Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392034



Endo

THE HAEMOPHILIA SOCIETY — Annual Report & Accounts 1990



The Haemophilia Society Annual Report & Accounts 1990

HAEMOPHILIA

is a condition in which a lack of an essential factor prevents blood from clotting

Because of this, people with haemophilia can suffer from prolonged and painful bleeding, especially into joints and muscles

The Haemophilia Society exists to improve the quality of life for people with haemophilia and their families.

The Chairman's Statement 1990



The Reverend Alan Tanner

From time to time, people remind me of the way in which the Society was formed by volunteers meeting in their spare time to support each other and offer help to all whose lives were affected by haemophilia. In those early days, there was a strong sense of solidarity and fellowship among our members and we shall always be grateful to those who set down such secure foundations for the Society as we know it today. We are constantly vigilant to ensure that, while the organisation expands, that personal relationship is maintained.

The demands made upon us have increased inexorably in recent years. Government Departments and Voluntary Agencies expect us to provide information about the special interests and needs of people with haemophilia and we take every opportunity for seeing that proper standards of treatment and care are achieved.

This report shows how the organisation has developed in the course of the year to serve all concerned with haemophilia. We have taken seriously the recommendations made by the Charities Effectiveness Review Trust (CERT) to help us use our resources as efficiently as possible. In common with other Voluntary Organisations, we have studied carefully the way in which professional staff and

members of the Executive Committee may bring together their various skills and experience for the benefit of the organisation as a whole.

The Campaign for recompense for people with haemophilia affected by HIV infection was brought to a conclusion by the Government accepting proposals for a settlement — the terms were less generous than those we had been seeking but they will be accepted by the majority of the litigants involved.

The conduct of the campaign consumed a high proportion of our time and resources but we have made every effort to see that other aspects of haemophilia were not neglected through the high priority given to the distressing situation of those affected by HIV infection.

We shall now be able to give greater attention to other vital concerns such as the supply of blood products, and the effect which the review of the National Health Service may have on the facilities which are available.

So there is still much to be done and this will require increased financial support in the year ahead. I take this opportunity to thank members of the Executive Committee, who have worked with such commitment throughout the year, and the General Secretary and his staff for their efficiency in managing our affairs.

The Society is going through difficult times as we struggle to overcome the effects of HIV infections and

the other problems associated with haemophilia, but we look to the future with hope and the confidence that our friends will continue to support us in caring for people with haemophilia and their families.

The Revd Alan Tanner

Member Services Committee

Our Groups are very important to the Society and in 1990 we nurtured and fostered them. Throughout the year we give advice and represent our members. We give cash help where needed. We organised a 'Women's Weekend' for women touched by HIV. We continually press for research and high quality blood products.

The member Services Committee continues to review and monitor the standards of treatment available to people with haemophilia, and has concerned itself particularly with the quality of blood products available. The provision of blood products of the highest possible quality remains a major concern. Developments in medical technology and in the pharmaceutical industry are of great importance. The Society has a role in keeping people with haemophilia informed about the range of products available for therapeutic use.

The Charities Effectiveness Review Trust (CERT) recommended in its report on the Society in 1989 that greater resources should be devoted to fostering and nurturing the local Groups of the Society. In accepting this advice the Society set up a new Committee, the Member Services Committee, with direct responsibility for the Society's thirty Groups. A programme of assisting Groups to review their strengths and weaknesses and to help in planning future local activities was established.

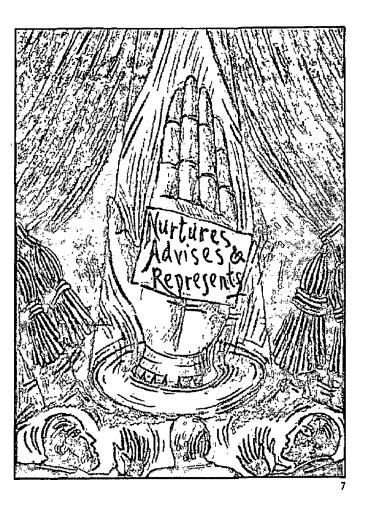
The Society's Groups will play an increasingly important role in monitoring, and wherever possible

influencing, the effects of changes in health care for people with haemophilia, especially those arising from the imminent changes in Health Service organisation and finance. To supplement the use made of meetings of the Council of the Society in informing and empowering Groups on such matters, a new publication, Group News, has been introduced. A Group Resources File, containing information on most aspects of the work of Groups, has also been made available.

The Member Services Committee has also undertaken responsibility for services to individual members, for example the support and advice given to those applying for Mobility or Attendance Allowances. These allowances are of great importance to the Society's members (estimated to be worth more than £3m per year).

Direct grants to members who are in financial difficulties because of the effects of haemophilia are another important aspect of the Society's work.

A new highly successful venture in 1990 was to hold a Residential Weekend Seminar for women involved in the care of someone with haemophilia and HIV. It was felt that whereas the person with haemophilia was often (but by no means always!) well-supported by his Haemophilia Centre, such support was rarely available to mothers, wives or girlfriends, for example. The success of the weekend, held in Newcastle in March, confirmed the need for help for so many women in this position. A printed report of the weekend has been produced.



Policy Committee

This Committee ran the successful Campaign for Compensation for people with haemophilia and HIV. The Committee is active in monitoring the NHS Review. We monitored the US Immigration ban on people with HIV and took appropriate action. The Committee is responsible for Society publications — the Bulletin, Update, and information booklets.

The issue which dominated the work of the Policy Committee during 1990 was the compensation campaign on behalf of people with haemophilia and HIV. The Society's role, which was to raise public and political awareness of the situation, was a demanding one. It required a great deal of effort to keep the public spotlight on our case, and in this we received a great deal of help from members, professional advisers such as GJW Government Relations, the Health Network, the Sunday Times and many politicians.

Our responsibility to all people with haemophilia was not forgotten however. The changes which will be implemented as a result of the Government's NHS Review were studied in detail. We are ready to press for the safeguarding and improvement of haemophilia treatment and care when the new arrangements take effect in 1991.

During 1990 we were extremely concerned about the discriminatory immigration policy operated in the USA, which prevented people with HIV infection from entering that country. We had been looking forward to sending delegates to the World Federation of Hemophilia Congress held in Washington in July but found ourselves unable to attend because of the immigration restrictions. The Society's boycott helped to draw attention to this unfair law, which is due to be repealed in 1991.

During 1990, the Policy Committee had responsibility for the Society's publications programme. It is seen as a vital part of the Society's work to keep members informed of developments in haemophilia treatment and care, and much of this work is done through our two quarterly publications, the Bulletin and Update. Occasional publications provide specialist items for our members and general information about haemophilia aimed at the wider public.

In 1990 "Haemophilia HIV and Safer Sex — The Choice is Here" was published in collaboration with the Health Education Authority and has since won a national award for health education publications.

Media interest in haemophilia has, of course, been increased by the compensation campaign and the Society has gone to considerable lengths to foster good relations with the press in order to ensure accurate and sensitive reporting about haemophilia.



The Resources Committee

The Resources Committee deals with staffing, income & expenditure and premises.

The Resources Committee is responsible for the management of all resources of the Society — financial, human and physical. Good management has become an essential feature of the Society's work as opportunities for service to our members increase steadily and more demands are made upon the limited resources available to us.

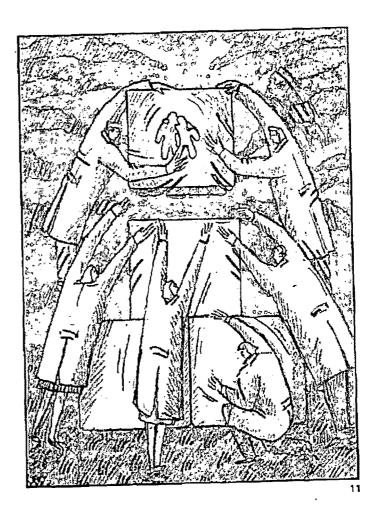
Income and expenditure are now monitored closely, with monthly management accounts checked against the budget, and the funds available allocated according to priorities established, so that our resources are used to the best advantage. As the Treasurer's report shows, the yearly income of the Society exceeded £500,000 for the first time but this increase was matched by the rise in expenditure. This led the Resources Committee to take advantage of the services provided by Tim McDonald and his partners as fundraising consultants. They came to us with an impressive record of helping charitable organisations and their efficiency is demonstrated already in the support they are giving to the efforts of local Groups and in developing contacts with potential donors at a national level.

A major concern has been in attending to our responsibilities as employers of a team of ten

members of staff. Appropriate contracts have been agreed, job-descriptions composed, together with terms and conditions of employment, and we have made good progress in our intention to establish an equal opportunities policy. Where appropriate staff development and training programmes have been used to help our staff make the best use of their professional skills in the service of the Society.

Our office in London, although small, is now well equipped and provides an efficient base from which to manage our activities. Its location — close to Westminster — was a great asset during the Compensation Campaign. It also serves as a venue for small meetings.

We record our gratitude to all who have worked so diligently throughout the year to help us exercise proper stewardship of the resources entrusted to our care.



DONATIONS

In 1990 we received a large number of donations and we are very grateful for each and every one of them. However, simple pressure of space does not allow a complete listing to appear. We have restricted our printed acknowledgements to those Trusts and Corporate Donors who gave £500 and over and individuals to those who gave £100 and over.

We also want to mention most especially those who supported us by donating prizes for events; those who sponsored runners in various Marathons and especially the London Marathon; the Committee of the international Airlines Charity Ball; those who gave by Deed of Covenant and Give As You Earn Schemes; Crusaid for allowing the Society to benefit from an early view of the Franz Hals Exhibition; Helen Cooper Associates for their interest in promoting our work through Prison Art Exhibitions, those who sent donations in memory of loved ones and lastly everyone who supported us in any way during what was a demanding and difficult year.

Corporate Donors and Trusts w	the gave £500 and above:-		,
A M Pilkington Charitable Trust	HSA	Stakis	
Abboy National	lan Romming Charitable Trust	T&N	i
Allan Lana Foundation	Immuno	TSB	i
Alliance and Leicester	Invertorm Charitable Settlement	United Distillers	
Alpha Therapeutics	J T H Charitable Trust	Willan Chariteble Trust	<u> </u>
Armour Pharmacoulical	Jamas Weir Foundation	Willis Faber	
Arthur James Paterson Charitable Trust	Jan Branford Charitable Trust	Wolfson Family Charitable Trust	;
Arthur Morphy Memorial Trust	Jane Hodge Foundation	Worshipful Company of Carpenters	į.
Asha Foundation	John Lewis		
Aster Foundation	John Swire	Individuals and Groups over £100	0:
Bank of Scotland	Kingfisher -	· · · · · · · · · · · · · · · · · · ·	"
Barclays	Lady Hind Trust		
Destrict faire Tours	Land Securities	!	
Beatrice Laing Trust		!	
Berris Charltable Trust	Lloyds		
Bio-Producta Laboratory	McCrona Charitable Trust	1	
Boots	MacTaggert Third Fund		
Brixton Estate	Members of Lloyd's and Lloyd's Brokers	!	į.
C&A	MEPC	!	GRO-D
Charles and Elsio Sykes Trust	Millichope Foundation	1	GRO-D
Charles Littlewood Hill Trust	Moorgate Trust Fund	į į	i
Christopher H R Reeves Charliable Trust	Morton Charitable Trust	!	į.
Christopher Laing Trust	Mr and Mrs J A Pye's Charitable Settlement	!	!
City and Metropolitan Walfare Charity	Mrs F B Laurence 1976 Charitable Settlement	į į	
Cogent Elliott	Mrs Kathisan Laurence's Charitable Settlement	i !	i
Commercial Union	Mrs Vera Leigh's Charity	!	į
Cotton Trust	Murphy-Neumann	!	!
	N A J Franklin Trust	: i	
Cutter Biological	National Westminster	i i	<u> </u>
Dalgety	NFC	GRO-D	į.
Donald Forrester Charitable Trust		!	!
Douglas Turner Trust	Old Codgers Fund	; i	
Dowager Counters Eleanor Peel Trust	P F Charitable Trust	į į	•
Edgar Lee Foundation	Patricia A Beecham Charitable Settlement	! ! .	. i
Edward Cadbury Charitable Trust	Peacock Charitable Trust	!	· !
Ely Webster Trust	Pater Courtauld Charitable Trust	!	!
Fishmongers' Company	Pionear Mutual	i i	, i
Freemasons' Grand Charity	Porton Products	i i	1
General Accident	Prudential	!	Ĺ
George Henry Callins Trust	Racal Electronics	!	
Godinton Charitable Trust	Rayanadale Trust	i .	
Halecat Charitable Trust	Rothmans	i i	
Hanson	Simon Whitbread Charitable Trust	į	
Harold Hyam Wingate Trust	Sir Jules Thorn Charitable Trust	!	•
Health Education Authority	Smiths Industries	i	
		i i	*
Heinz and Anna Kroch Foundation	Sovereign	!	
Henry Ansbacher	St Katherine's Fund	!	
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Report of the Treasurer, on behalf of the Executive Committee, of the Haemophilia Society, for the year ended 31 December 1990

The accounts included with this report show that the Society's annual income increased by over 50 per cent in 1990: a remarkable achievement in a year when so much of the time of our General Secretary and his support staff was taken up with the HIV Compensation Campaign.

The Society was particularly grateful to receive over £70,000 in Legacies (bearing testimony to our increased expenditure in advertising) and to secure sponsorship for many of its projects. The co-ordination of local Group funds with those held by the national office, along with the expansion of the centralised banking system for our local Groups, helped to achieve a 75 per cent increase in interest receivable.

Despite the most careful monitoring, such were the demands on the Society, and the needs of our members, that the surplus for 1990 was again modest, and slightly less than in 1989. Implementation of the CERT report necessitated an increase in staff with a corresponding increase in services provided. We were disappointed that our Section 64 Grant from the Government was reduced by two thirds. The rent for the national office increased sharply. Our public relations and information expenses also increased sharply, by nearly £50,000, but such an increase only partly reflects the increased activity achieved.

We are determined to secure the Society's future, to broaden the base of services supplied and recognise the need to plan on a longer term basis. We have, therefore, appointed McDonald and Associates to provide professional fundraising services and we expect to benefit from the results of their endeavours in future years.

We are again grateful to Messrs Pridie Brewster, our auditors, and in particular to their partner, Matthew Dodson, who has regularly assisted the Resources Committee throughout 1990, enabling the Annual Report and Accounts to be produced in accordance with SORP 2 Guidelines.

The auditors, Pridie Brewster, have indicated their willingness to continue in office and a resolution concerning their reappointment will be proposed at the Annual General Meeting.

Julian Lander Honorary Treasurer

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Income and Expenditure Account for the year ended 31 December, 1990

	Note		1990		1989
		£	£	£	£
Income Donations Legacies	· ·		429 949 71 856		301 955 512
Voluntary Income Services and Goods Grants Receivable Interest Receivable	3 4 5		501 805 22 214 15 500 20 322		302 467 9 230 46 625 11 486
			559 841		369 808
Indirect expenditure Fund Raising Expenses Public Relations & Information Administration Expenses	6 7 8	75 839 186 802 180 607		34 000 137 981 131 063	
			443 248		303 044
Income Less Indirect Expenditure			116 593		66 764
Direct Charitable Expenditure	11 .		107 185		55 973
Income Less Expenditure	2		9 408		10 791

Balance Sheet at 31 December, 1990

	Note		1990		1989
		£	£	£	£
Fixed Assets	14		49 748		26 818
Current Assets Stock Debtors Cash at bank and in hand	9	500 29 946 177 610		2 260 14 880 155 256	
		208 056		172 396	
Creditors (amounts falling due within one year)	10	(61 811)		(12 629)	
Net current assets			146 245		159 767
Total Assets less current liabilities			195 993	•	186 585
Funds General Accumulated Fund John Prothero Memorial Fu Group Funds			166 008 29 985 195 993		140 104 8 366 38 115 186 585

The financial statements were approved by the Executive Committee on 28 February 1990.

A. Tanner J. Lander

Source and Application of Funds Statement for the year ended 31 December, 1990.

	1990	1989
	£	£
Source of Funds Surplus for the Year	9 408	· 10 791
Adjustments for Items not involving the Movement of Funds		
Depreciation	15 442	16 697
	24 850	27 488
Funds from other Sources Local Group Funds	_	38 115
	24 850	65 603
Application of Funds Purchase of Fixed Assets	(38 372)	(7 650)
	(£13 522)	£57 953
Movement in Working Capital Stock Debtors Creditors	(1 760) 15 066 (49 182)	(3 505) (5 341) (8 172)
Increase in Liquid Funds	(35 876) 22 354	(17 018) 74 971
•	(£13 522)	£57 953

Notes to the Accounts - 31 December 1990

1. ACCOUNTING POLICIES

The financial statements have been prepared under the historical cost convention using the following accounting policies:

Income and Expenditure includes all amounts receivable/expendable during the financial year and have been accounted for on an accruals concept.

Donations in kind have been appropriately valued, credited to income and treated as a fixed asset addition.

Depreciation. Tangible fixed assets are stated at cost or valuation less depreciation.

Depreciation is provided to write off the cost less estimated residual values of all fixed assets over their expected useful lives. It is calculated on the original cost of the assets at the following rates:

original cost of the assets at the following rates:
Freehold buildings 2%, per annum, straight line
Office Equipment & Furniture 25%, per annum, written down value
Caravans 25%, per annum, straight line

Pension Costs in respect of qualifying employees are provided by individual money purchase schemes. The Society's contributions to these schemes are charged to the income and expenditure account in the year in which they arise.

Group Funds. The Society is represented throughout the country by local Groups. Local Groups are required to submit any excess funds raised to the national office. Group funds were incorporated into the Society's financial statements for the first time in 1989, Subsequently the nat increase in Group funds has been included within the Society's income and expenditure account as part of voluntary income.

John Prothero Memorial Fund. All amounts raised and spent in respect of this fund have been recorded in the income and expenditure account. Details of the amounts credited and debited to this fund are disclosed in note 15.

Research and Charitable Grants are included in the income and expenditure account when they have been claimed by the beneficiary.

2. INCOME LESS EXPENDITURE

income less expenditure is stated after charging:

•		1990	:.	1989
,		£		E
Auditors' remuneration	٠.	2 000	٠.	1 150
Depreciation		15 442		16 697
Operating lease rentals		15 964		11 569

3. VOLUNTARY INCOME
Voluntary income includes proceeds of all fund raising events, gifts raceived, donations received and legacies. The following are some of the larger individual amounts received.

	. 1990	1989
•	E	£
Annual Draw	21 880	19 256
Local Groups	52 864	49 591
Airlines Ball	6 422	5 720
London Marathon	4 993	4 112
Freehold Legacy	22 000	
Art Exhibitions	5 250	4 592
Sponsorship for:		
Safer Sex booklet	20 000	
The Bulletin	10 000	-

4. SERVICES AND GOODS

	1990 £	1989 £
Subscriptions	8 070	7 800
Fees Charged Goods Sold	1 426 12 718	1 430
	22 214	9 230

5. GRANTS RECEIVABLE

Grants received in the year, of £15 500 (1989 £46 625), were in respect of a Section 64 charitable government grant.

6. FUND RAISING EXPENSES

	1999	1989
	<u></u>	
Promotional items	15 588	10 068
Airline Ball costs	1 305	508
Advertising	27 831	5 406
Services of professional fund raisers	4 600	-
Staff costs and other expenses	26 514	18 018
	75 839	34 000

7. PUBLIC RELATIONS AND INFORMATION

	1990 £	1989 £
Members' Publications	64 285	56 705
Council, AGM, Executive and MAP	37 665	24 350
Education Events	14 439	18 247
Publicity and Public Relations	17 725	*****
Staff costs and other expenses	52 688	38_679
	185 BO2	137 981

8. ADMINISTRATION EXPENSES
The administration expenses include all the costs associated with the running of the national office; rent, rates, etc. co-ordination of the Society's activities, dealing with members enquiries by telephone and letter and the provision of other ongoing services.

	1990 £	1989 £
Premises	54 175	37 516
Depreciation	15 442	16 697
Professional Fees	8 154	5 495
Office Expenses	38 840	26 309
Staff costs and other expenses	64 196	45 046
	180 607	131 063
9. DEBTORS	1990	1989
	£	£
Prepayments	20 859	5 038
Other Debtors	9 087	9 842
	29 946	14 880

10. CREDITORS (Amounts falling due within one year)

	1990	1989
Accruals and other Creditors	61 811	12 629

11. DIRECT CHARITABLE EXPENDITURE

	1990	1989
	É	£
Research grants paid in year	35 101	22 871
Welfare grants paid in year	17 577	23 358
Other charitable grants paid in year	54 507	9 744
	107 185	55 973

Research grants agreed to be paid in future years total £24,793, (£29 661 for 1989). The Executive Committee have also agreed to underwrite the costs of the 1991 North Wales Adventure Holiday and 1991 Pisa Camp.

12. EMPLOYEES

The average number of staff employed by the Society during the year was 9 (1987: 7).

The aggregate payroll costs were:

	1990	1989
	£	£
Wages and Salaries	110 315	79 343
Employers' National Insurance	11 652	8 560
Employee's Pension Contributions	2 530	2 189
	124 497	90 092

13. LEASE OBLIGATIONS

As at 31 December 1990, the Society has annual commitments under operating leases as set out below:

	1990	1989
Operating Leases which expire:	£	£
Operating Leases which expire: In the second to fifth year inclusive In more than five years	11 356 9 816	
	21 172	11 538
		19

14. TANGIBLE FIXED ASSETS	Freehold Land & Buildings	Leasehold Property	Improvements to Leasehold Property	Office Equipment & Furniture	Caravans	TOTAL
•	£	£	£	£	£	£
COST OR VALUATION At 1/1/90 Additions Disposals	22 000	7 944 (7 944)	19 853 883 (20 736)	33 881 6 328	24 221 9 162 —	85 899 38 372 (28 680)
At 31/12/90	22 000			40 209	33 383	95 591
DEPRECIATION At 1/1/90 Charge for year Disposals	440	7 944 (7 944)	19 853 883 (20 736)	17 113 5 774	14 171 8 346	59 0 81 15 442 (28 680)
At 31/12/90	440			22 887	22 517	45 844
NET BOOK AMOUNT At 31/12/90	21 560			17 313	10 866	49 748
At 31/12/89				16 768	10 050	26 818

The office leasehold became renewable in January 1990 and a new twenty year lease will be signed in due course. The freehold has become available, further to the year end and a bid for its purchase is being considered.

15. SUMMARY OF MOVEMENT OF FUNDS	General E	Group	*JPM fund	TOTAL
Income Indirect Expenditure	503 734 443 248	· 52 864	3 243	559 841 44 3 248
Opening Fund Values	60 486 140 104	52 864 38 115	3 243 8 366	116 593 186 585
Funds Available for use Charitable Expenditure	200 590 95 576	90 979	11 609 11 609	303 178 107 185
Transfers	105 014 60 994 166 008	90 979 (60 994) 29 985		195 993 195 993

^{*} The John Prothero Memorial Fund
John Prothero, a Vice Chairman of the Society, died during 1989 and the John Prothero Memorial Fund was established in his memory. This year the
monies in the fund were spent to help equip the new Haemophilia Centre at St Thomas' Hospital.

16. REPORT OF THE AUDITORS TO THE GUARANTORS OF THE HAEMOPHILIA SOCIETY

We have audited the financial statements, on pages 14 to 21, in accordance with Auditing Standards.

In our opinion the financial statements give a true and fair view of the state of the Society's affairs at 31 December 1990 and of its surplus and source and application of funds for the year ended then and have been properly prepared in accordance with the Companies Act 1985.

Pridie Brewster 28 February 1990

OFFICERS OF THE SOCIETY

Chairman Vice-Chairmen The Revd A J Tanner MA Mr K E Milne BSc

Mr R A Cowe BA, MBA, ACIS, MBIM

Treasurer

Mr J Lander, LLB

MEMBERS OF EXECUTIVE COMMITTEE

Mr K Colthorpe Mrs C Hazlewood Mr G Kirman Mr N Lawson Mr R Dickason, BSc Mrs J Hodgson Mr C Knight, BA Mr J Miller, B. Comm

General Secretary

Mr D Watters, JP

AUDITORSPridie Brewster

BANKERS

National Westminster Bank Plc

SOLICITORS

Paisner & Co., London

Registered Charity No. 288260

Company limited by guarantee (Reg No. 1763614)

Registered office 123 Westminster Bridge Road London SE1 7HR

AWARDS

THE HAEMOPHILIA SOCIETY AWARD 1990

During 1990, GJW Government Relations gave the Society the benefit of their considerable experience in relation to the campaign for compensation for those who were HIV antibody positive. This was readily and freely given for the benefit of people with haemophilia and it was in recognition of this that we were proud to present them with the 1990 Haemophilia Society Award which was received by Rory Chisholm on behalf of GJW.

THE 1990 HAEMOPHILIA SOCIETY AWARD FOR OUTSTANDING SERVICE

This award is made in recognition of outstanding service to the Society through its local groups and was introduced in 1990 for the first time. The recipient of the first such award, in the form of an inscribed crystal bowl, was Mrs Irene Clinton who had given almost thirty years service to our North East Group, attending almost every Council meeting for 25 years.

AWARDS RECEIVED

Haemophilia, HIV and Safer Sex: the Choice is Here

The Haemophilia Society publication, which was produced with funding provided by the Health Education Authority, won First Prize in the 1990 Domestos Health Education Awards. The Award took the form of a Certificate and a cheque for £1,000 which was received by the General Secretary from Theresa Gorman MP on behalf of Domestos. The prize will be used to fund other educational projects within the Society.

123 Westminster Bridge Road, London SE1 7HR