



**The  
Haemophilia  
Society**

# **ANNUAL REPORT 1981**

P.O. Box 9 16 Trinity Street London SE1 1DE

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L. Kuttner, LLD (Group Liaison Officer to September 1981)  
K. Milne, BSc. (Assistant Editor: The Bulletin)  
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J. Ritchie (Chairman: World Hemophilia Youth)  
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*Co-ordinator:*

David G. Watters, J.P.



*The Society's Patron: H.R.H. The Duchess of Kent*

## ANNUAL REPORT

### WHAT IS HAEMOPHILIA?

Put simply, haemophilia is a hereditary bleeding disorder. The blood in a person with haemophilia does not 'clot' in the same way as other people's. Most especially, bleeding is into muscles and joints causing pain and permanent damage. Today, modern treatment is reducing the damage which arises from prolonged bleeding but there is still a long way to go until the CURE is found.

### INTRODUCTION

The Haemophilia Society was established in 1950.

The aims of the Society are:

- To provide a fellowship for haemophiliacs and those concerned with their health and welfare; and to give advice on their problems.
- To safeguard the social and economic interests of haemophiliacs and to give financial or other help in cases of difficulty or hardship.
- To promote the study of the causes and treatment of haemophilia and similar conditions.
- To bring to the notice of the authorities the special needs of haemophiliacs, and to co-operate with the medical and allied professions to further their care.
- To co-operate with other bodies concerned with the welfare of the physically handicapped.
- To gather and distribute information useful to haemophiliacs and of interest to the general public.

In practice the Society operates at two levels — first of all that of providing support, friendship, advice and information to people with haemophilia — and those involved in their care. This is achieved through various publications, including The Bulletin, and by encouraging, for example, the formation of professional groups for nurses and social workers as well as local groups of members. Secondly, the Society seeks to encourage and support research into the condition; since the Society was formed more than £250,000 has been invested in such research and this has contributed greatly to the advances in treatment and care which benefit so many today.

### *"Times change and we change with them"*

"Change" was the keyword for The Haemophilia Society in 1981. For some years we have been aware that the progress being made in the treatment and management of haemophilia was leading to increasing requests for information and advice, so we have seen the need to improve facilities offered to our members.

With this in mind, two important decisions were put into effect in 1981.

### *Appointment of Co-ordinator*

First, we appointed a full-time officer to act as the Co-ordinator of all our activities. In the early days of the Society, the honorary officers were able to deal with general enquiries and correspondence by attending to these matters in their spare time but, in recent years, it has become increasingly difficult to deal efficiently with the administration in this way.

By the time this Report is published it will be well known that we were singularly fortunate in being able to appoint Mr. David Watters as our first Co-ordinator. He began work with us in February 1981 and has shown an insatiable appetite for work. He is an efficient administrator and, most importantly of all, he has all the admirable qualities of one who has been taught to "smile and whistle under all difficulties"!

Now that the Co-ordinator attends to the day-to-day administration, the officers are more free to devote their time to forming the policy of the Society and studying particular aspects of haemophilia more deeply.

### *The Group Seminars*

A plea from the Groups which reached a crescendo during the year was for more information to be available about the Society's work, the benefits available and other matters concerning haemophilia.

"Communication" became one of the regular concerns of the Executive Committee and our efforts to meet the demand bore fruit in the first Group Seminar held from 13 to 15 March 1981, at the Hendon Hall Hotel, London. In the Report of the weekend it was described as being "embarrassingly well attended" and that is a fitting tribute to the success of the experiment.

A special issue of The Bulletin was published in December 1981 to record the "Group Seminar Proceedings" and the interest generated was so great that a similar educational event is to be promoted in 1982.

## THE SUPPLY OF BLOOD PRODUCTS

The supply of blood products has continued to be a matter of great concern and the sub-committee appointed to advise the Executive Committee has helped to form the Society's policy in approaching the Government.

We have pressed for an increase in both the total amount of Factor VIII to be available for treatment, and, more particularly, the proportion provided by the National Health Service.

Mr. Gerard Vaughan, the Minister of Health, met the officers of the Society in October 1981 when the supply of blood products was the main subject discussed.

The Minister gave an assurance that the Government continues to aim for a position where NHS facilities will be sufficient for the production of the amount of Factor VIII required, though in view of the current national economic difficulties, this could not be regarded as a goal to be achieved in the immediate future.

Mr. Vaughan invited the officers to meet him again in the following year to take stock of the progress made.

## THE BULLETIN

The high standard of the Bulletin has drawn many favourable comments, not only from our own members but from other National Societies who regard this as being an ideal means of communication and information. Three Special Bulletins were published to include reports on "Pre-natal Diagnosis", "Factor VIII and Factor IX, What they are and what they do" and "The Group Seminar Proceedings".

The Editor, Mr. Clive Knight, is to be congratulated for the excellence of these publications.

## PROFESSIONAL ASSOCIATIONS

The social workers at the Centres have developed their professional relationships with each other by the formation of the "Special Interest Group in Haemophilia and Related Haemostatic Disorders". This Group is jointly sponsored by the Society and the British Association of Social Workers. Nurses have been encouraged to form the Haemophilia Nurses Association.

We have been pleased to support both these organisations and to welcome their desire to work closely with the Society. It will be obvious to all that we are greatly indebted to the members of both these professional groups for the care they extend to people with haemophilia.



*The Society's President: Professor R. G. Macfarlane, CBE, MA, MD, FRCP, FRS.*

### PERSONALITIES

**The President:** The Society has been honoured by Professor R. G. Macfarlane's accepting the invitation to become the Society's President. Professor Macfarlane is known throughout the world as one of the pioneers in the field of haemophilia and his election as President was unanimous and enthusiastic.

**The Group Liaison Officer:** Dr. Ludwig Kuttner retired from the office of Group Liaison Officer after nine years, during which the number of Groups increased steadily. It was due

Dr. Kuttner's suggestion that the practice was established to hold Group meetings in the mornings before Council meetings. To mark his retirement Dr. Kuttner was presented with two antique candlesticks.

Dr. and Mrs. Kuttner, together with the Honorary Secretary, Mr. K. R. Polton and **GRO-D** represented the Society at a Garden Party held at Buckingham Palace in the summer, when they were privileged to meet again the Society's Patron, Her Royal Highness, the Duchess of Kent.

## AWARDS

*The Macfarlane Award:* The Award for 1980 was presented to Professor Eddie Blackburn at Sheffield on 15 October. At a most happy occasion the Chairman spoke of Professor Blackburn's achievements and read the citation for the Award.

THE R. G. MACFARLANE AWARD 1980.  
Presented to EDWARD KENYON BLACKBURN by  
THE HAEMOPHILIA SOCIETY to mark his deep commitment to the care of people with haemophilia and his concern for their well-being and that of their families.

We are pleased to record the following Awards made in 1981:

*The Catherine Cookson Award for academic achievement:*

SENIOR AWARD

**GRO-A**

*The Brendan Foster Award for achievement in Sport:*

SENIOR AWARD

This was presented to a 17 year old who has played badminton for his County Schools' Team for the past three years.

JUNIOR AWARD

Was presented to **GRO-A** for achievement in ski-ing.

*Dr. Barnardo's Champion Children of the Year Award*

One of our younger members, **GRO-A** also received a "Champion Children's Award", given by Dr. Barnardo's at an impressive ceremony in the Savoy Hotel. We offer him our warm congratulations.

## CASE COMMITTEE

The Case Committee continues as a Sub-Committee of the Executive Committee and administers the Benefit Fund.

The Committee met twelve times in 1982 and considered 33 requests for help. Of those, 79 received financial assistance totalling £1,015.

Requests for assistance may come from families, individuals, Groups, Centres, Social Workers or any other person involved in the professional care of people with haemophilia. Co-operation between these and the Case Committee do much to ensure that any help provided by the Society is more informed, effective and worthwhile than it might otherwise be.

## OVERSEAS MEMBERS

The Society has a number of overseas members and we learn from Mrs. Peggy Britten, the World Federation of Hemophilia's London Secretary, that requests for help also come at times to the Society from other foreign patients, their families and their doctors. So we have been able to give advice and information to, among others, an Italian patient, a Yugoslavian professor of Psychiatry and a nurse in Hong Kong.

However, the problems of the Third World remain, as we see from letters which come from India, Pakistan and parts of Africa. Some such places lack the most basic treatment facilities: even fresh plasma is unavailable and there are no opportunities for accurate diagnosis to be made.

As the prospects for treatment improve so steadily and substantially, here at home, we must be vigilant to respond to opportunities to help those less fortunate than ourselves. The World Federation has done much to inspire us with the idea of supporting others and is now making available educational programmes and workshops by which people in other countries may be helped to help themselves.

## THE WORLD FEDERATION OF HEMOPHILIA

### *European Advisory Board*

We have maintained our enthusiastic support for the World Federation of Hemophilia with some of our own officers holding important offices in the organisation.

In particular, Mr. John Prothero has continued as Chairman of the European Advisory Board and he has sought to develop co-operation among the countries concerned. There has been some measure of disappointment at the lack of response from some other National Societies after meetings of the Board have taken place and by the fact that only two or three of the National Societies in Europe are able to take an active part in the work of the Board.

The Council of the World Federation has taken some initiative in developing new phases of work in Europe and the Society will welcome any further progress made as a result of these plans.

### *World Hemophilia Youth*

We have supported the development of the organisation of "WHY" which was launched at the WFH Congress in Israel in 1979. The declared aim of WHY is in stimulating the interest of young people to help each other, their National Societies, and people from other countries. Mr. John Ritchie and Mr. Mike Payne, the United Kingdom Secretary, have travelled extensively throughout Scotland, Northern Ireland, England and Wales. They attended meetings organised by the local Groups, often with the help of staff from the Centres, and met a substantial cross-section of young-minded people with haemophilia, many of whom are interested in WHY and are prepared to play an active part in its development. Mr. John Ritchie was appointed Chairman of the Executive Committee of WHY in July 1981.

### *WHF Congress: Costa Rica 1981*

The Society was represented officially at the XIVth Congress of the World Federation of Hemophilia held in San José, Costa Rica, in July 1981. The theme of the Congress was "Hemophilia Care in the Developing Countries" and it became evident that the World Federation itself and its member organisations have a responsibility to consider more seriously and urgently the problems of the enormous number of people with haemophilia throughout the world for whom treatment facilities are not available. We were pleased to note that the Hemophilia Society is held in high regard by members of other National Societies whose members are eager to learn about ways of encouraging people with hemophilia to be responsible for their own welfare by establishing similar Societies in their own countries.

Once again, the WFH Congress provided the opportunity to strengthen personal contacts with members of other Societies and to exchange information about the developments in the care and benefits available.

### *WH "Blueprint for the 1980's"*

The World Federation has entered on the present decade with an imaginative plan for developing its work. "Blueprint for the 1980's" sets down plans for the 'Hemophilia Action Group' and particular Task Forces to deal with special subjects and take appropriate action. These plans involve more actively many of the doctors, scientists and other professional people who are recognised internationally for their original work. We are actively supporting the World Federation in its plans for the future.

## **RESEARCH FUND**

The £250,000 Research Appeal Fund was established in 1979. All money raised for this fund goes directly to research into the condition, its cause, management and care, there being absolutely no administrative charge or costs against it.

At 31 December the total income to the Research Appeal Fund was £130,355.39.

The Appeal Fund was established to give research workers ease of access to funds for the support and encouragement of their work.

The Society is advised by a distinguished panel of haematologists with specialist knowledge of haemophilia and their advice is sought on applications, especially those involving new aspects of care.

The ultimate purpose of the fund is, of course, that of helping to find the long sought after cure to the condition. While that answer is undoubtedly connected with genetic engineering there is much to be done in the meantime with other aspects of management and primary amongst those is that of securing adequate supplies of Factor VIII — the technical name for the clotting factor which is absent in haemophilic blood. Part of the answer to this lies in the synthetic production of Factor VIII. Other areas of work which the Society is keen to encourage and support include pre-natal diagnosis of haemophilia, research into methods of reducing gross joint damage, and all research programmes which ease the problems surrounding haemophilia management and care.

The ultimate goal remains that of assisting towards the identification and stimulation of the vital Factor VIII-producing gene.

## THE FUTURE

1981 has been a year in which we have made important advances in setting in order our administration and in defining our policy on a number of major matters.

We are now presented with the opportunity to consider the best way to take advantage of the progress made by doctors and scientists during the last decade.

Progress invariably brings new responsibilities and occasions for decision.

For instance, pre-natal diagnosis leads to parents having to make choices which have not previously been required from them.

Doctors and scientists are introducing us to new prospects for the future when, for example, synthesis of Factor VIII may be a practical possibility and our minds are even now turned towards the benefits which may come from genetic engineering. Meanwhile, life has to be lived here and now and people are still having to learn how to live with haemophilia. We are now concerned increasingly with the quality of life which is possible for us and the way in which we may help each other to make our unique contribution to the community in which we live.

*"Times change and we change with them".*

An apt quotation to open an annual report.

And another to close: *"Plus ça change, plus c'est la même chose".*

The developments which have marked our work during the year have helped us to recognize that to be true: *"the more things change, the more they are the same".*

Our primary objective remains unchanged. We strive to provide "A fellowship for the people with haemophilia, their families and those concerned with their health and welfare".

We present this Report with gratitude to all who have helped to strengthen this fellowship in the course of the year.

## FINANCIAL REPORT

The Society's overall running expenditure for the year amounted to over £47,000. Although this is a considerable increase compared to previous years, largely due to the reorganisation of the office following the appointment of the Co-ordinator, the General Fund still shows a surplus for the year in excess of £3,600. Out of this sum we propose transferring £1,000 to the Benefit Fund to cover various grants made from that Fund.

In view of the resulting small surplus balance on the General Fund for the current year it has been decided to defer for a further year the question of making a charge on the Research Fund in respect of the administrative costs incurred in connection with the Fund.

Research Fund Grants made during 1981 total over £43,000 to twelve hospitals. This compares with the five previous years as follows:

1976	£21,401	14 grants
1977	£25,566	16 grants
1978	£13,149	13 grants
1979	£ 7,764	6 grants
1980	£31,585	9 grants

The actual income to the Research Fund during the year totalled £46,800 compared with £60,707 in the previous year. Donations to the General Fund were also lower compared to the previous year, but we received three sizeable legacies, totalling £28,000. Without the benefit of these legacies the General Fund would have incurred a deficit for the year.

We are examining various avenues of increasing the Society's sources of finance. Among them is an attempt to increase donations received under Deed of Covenant. We are also in the process of co-ordinating more closely with the Groups' accounts and we anticipate an improved management of the Society's financial affairs.

\* \* \* \* \*

We report that we have examined the Balance Sheet below, together with the annexed Income and Expenditure Account and have obtained all the information and explanations which to the best of our knowledge and belief were necessary for the purpose of the audit. In our opinion proper books have been kept as far as appears from our examination thereof, and the Society's Balance Sheet and Income and Expenditure Accounts dealt with in our report are in agreement with these books. In our opinion and the best of our information and according to the explanations given to us the said Balance Sheet gives a true and fair view of the state of the Society's affairs as at 31st December 1981 and of the Income over Expenditure for the year ended on that date.

TAYLOR, VINEY & MARLOW  
Chartered Accountants,  
60a, Station Road,  
Upminster, Essex.

5th March 1982

# THE HAEMOPHILIA SOCIETY

## BALANCE SHEET AS AT 31st DECEMBER 1981

### FIXED ASSETS

496	Written down value brought forward	496
	Less: Sale Proceeds of Typewriter	<u>115</u>
		381
	Depreciation	<u>57</u>
		324

### CURRENT ASSETS

—	Legacies Receivable	28,603
1,600	Debtors and Prepayments	727
1,697	Stocks in Hand	2,310
1,352	Balance at Bank — Current Account	2,669
	Balance at National Westminster Bank —	
18,909	Deposit Account	9,066
	Balance at National Westminster Bank —	
51,000	Special Deposit Account	51,000
<u>6</u>	Cash in Hand	<u>23</u>
£74,564		£94,398

### Deduct — CURRENT LIABILITIES

12,085	Sundry Creditors	4,649
—	Research Fund Grants Payable	<u>20,865</u>
£12,085		25,514

62,479	Excess Current Assets	<u>68,884</u>
£62,975	Total Net Assets	<u>£69,208</u>

### REPRESENTING — GENERAL ACCUMULATED FUND

5,841	Balance as at 1st January 1981	9,106
<u>3,265</u>	Add: Surplus for year ended 31st December 1981	<u>2,464</u>
9,106	Balance as at 31st December 1981	11,570
51,419	<i>Research Fund</i>	54,987
32	<i>Social Worker Fund</i>	171
1,857	<i>Home Treatment Fund</i>	1,857
551	<i>Benefit Fund</i>	602
<u>10</u>	<i>Katharine Dormandy Fund</i>	<u>21</u>
£62,975		<u>£69,208</u>

# **BALANCE SHEET — YEAR ENDED 31st DECEMBER 1981**

<b>Research Fund</b>		
22,297	Balance as at 1st January 1981	51,419
60,707	Add: Various Donations and sums raised by groups including funds raised from sale of ball pens	46,811
<u>£83,004</u>		<u>£98,230</u>
<b>Deduct</b>		
42	Grants paid and payable St. Thomas' Hospital Haemophilia	4,497
3,000	Royal Free Hospital Haemophilia Centre	2,402
1,137	Oxford Haemophilia Centre	7,409
—	Liverpool Royal Hospital	200
10,000	Welsh National School of Medicine	—
—	Birmingham Children's Hospital	6,934
1,000	Sheffield Haemostasis Research Fund and Royal Hallamshire Hospital	5,500
—	Lincoln General Hospital	1,923
3,000	Lewisham Haemophilia Centre	3,314
—	Bangor Haemophilia Centre	1,064
350	St. James's University, Leeds	2,000
—	Manchester Royal Infirmary	4,500
450	University of Liverpool, Dept. of Haematology	—
—	Isle of Thanet District Hospital	3,500
12,606	King's College Hospital School of Medicine	—
<u>£31,585</u>		<u>£43,243</u>
<u>£51,419</u>	Balance as at 31st December 1981	<u>£54,987</u>
<b>Social Work Fund</b>		
142	Balance as at 1st January 1981	32
	Donations Received	248
		280
110	Deduct — Cost of Seminars and Secretarial Assistance	109
<u>£ 32</u>	Balance as at 31st December 1981	<u>£ 171</u>
<b>Home Treatment Fund</b>		
<u>£ 1,857</u>	Balance as at 1st January 1981 and 31st December 1981	<u>£ 1,857</u>

# **BALANCE SHEET – YEAR ENDED 31st DECEMBER 1981**

## **Benefit Fund**

513	Balance as at 1st January 1981	551
500	Add: Transfer from General Fund	1,000
—	Donation Received	66
		<u>£ 1,617</u>
£ 1,013		
155	Deduct — Loans Outstanding 1st January 1981	155
462	Grants to Members	<u>1,015</u>
		1,170
617		<u>155</u>
155	Loans Outstanding 31st December 1981	
		<u>1015</u>
462		
£ 551	Balance as at 31st December 1981	<u>£ 602</u>

## **Katharine Dormandy Trust Fund**

5	Balance as at 1st January 1981	10
	<i>Add:</i>	
5	Donation Received	11
		<u>21</u>
£ 10	Balance as at 31st December 1981	<u>£ 21</u>

# THE HAEMOPHILIA SOCIETY

## INCOME AND EXPENDITURE ACCOUNT YEAR ENDED 31st DECEMBER 1981

<b>INCOME</b>		
1,151	Subscriptions	1,086
13,181	Donations	11,782
—	Value of Legacies Receivable	28,603
218	Collections	—
2,529	Annual Draw (Net)	2,551
8,083	Interest Received	7,886
13	Sale of Christmas Cards	1
106	Sale of Booklets	127
<u>£25,281</u>		<u>£52,036</u>
<b>Deduct — EXPENDITURE</b>		
2,500	Office Rent	2,500
741	Rates and Water	1,018
143	Light and Heat	297
—	Lease of Office Equipment	2,021
374	General Office Expenses	1,850
4,834	Salaries and NIC	14,467
839	Net Travel Cost to Society of Bonn Conference	141
—	Net Travel Cost to Society to Costa Rica Congress	1,001
3,429	Travelling Expenses	4,368
2,217	Postage and Telephone	3,705
1,770	Printing and Stationery	8,806
788	Subscriptions to Affiliated Organisations	918
238	Appeals Expenses	1,128
201	Auditors' Remuneration	230
3	Publications	263
—	Net Cost of Seminar Weekend	2,283
1,263	Meeting Expenses and Hire of Halls	1,924
1,819	Grants to Hostel	125
16	Loss on Sale of Key Rings	43
124	Professor Macfarlane Award	377
130	Grants to Groups	50
87	Depreciation	57
—	Provision for Purchase of Wheelchair at Lord Mayor Treloar College	<u>1,000</u>
<u>£21,516</u>		<u>£48,572</u>
3,765	Excess of Income over Expenditure for year	3,464
500	Less: Transfer to Benefit Fund	<u>1,000</u>
<u>£ 3,265</u>		<u>£ 2,464</u>

# THE HAEMOPHILIA SOCIETY

## NOTES TO ACCOUNTS YEAR ENDED 31st DECEMBER 1981

### Schedule of General Expenses

1.	Sundry Office Petty Cash Expenditure	340
	Repairs, Renewals and Maintenance of Office Equipment	352
	Consultancy Costs relating to Employment of D. Walters	575
	Sundry Subscriptions	179
	Office and Employee Insurance Costs	176
	Fire Extinguisher and Maintenance	19
	Equipment Training Course	86
	Refuse Clearance	
	Sundry Typing Costs	15
	Lottery Fee	10
	Bulletin Dispatch	35
	Dr. Kuttner's Farewell Gift Less Group Donations	10
		<u>£ 1,849</u>

### 2. Legacies Receivable

During the year ended 31st December 1981 the Society has been formally notified of three legacies. As at the Balance Sheet date the majority of the amounts involved had not been distributed to the Society by the various Executors. It is estimated therefore based on information in our possession that our interests in the estates concerned are as follows:—

The Estate of	GRO-A	Deceased	1,666.66
The Estate of	GRO-A	Deceased	18,000.00
The Estate of	GRO-A		9,059.32
Less: Distribution received on account			<u>123,30</u>
			<u>8,936.68</u>
			<u>£28,602.68</u>

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