Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392027

The
Haemophilia
Society

ANNUAL REPORT
1983

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

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HRH The Duchess of Kent

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

Portrait Study by Norman Parkinson, Camera Press

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 some 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 £400,000 has been collected for research and this has contributed greatly to the advances in treatment and care which benefit so many today.

In recent years, we have recorded the steady growth which has taken place in the Society's activities and the way in which the administration has been improved to deal more efficiently with the increasing requests for information and practical support.

As we have remarked on previous occasions, the demands being made upon the officers and other members of the Executive Committee had become so substantial that they could be met no longer by people giving their services voluntarily in their spare time. The appointment of Mr David Watters as the Society's first full-time Co-ordinator transformed the administration and, as we had hoped, left members of the Executive Committee more free to deal with matters of policy regarding the Society's affairs.

This development in the Society's administration was most opportune in allowing us to meet the unexpected, serious problems presented by the spread of "The Acquired Immune Deficiency Syndrome", known as AIDS. In 1983 it became clear that the number of cases of AIDS had increased significantly in the United States of America and as it was suspected that its source was in a virus transmitted in Blood Products it was a matter of great concern to people with haemophilia who use them frequently.

The Executive Committee acted speedily to provide accurate information to all our members about AIDS and the steps being taken to identify its source and to provide a remedy as soon as possible.

1983 proved to be a worrying period for people with haemophilia but, due to such effective means of communication as the special issues of HAEMOFACT, much unnecessary anxiety was alleviated. We are confident that doctors and scientists will provide the solution to the whole problem of AIDS and, in the meantime, all possible opportunities will be taken to keep our members up-to-date with the latest information. The Executive Committee published its policy as being that the benefits arising from the continued use of blood products far outweighed any risk involved with regard to AIDS.

However, such a concentrated effort in communication has inevitably been at the expense of some other services provided by the Central Office so that, for instance, less attention was paid to fund-raising than had been intended.

COMMUNICATION

The Haemofact leaflets were designed so that information might be given immediately it became available thus avoiding any delay by waiting for the next regular issue of the Bulletin. Members have expressed their appreciation for this special effort to keep them informed.

The Bulletin has continued to provide other information and it is widely regarded as being one of the most informative and well-produced by any National Society. We continue to be grateful to the Editor, Mr Clive Knight, and his team for the excellence of this publication.

The Seminars

The third residential Seminar was held in March 1983 at the Durlston Court Hotel, Bournemouth. As on the previous occasions, the demand for places was very high from members of the Groups. The weekend was, again, a most valuable event in providing the opportunity for communication among our members.

As the number of people who can be accommodated for these Seminars is very limited, a Regional Seminar was held in Newcastle in order that more members could be involved. This was in the nature of an experiment but it was so evidently successful that the officers of the Northern Group are to be congratulated on their initiative in arranging the Regional seminar and their efficiency in conducting it.

THE SUPPLY OF BLOOD PRODUCTS

The major concern of the Blood Products' Sub-Committee during 1983 was the call from some quarters to ban the importation of blood products into the UK, because of the possibility of AIDS being transmitted by such products. Such a ban would deprive us of two-thirds of the factor VIII needed by British haemophiliacs and expose them to risks from inadequate treatment, greater than the risks of AIDS. Consequently at the regular meeting between representatives of the Society and the Minister of Health, Lord Glenarthur, he was asked to ensure that blood products would continue to be imported until Britain was self-sufficient in blood products. The Minister reassured us of this and emphasised the Government's commitment to expansion of the Blood Products Laboratory at Elstree, which is hoped will greatly increase production after 1986.

Elsewhere within the field of blood products, efforts continue towards the production of hepatitis-free concentrates, and encouraging progress has been made in the attempts to develop methods for producing factor VIII by genetic manipulation techniques.

PROFESSIONAL ASSOCIATIONS

We continue to derive benefit from our association with other groups interested in the treatment and care of people with haemophilia. Notable among them are the Special Interest Group in Haemophilia and Related Haemostatic disorders, which is jointly sponsored by the British Association of Social Workers and the Society. During the year the Group met regularly and the Society was represented at all their meetings.

Equally notable is our association with the Haemophilia Nurses' Association which made substantial progress during the year in the standards of training and practice applicable to nursing staff in Centres.

We are also pleased to record our association with the meetings of the UK Haemophilia Centre Directors. As will be appreciated there is much consultation between their group and the Society and we were represented at their Annual Meeting by Howard Abrahams and John Prothero.

AWARDS

The Catherine Cookson Awards for Achievement in Education

We are indebted once again to Catherine Cookson for her generosity in making those two awards available. The annual awards (one senior and one junior) are given for academic achievement. The 1983 Awards were presented at the Annual General Meeting to:–

SENIOR AWARD	GRO-A
JUNIOR AWARD	GRO-A

The Brendan Foster Awards for Achievement in Sport

The Society is equally indebted to Brendan Foster who continues to support those Awards made annually for achievement in any field of indoor or outdoor sport.

The 1983 Awards were presented to:–

SENIOR AWARD	GRO-A
JUNIOR AWARD	GRO-A

The Society congratulates the recipients of those Awards for their achievements.

THE CASE COMMITTEE

This Committee met regularly during 1983 and considered 57 applications for financial assistance. Of those applications only four were refused help after all applications had received careful and details consideration. Where appropriate references were sought from the relevant Centre staff but it has been an essential feature of the Committee's attitude to make every effort to meet every request for assistance.

It may be of interest to members to know that all applications are dealt with on a monthly basis and that decisions are most usually made within a four week period from the application being received. In very special cases of urgency interim grants can be made more speedily.

OVERSEAS

For some time, there has been increasing interest in exploring ways in which assistance migh be given to help people with haemophilia in developing countries, particularly in India.

In November, the Chairman of the Society visited India, as Chairman of the World Federation of Hemophilia, and took part in a Conference of the Indian Society of Blood Transfusion and Immunology, held at the Medical School, Rohtak, near Delhi.

Following the Conference, a Clinic was conducted in Delhi, led by Professor Mannucci, Chairman of the WFH IHTC Committee. All people with haemophilia in India who were known to the organisers were invited to the Clinic and seventy-four attended, some having travelled very great distances to do so.

At this first meeting of people with haemophilia in India, "The Indian Federation of Hemophilia" was formed and a major decision taken to concentrate on the development of a Haemophilia Centre in Delhi, to be followed by similar projects in some other major cities in India as funds become available.

These encouraging developments in India have caught the interest of a number of our members who have expressed a desire to give practical support to the projects there.

PERSONALIA

Mr J. R. Hunter, the Vice-Chairman, decided to retire from office in 1983. He had previously been Chairman from 1961 to 1975 and had seen the Society develop its activities very substantially from quite modest beginnings.

Tribute to his work as Chairman was expressed when he retired from that position but we now record our gratitude for his having stayed on the Executive Committee for a further period so that, as Vice-Chairman, he could continue to give us the benefit of his long experience.

Mr K. R. Polton, MBE, the Honorary Secretary, also withdrew from office and a record of his work appeared in the Bulletin (No. 2, 1983). The inclusion of his name in the Honours List for 1971, as a Member of the Order of the British Empire, was an appropriate recognition of his unique contribution to the work of the Society.

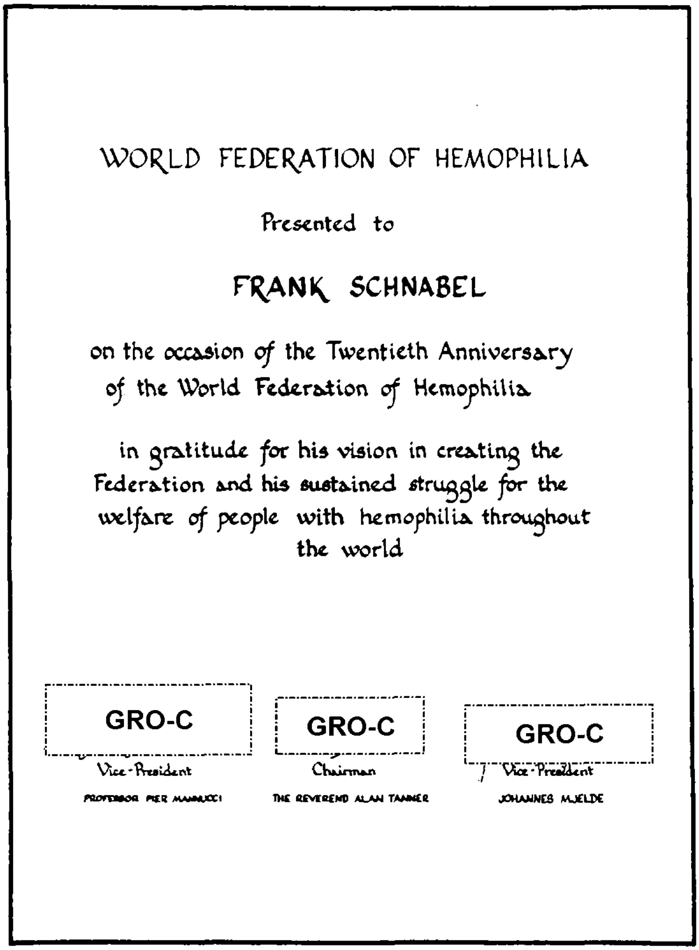
Vice-Chairmen

In common with many other Voluntary Organisations and Charities the Society was incorporated and, under the new Constitution, two Vice-Chairmen were elected, Mr David Rosenblatt and Mr John Prothero.

THE WORLD FEDERATION OF HEMOPHILIA

We have continued to be actively involved in the World Federation of Hemophilia (WFH) and were well represented at the XV Congress in Stockholm in June 1983 when the Federation celebrated the twentieth anniversary of its Foundation.

It should be recorded that, at the first meeting in Copenhagen in 1983, only six National Societies were represented. There are now sixty such organisations which are members of the Federation, this substantial increase being due largely to the initiative and industry of Mr Frank Schnabel, the Founder and President of WFH. In Stockholm a presentation was made to him of an inscribed parchment.



WORLD FEDERATION OF HEMOPHILIA

Presented to

FRANK SCHNABEL

on the occasion of the Twentieth Anniversary
of the World Federation of Hemophilia

in gratitude for his vision in creating the
Federation and his sustained struggle for the
welfare of people with hemophilia throughout
the world

GRO-C
Vice-President
PROFESSOR PIER MANNUCCI

GRO-C
Chairman
THE REVEREND ALAN TANNER

GRO-C
Vice-President
JOHANNES MJELDE

An important development in the WFH's work was the establishment of a central agency for the collection of information about AIDS. Dr Shelby Dietrich now controls this data collection activity at her Haemophilia Centre in Los Angeles.

THE FUTURE

In the mid-1960s, the late Dr Judith Pool of Stamford University, California, introduced people with haemophilia to a new way of life by her discovery of cryoprecipitate and, since then each year has seen steady progress, especially in the supply of concentrates for home treatment.

However, as in other branches of science, each step forward presents opportunities for further study to resolve new problems. Now all possible efforts must be directed towards certain priorities such as the elimination of hepatitis from blood products, the solution of the unanswered questions regarding AIDS and the support of projects for research into other aspects of haemophilia.

The Society is committed to pursuing these areas so that the quality of life may be improved for all people with haemophilia who will then be able increasingly to develop their individual talents, not only for their own satisfaction but for the benefit of the communities in which they live.

This report would not be complete without recording our gratitude to those who serve as members of the Executive Committee, the Council and the Groups. We are indebted to them, as well as to the staff at the Society's office, led by the Co-ordinator whose professional competence has made the Society so much more effective in serving our members.

1983 was a year of outstanding progress and we look forward to even more achievement in the days to come.

INCOME AND EXPENDITURE ACCOUNT YEAR ENDED 31st DECEMBER, 1983

1982			
	INCOME		
1,222	Subscriptions		1,199
31,475	Donations (Including Income Tax Repayments on Deed of Covenant and Taxes Income)		29,143
11,126	Value of Legacies Receivable		—
392	Dividends Received (Net of ACT)		—
2,215	Income arising from Legacies prior to Fund Distribution		470
2,835	Annual Draw (Net)		3,227
8,337	Interest Received		9,342
—	Profit on Sale of Quoted Investments		472
476	Sale of Booklets		486
354	Profit on Sale of Key Rings and Badges		—
—	Donations Towards Grant to Indian Haemophilia Society		700
£58,432			£45,039
	Deduct — EXPENDITURE		
2,500	Office Rent	2,700	
999	Rates and Water	1,233	
490	Light and Heat	555	
1,813	Lease of Office Equipment	1,744	
1,578	General Office Expenses	2,722	
17,930	Salaries and NIC	22,711	
605	Net Travel Cost to Society of World Federation of Haemophilia Conferences in Stockholm	3,639	
5,726	Travelling Expenses (Including Chairman's Expenses to India of £604)	8,316	
4,311	Postage and Telephone	6,713	
6,698	Printing and Stationery	10,015	
1,267	Subscriptions and Donations to Affiliated Organisations	1,290	
1,771	Appeals Expenses	2,949	
265	Auditors Remuneration	288	
175	Publications	356	
2,547	Net Cost of Seminar Weekend	2,006	
—	Northern Group Seminar Weekend Grant	2,500	
3,021	Meeting Expenses and Hire of Halls	3,021	
9	Grants to Hostel	—	
—	Bank Charges	8	
355	Professor Macfarlane Award	—	
1,233	Grants and Assistance to Local Groups	—	
196	Depreciation	343	
(300)	Provision for Purchase of Wheelchair at Lord Mayor Trelor College (over-provision written back)	—	
	Non Research Fund Donations:		
1,500	Ladywood Childrens Hospital Birmingham	—	
—	North West Adventure Holiday Project	1,100	
—	India Haemophilia Society	1,000	
54,689			75,209

3,743	Excess if Expenditure over Income for year	(30,170)
—	Less: Transfer to Benefit Fund	300
100	Transfer to Social Worker Fund	—
3,643	Surplus/(Deficit) for year	(30,470)

NOTES TO THE ACCOUNTS YEAR ENDED 31st DECEMBER, 1983

Schedule of General Expenses

1.

Sundry Office Petty Cash Expenditure	732
Repairs, Renewals and Maintenance of Office Equipment	1,034
Sundry Subscriptions	291
Office and Employee Insurance Costs	148
Sundry Typing Costs	139
Legal Costs relating to Staff Dismissal	23
Lottery Fees	26
Incorporation Fee	50
Bulletin Dispatch	60
Staff Advertisement Costs	163
Photographs	56
	£2,722

2. **Legacies Receivable**

As at the Balance Sheet date, balance due from previous years legacies had not yet been distributed to the Society by the Executors. It is estimated therefore based on information in our possession that our interest in the remaining estate concerned is as follows:—

The Estate of GRO-A £1,123

3. **Quoted Investments**

All quoted investments held previously were disposed of during the year and a net profit of £472 was realised on those sales.

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