrs Vera Leighs Charity, Murphy-Neumann Charity, N M Rothschild, National Westminster, Nationwide Anglia, NEL Britannia, News International, Northern Rock Building Society, Norton Abrasives, Norwich Union, The Onneley Trust, P F Charitable Trust, Pan Britannica, Paterson Jenks, Pearl, Phillips & Drew, Pioneer Mutual, Podde Trust, Provident Life, Provincial, Prudential, R & J Lass, R M Burton, Rank Hovis McDougall, The Rayne Foundation, Readers Digest, Refuge, Reliance Gear Co, Richard Pearson, Robert Fleming, Rotork, Royal Bank of Scotland, Royal Life, RTZ, The S & W Berrisford Charity, Simon Gibson Charitable Trust, Simon's Charity, Sir Andrew Carnwath's Charitable Trust, Sir Arthur Black Trust, Sir Edward Lewish Foundation, The Sir John Sumner's Trust, Sketchley, Skorimpex Rind, Smith's Charity, The Sobell Foundation, Sovereign, Stadium, Standard Chartered, Stanley Charitable Trust, Stewart Wrightson Charitable Trust, Strutt & Parker, Sun Alliance, Sun Life, The Sylvia Shine Charitable Trust, Tarmac, Thomas Reed, Thomas Tunnock, The Thomson Organisation, TI Group, Tom & Miriam Stoppard's Charitable Trust, The Trades House of Glasgow, Trafalgar Chapter No 593, Trust House Forte, TSB Group, The Turner Trust, United Distillers, Vincent Finance, W Canning, Wallace & Tiernan, Welconstruct, William Vere, Y J Lovell.

Draw Prizes:

Lawson International Travel Service, Marks & Spencer, P&O European Ferries, Pirelli, South London Stationers & Printers.

Individuals:

GRO-D

Tombola Prizes:

Agfa-Gavaert, Alfred Dunhill, Allied-Lyons, Argos, Argyll, Arthur Sanderson, Avon, Britoil, Brooke Bond Oxo, CBS, Clarks Shoes, Coloroll, Costa Coffee Company, Derby Group, George Ballantine, Grampian Group, Grand Metropolitan, Hampshire Group, Harrods, Hedges & Butler, Jacobs Suchard, John Menzies, John Wallington, Johnson & Johnson, Josiah Wedgwood, K-Tel, Lewisham Group, Martini & Rossi, Max Factor, Nestlé, Nice Irmas's, Norfolk & Norwich Group, North East Group, North Wales Group, Northampton Group, P & O European Ferries, Panasonic, Paramount, Rank Hovis McDougall, Rowntree, Royal Doulton, Sainsbury's, Tayside Group, The Invergordon Distillers, The Wiggins Teape Group, W H Smith, Whitbread, Yale & Valor, Yardley.

TREASURER'S REPORT

When presenting the 1987 Accounts reference was made to the growing demands being made upon the Society and the need to broaden the base of our support. 1988 saw just such an increase in the demands made on the Society – and a corresponding increase in our expenditure. Regrettably this was not totally reflected in our income and while our financial position is not altogether pessimistic we must, nonetheless, continue to aim to strengthen the funding available to the Society.

We are grateful to Pridie Brewster, Chartered Accountants, for their work in auditing the 1988 Annual Accounts and for their help throughout the year. A special word of thanks must also go to Linda Matthews, the Administrative Secretary, for her hard work in ensuring that computerisation of the accounts was completed in 1988.

Once again a simplified version of the Accounts is presented in this report. A full set will be made available to all members attending the Annual General Meeting and in response to requests received from members through the post.

John L Prothero
Treasurer

AUDITORS' REPORT TO THE GUARANTORS OF THE HAEMOPHILIA SOCIETY

We have audited the financial statements annexed in accordance with approved Auditing Standards.

In our opinion the financial statements give a true and fair view of the state of the company's affairs at 31st December 1988 and of its surplus and source and application of funds for the year then ended and comply with the Companies Act 1985.

Carolyn House
29-31 Greville Street
London EC1N 8RB

PRIDIE BREWSTER
CHARTERED ACCOUNTANTS

A full copy of the accounts will be sent to any member who requires them.

INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31st DECEMBER 1988

		1988		1987
	£	£	£	£
Income		284,407		274,257
Case Committee Grants		15,935		22,853
		268,472		251,404
Other Expenditure		278,743		238,325
EXCESS OF INCOME OVER EXPENDITURE		(10,271)		13,079
Corporation Tax		(2,847)		1,767
		(7,424)		11,312
General Accumulated Fund at beginning of year	86,533		75,018	
Transfer from Social Worker Fund	—		51	
Transfer from Benefit Fund	—		152	
Transfer from Research Fund	58,570		—	
		145,103		75,221
GENERAL ACCUMULATED FUND AT END OF YEAR		137,679		86,533

BALANCE SHEET AS AT 31st DECEMBER 1988

	1988		1987	
FIXED ASSETS	£	£	£	£
Leasehold Property		850		2,648
Improvements to Leasehold Property		3,021		5,820
Office equipment and furniture		19,881		20,992
Caravans		12,113		9,170
		35,865		38,630
CURRENT ASSETS				
Stocks	5,765		9,333	
Debtors	20,221		12,843	
Cash at bank and in hand	80,285		119,756	
	106,271		141,932	
CREDITORS (amounts falling due within one year)	4,457		35,459	
Net current assets		101,814		106,473
TOTAL ASSETS LESS LIABILITIES		137,679		145,103
RESERVES				
General Accumulated Fund		137,679		86,533
Research Fund		—		58,570
		137,679		145,103

Approved by:
Revd. A. J. Tanner, M.A.
J. L. Prothero Members of the Executive Committee

DETAILED INCOME AND EXPENDITURE ACCOUNT

FOR THE YEAR ENDED 31st DECEMBER 1988

	1988			1987
	£	£	£	£
INCOME				
Subscriptions		7,165		6,955
Donations		189,244		202,473
Research donations		7,111		—
Legacies received		39,110		25,684
Annual Draw		18,340		15,354
Sale of Badges, Books, etc.		10,907		12,702
Interest received		8,141		11,089
Expenses recovered re: prior year		4,389		—
		284,407		274,257
EXPENDITURE				
Case Committee Grants	15,935		22,853	
Local Grants	400		—	
Research Grants (see below)	17,770		—	
Office Rent	10,696		10,562	
Rates	4,000		4,325	
Light and heat	1,287		1,483	
Lease of office equipment	14,979		8,991	
General office expenses	5,119		5,587	
Salaries and National Insurance	72,891		49,783	
Travelling expenses	19,868		18,857	
Cost of Attendances at World Federation of Hemophilia Congress	6,450		—	
Appeal costs	25,730		32,630	
Insurance	1,033		159	
Postage and telephone	23,644		24,280	
Printing and stationery	25,289		37,185	
Publications and subscriptions	8,900		5,433	
Audit and accountancy charges	1,376		750	
Seminar weekends	11,639		9,749	
Meeting expenses and hall hire	8,773		6,934	
Indian Haemophilia Society Grant	434		1,222	
Computer maintenance costs	553		1,018	
Legal and professional fees	1,150		4,943	
Depreciation	16,762		14,434	
		294,678		261,178
		(10,271)		13,079
Corporation tax		(2,847)		1,767
EXCESS OF INCOME OVER EXPENDITURE		(7,424)		11,312

Note: Grants

Previously grants were accounted for when approved. It is now the company's policy to account for grants when paid. Research grants included in the income and expenditure for the year ended 31st December 1988 are as follows:

	£
University of Stirling	4,237
Lewisham	936
Lincoln	2,986
UMDS	8,018
RVH Belfast	1,170
Clinical Research Centre	2,312
St. Thomas's	10,000
Royal Liverpool	1,500
Royal Free	9.810
	40,969
Accrued for in 1987	(23,199)
	17,770

Grants approved to be paid in 1989 are as follow:

	£
Lewisham	563
UMDS	6,459
Royal Liverpool	7,500
Royal Free	6,255
	20,777