Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392025

The
Haemophilia
Society

ANNUAL REPORT
1981

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

PATRON

HRH The Duchess of Kent

President:

R. G. Macfarlane, CBE., MA., MD., FRCP., FRS.

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Mrs. M. I. Britten, BSc. (London Secretary, WFH)
W. Johnstone
C. Knight, BA. (Editor: The Bulletin)
L. Kuttner, LLD (Group Liaison Officer to September 1981)
K. Milne, BSc. (Assistant Editor: The Bulletin)
J. L. Prothero (Chairman: European Advisory Board)
J. Ritchie (Chairman: World Hemophilia Youth)
D. Rosenblatt, BSc.

Medical Advisory Panel:

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Dr. E. E. Mayne, MD., MRCPath.
Dr. C. R. Rizza, MD., FRCP.
Dr. E. G. D. Tuddenham, MRCP., MRCPath.

Co-ordinator:

David G. Watters, J.P.

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

ANNUAL REPORT

HAT IS HAEMOPHILIA?

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

TRODUCTION

he Haemophilia Society was established in 1950.

he 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.

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

"Times change and we change with them"

'Change" was the keyword for The Haemophilia Society in 1981. For some years we have een 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 mprove 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 th early days of the Society, the honorary officers were able to deal with general enquiries an correspondence by attending to these matters in their spare time but, in recent years, it ha 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 i being able to appoint Mr. David Watters as our first Co-ordinator. He began work with us i February 1981 and has shown an insatiable appetite for work. He is an efficient administrato and, most importantly of all, he has all the admirable qualities of one who has been taught t "smile and whistle under all difficulties"!

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

The Group Seminars

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

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

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

THE SUPPLY OF BLOOD PRODUCTS

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

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

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

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

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

THE BULLETIN

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

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

PROFESSIONAL ASSOCIATIONS

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

have been pleased to support both these organisations and to welcome their desire to work
sely with the Society. It will be obvious to all that we are greatly indebted to the members
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 througho the world as one of the pioneers in the field of haemophilia and his election as President w unanimous and enthusiastic.

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

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

r. and Mrs. Kuttner, together with the Honorary Secretary, Mr. K. R. Polton and Mrs. Polton, epresented the Society at a Garden Party held at Buckingham Palace in the summer, when ney were privileged to meet again the Society's Patron, Her Royal Highness, the Duchess of ent.

AWARDS

he Macfarlane Award: The Award for 1980 was presented to Professor Eddie Blackburn at heffield on 15 October. At a most happy occasion the Chairman spoke of Professor lackburn'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.

/e are pleased to record the following Awards made in 1981:

he Catherine Cookson Award for academic achievement:

ENIOR AWARD GRO-A GRO-A and GRO-A

he Brendan Foster Award for achievement in Sport:

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

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

r. Barnardo's Champion Children of the Year Award

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

CASE COMMITTEE

he Case Committee continues as a Sub-Committee of the Executive Committee and adminsters the Benefit Fund.

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

equests for assistance may come from families, individuals, Groups, Centres, Social Workers r any other person involved in the professional care of people with haemophilia. Coperation between these and the Case Committee do much to ensure that any help provided y 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, th World Federation of Hemophilia's London Secretary, that requests for help also come at tim to the Society from other foreign patients, their families and their doctors. So we have bee able to give advice and information to, among others, an Italian patient, a Yugoslavia professor of Psychiatry and a nurse in Hong Kong.

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

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

THE WORLD FEDERATION OF HEMOPHILIA

European Advisory Board

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

In particular, Mr. John Prothero has continued as Chairman of the European Advisory Boar and he has sought to develop co-operation among the countries concerned. There has bee some measure of disappointment at the lack of response from some other National Societie after meetings of the Board have taken place and by the fact that only two or three of th 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 o work in Europe and the Society will welcome any further progress made as a result of thes plans.

World Hemophilia Youth

We have supported the development of the organisation of "WHY" which was launched at th WFH Congress in Israel in 1979. The declared aim of WHY is in stimulating the interest o 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 meeting 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 intereste in WHY and are prepared to play an active part in its development. Mr. John Ritchie wa 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.

H "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 no 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,
Upminister, Essex.

5th March 1982

THE HAEMOPHILIA SOCIETY

BALANCE SHEET AS AT 31st DECEMBER 1981

	FIXED ASSETS			
	Written down value brought forward			496
496	Less: Sale Proceeds of Typewriter			115
				381
	Depreciation			57
				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	
18,909	Balance at National Westminster Bank — Deposit Account		9,066	
51,000	Balance at National Westminster Bank — Special Deposit Account		51,000	
6	Cash in Hand		23	
£74,564			£94,398	
	Deduct — CURRENT LIABILITIES			
12,085	Sundry Creditors	4,649		
—	Research Fund Grants Payable	20,865		
£12,085			25,514	
62,479	Excess Current Assets			68,884
£62,975	Total Net Assets			£69,208
	REPRESENTING — GENERAL ACCUMULATED FUND			
5,841	Balance as at 1st January 1981			9,106
3,265	Add: Surplus for year ended 31st December 1981			2,464
9,106	Balance as at 31st December 1981			11,570
51,419	*Research Fund*			54,987
32	*Social Worker Fund*			171
1,857	*Home Treatment Fund*			1,857
551	*Benefit Fund*			602
10	*Katharine Dormandy Fund*			21
£62,975				£69,208

BALANCE SHEET – YEAR ENDED 31st DECEMBER 1981

	Research Fund		
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
£83,004			£98,230
	Deduct		
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 Haemotology	–	
–	Isle of Thanet District Hospital	3,500	
12,606	King's College Hospital School of Medicine	–	
£31,585			£43,243
£51,419	Balance as at 31st December 1981		£54,987
	Social Work Fund		
142	Balance as at 1st January 1981		32
	Donations Received		248
			280
110	Deduct – Cost of Seminars and Secretarial Assistance		109
£ 32	Balance as at 31st December 1981		£ 171
	Home Treatment Fund		
£ 1,857	Balance as at 1st January 1981 and 31st December 1981		£ 1,857

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
£ 1,013			£ 1,617
155	Deduct – Loans Outstanding 1st January 1981	155	
462	Grants to Members	1,015	
617		1,170	
155	Loans Outstanding 31st December 1981	155	
462			1015
£ 551	Balance as at 31st December 1981		£ 602

	Katharine Dormandy Trust Fund	
5	Balance as at 1st January 1981	10
	Add:	
5	Donation Received	11
£ 10	Balance as at 31st December 1981	£ 21

THE HAEMOPHILIA SOCIETY

INCOME AND EXPENDITURE ACCOUNT YEAR ENDED 31st DECEMBER 1981

	INCOME		
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
£25,281			£52,036
	Deduct — EXPENDITURE		
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	1,000	
£21,516			£48,572
3,765	Excess of Income over Expenditure for year		3,464
500	Less: Transfer to Benefit Fund		1,000
£ 3,265			£ 2,464

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	[illegible]
Sundry Typing Costs	15
Lottery Fee	10
Bulletin Dispatch	35
Dr. Kuttner's Farewell Gift Less Group Donations	10
	£ 1,849

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		1,666.66
The Estate of			18,000.00
The Estate of		9,059.32	
Less: Distribution received on account		123,30	
			8,936.0[illegible]
			£28,602.68

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