Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392035

Introduction

It is a pleasure to introduce this report, the second for me as Society chairman. Looking back 1998 was an eventful year, which saw a change of Chief Executive for the organisation, as well as many external developments in the field of haemophilia care and the NHS itself. Not least among these is the Government's emphasis on consulting the views and wishes of patients and users of NHS services. For the Haemophilia Society, as a national patient group, this is very welcome. Sadly, 1998 saw the loss of our President, and one of our most staunch supporters, Dame Catherine Cookson, who died in June. She will be greatly missed.

Our mission remains, as it has ever been, to ensure that people with haemophilia and other bleeding disorders receive the best possible treatment, care and support. This we achieve in two ways. First, through providing services directly ourselves, and I thank our dedicated staff team and many volunteers all over the country for their efforts. Second, through encouraging best practice in healthcare and seeking to influence health policy, nationally and locally. In this, we act as a voice for people with haemophilia and other bleeding disorders, pressing for improvements wherever possible in treatment and care.

The Government's decision in 1998 that children under 16 should be treated with recombinant was a milestone, and a victory for the Society's campaigning in support of patient choice. We know this has given parents new peace of mind, and, together with the use of prophylactic and home treatment, this means children with haemophilia can look forward to a brighter future.

On the international front, I was pleased to be involved, together with Vice Chairman Gordon Clarke, in the Society's twinning programme with Russia.

> *"Our mission remains, as it has ever been, to ensure that people with haemophilia and other bleeding disorders receive the best possible treatment, care and support."*

With the Society's 50th anniversary approaching in the year 2000, we reflect on how far treatment and care for people with bleeding disorders has advanced. This provides much cause for optimism. But there is as yet no cure for haemophilia. And the haemophilia community still lives with the aftermath of the tragedy of the widespread HIV and hepatitis C infection through contaminated blood products. There is still much work for the Society to do to meet the complex and very varied needs of people with bleeding disorders and their families.

To achieve this we are grateful for the support of all those who have helped fund the Society's work from individual donors to our many trusts and corporate supporters, and, of course, the Department of Health for their grant. As chairman of the Trustee Board, I also wish to thank my fellow Trustees for their energy and hard work over the year.

GRO-C

Mr CMC Hodgson
Chairman

Looking forward

> *"A central principle is that we are led by the needs of people with bleeding disorders, not only those with haemophilia but the many others affected by von Willebrands and other factor deficiencies."*

This is my first annual report as Chief Executive of the Haemophilia Society, and, while outlining last year's achievements, I hope the flavour of this report is forward looking. Within the Society, we have been thinking hard about our mission and the strategies and programmes of work needed to deliver it. A central principle is that we are led by the needs of people with bleeding disorders, not only those with haemophilia but the many others affected by von Willebrands and other factor deficiencies. We have many means of assessing needs – consulting our members is key, as we did through a comprehensive membership survey in 1998. Our improved monitoring and evaluation systems also give invaluable feedback on the needs of individuals and their carers.

This information has guided us in developing new programmes for 1999 and beyond. At the heart of these are our information and advice services, covering everything from benefits and housing to medical treatment, provided mainly by telephone, although increasingly using internet and e-mail which open up the potential of far wider access. Alongside these core services are our special services for those with HIV and/or hepatitis C, which in 1999 will be particularly targeting the needs of young people in their teens and twenties who are growing up with these viruses.

We are also aiming to develop our children's and families work, which for the past three years has been generously funded by the Roald Dahl Foundation. With a strong staff team, clear plans and objectives, I am looking forward to a dynamic future for the Haemophilia Society.

Karin Pappenheim
Chief Executive

We would like to introduce you to a family who are living with haemophilia. GRO-A, aged 7 (to the right of the picture) has severe haemophilia A but, as can be seen throughout this Annual Report, haemophilia is no longer the disability it once was and does not prevent GRO-A from enjoying himself and behaving like any other seven year old! Pictured here are GRO-A and GRO-A GRO-A with their children GRO-A, GRO-A and GRO-A.

GRO-A

GRO-A

[illegible] Society

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The Society is a membership organisation, the majority of members being people with bleeding disorders and their families. People with haemophilia are involved at every level in the Society from the Trustee Board through to our local groups at grass roots level.

> *"People with haemophilia are involved at every level in the Society from the Trustee Board through to our local groups at grass roots level."*

Facts about Haemophilia

- **Haemophilia and related bleeding disorders are conditions where an essential blood clotting factor is either partly or completely missing or is faulty.**
- **Treatment is usually by replacing the missing clotting factor by regular injections.**
- **Left untreated, internal bleeding causes acute pain and long-term joint damage.**
- **Haemophilia and related disorders affect over 11,000 people in the UK and occur in all racial groups.**
- **Von Willebrand's Disease affects males and females.**
- **Haemophilia is a lifelong condition that one is born with. You cannot "catch" it as you would a cold.**
- **In the past, contaminated blood products have infected over 1,200 people with HIV virus and over 4,000 with hepatitis C.**
- **Blood products are not known to have caused new infections since 1986, but a synthetic clotting factor is now increasingly being used to reduce the risks of blood borne viruses.**

Information and advice services

GRO-A, GRO-A GRO-A, GRO-A **and friends** GRO-A **and** GRO-A **playing in the local park**

GRO-A

Information and advice giving is at the heart of the Society's work. People with haemophilia and related disorders need information, not only about medical and treatment issues, but on the social aspects of living with a long term medical condition. The Society's national office staff and volunteers are here to meet that need, handling queries on

- Treatment and treatment products
- Parenthood for haemophilia carriers and their partners
- Benefits and finance
- Housing
- Employment
- Education
- Insurance
- Travel abroad
- HIV
- Hepatitis C

Mostly information is provided by telephone and post, however in 1998 we have further developed the Society's popular website as a source of information and soon plan to set up a confidential e-mail advice service. The Society's publications, including the quarterly ***Bulletin***, are another source of information. Over 100 calls a week are handled by national office.

Advocacy

Some individuals need particular support, very often in securing their full social security benefits entitlement, or in obtaining the best possible treatment. The Society's services team are able to act as advocates in such situations, for instance, representing people at benefits tribunals, or writing to health authorities on matters concerning treatment and care.

> *'Thank you for organising a day of sharing'*

Events for people with haemophilia

By bringing people together for local Haemophilia and Family Days, the Society provides a focus for sharing information, and common experience, whilst hearing the latest on treatment and other topics from experts through presentations and workshops. Childcare is provided to enable parents to attend, and to give an opportunity to young people to meet each other and perhaps develop new friendships.

In 1998 we held day events in Belfast and Bristol.

Children and families

Bringing up a child with haemophilia or another bleeding disorder is a challenge. Thanks to modern treatment methods, today's young child with haemophilia can expect to lead a more or less normal life, and to avoid so much of the pain and disability experienced by previous generations. The emphasis in the Society's children's and families work therefore is on ability rather than disability, and our aim is to ensure children enjoy equal opportunities to participate and use their abilities and talents.

GRO-A

Services for children and young people

With funding provided by the Roald Dahl Foundation, the Society has been able to employ a Children and Families Worker who has built up a variety of activities and events from Adventure Weekends to a pen pals scheme. These offer fun and enjoyment, as well as a means of learning and sharing with others growing up with the same condition.

In 1998 the Society ran two Adventure Weekends in Hindhead, Surrey and Boreatton Park, near Shrewsbury. Each catered for around fifteen children. For some young people these Weekends may be their first taste of being away from home, and an important milestone in building self confidence and independence. Over the weekend children can test their physical skills, for instance, by go-karting, absailing or canoeing, as well as indoor activities such as computing.

Pager Scheme

The Society issued 82 free pagers to parents with a child under 16 years during 1998. The pager gives parents the security of knowing wherever they are they can be reached should their child need them. Thanks to the scheme, parents no longer have the worry of wondering 'what if', especially while their child is in nursery or school, and can go out to work or other activities. The Society is grateful to Centeon for continuing to fund the scheme.

GRO-A mother of a son with haemophilia. *"When I first got the diagnosis my mind galloped ahead about all sorts of worries about the future. When I talked to a parent with an older child this really helped me slow down and take one day at a time. I was reassured about the bruising and that this was okay and not a disaster."*

Our Children and Families programme costs over £50,000 per annum for information and advice, services, support for parents and our activities for children.

Parents Support Network

Learning to cope with a lifelong medical condition, requiring regular treatment, impacts on the whole family, and there can be many times of stress and anxiety when support from the Haemophilia Society is needed. For the one in three families who have no family history of haemophilia, the first diagnosis of their baby can be devastating. Our Parents Support Network is operated by volunteers who are themselves parents of a child with haemophilia. Through the Network we can put parent in touch with parent for mutual support.

'The children were well provided for. It was good to meet other families with like problems'

Hepatitis and HIV

Living with HIV and AIDS

Just under 500 people with haemophilia today are living with HIV contracted through contaminated treatment products prior to 1986. The Society's HIV development worker, appointed in January 1998, undertook a comprehensive needs assessment last year, involving visits to HIV services all over the UK and consultation with people with haemophilia and HIV.

The Society works in partnership with other relevant agencies. The Macfarlane Trust, which administers financial assistance to people with haemophilia who were infected with HIV, is a key partner. So too is the Birchgrove self help group, which, whilst remaining part of the Haemophilia Society, has its own separate identity, local network and drop-in centre in Cardiff. National and local HIV organisations are also important partners.

The Society will be developing a number of services in 1999 in response to the complex and changing needs of those with HIV. New combination therapies have dramatically reduced mortality for people with HIV, and this has had an impact for those with haemophilia and HIV.

But the regime is very demanding, and especially for those with haemophilia who also require regular treatment for their bleeding disorder. The other factor for many is co-infection with hepatitis C, also contracted through contaminated blood products. This presents an added complication for treatment.

There are two key areas of unmet need the Society plans to target. One is for patient information on HIV/HCV co-infection, and the other is support for younger men and teenagers with HIV and haemophilia. The HIV treatment field is fast moving, with new treatment approaches and products being developed, and the Society aims to provide an up-to-date reference point for both people with haemophilia and health professionals.

Plans for 1999 include:

- Support services for young men and teenagers with haemophilia and HIV
- Factsheets on aspects of living with HIV and haemophilia
- Events for HIV positive people with haemophilia and their partners and families
- Regular updates on treatment

Our programme to meet the needs of those coping with HIV and hepatitis C infection costs over £100,000 a year to cover a telephone advice line, co-ordinating support and information events, encouraging the development of local self-help groups and producing publications.

Responding to hepatitis C

Over 4000 people with haemophilia were infected with the Hepatitis C virus up until 1985/6 when viral inactivation processes were introduced to the manufacture of blood products. By employing a full time Hepatitis C Worker, the Society seeks to provide practical support for families affected by the virus in the form of information and advice, promoting self help networks and organising events around the country. One of the greatest difficulties faced by those with HCV is uncertainty, as there is still no fully effective treatment, whilst the progress of the virus varies between individuals. Those infected and their families therefore face much insecurity and stress in not knowing how the virus will affect their health in future.

July 1998: a delegation led by Roger Godsiff MP, delivers a petition and 90 white lilies, to represent people with haemophilia who have died of hepatitis C, to 10 Downing Street. The campaign for financial assistance is ongoing.

Advocacy and campaigning

There are variations in the quality of treatment and support provided to people with hepatitis C. The Society seeks to promote best practice wherever possible, and to ensure equal access to quality care. On an individual basis, this sometimes means taking up concerns with health authorities and treatment centres on behalf of individuals. Through such advocacy work, the Society's HCV worker has helped people secure better treatment and care.

On a national level, the Society continues to campaign for Government recognition of the plight of people with haemophilia infected with HCV, and specifically for some financial assistance similar to that provided for those infected with HIV via the Macfarlane Trust.

HCV support evenings

With project funding from the Department of Health, the Society organised a series of hepatitis C support evenings for people with the virus and their partners in different localities in England and Wales. In total over 200 people attended the ten meetings, and more are planned for 1999. Evaluation of these events showed they were very well received by participants:

"Positive approach to combined treatments."

"Discussions and interactions with other people."

"Down to earth information."

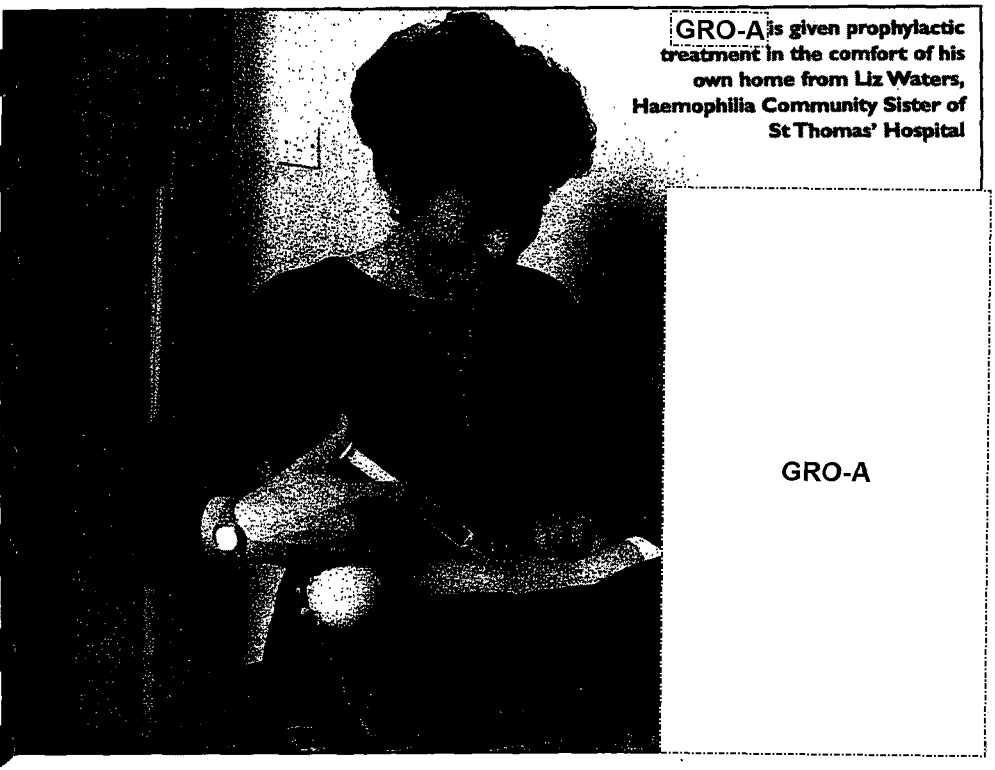
Research

In 1995 the Society commissioned the first formal research study of the social and economic impact of hepatitis C on people with haemophilia, which revealed widespread problems such as stigma, stress within families, financial hardship due to impaired health and loss of earnings, difficulties in obtaining mortgages and life assurance resulting from being diagnosed with HCV. It remains a crucial role of the Society to undertake this type of research without which the full impact of the virus on people's lives might not be recognised. A further study has been commissioned from Dr Jenny Roberts at the London School of Hygiene and Tropical Medicine for publication in 1999.

Self help

The Society's HCV worker co-ordinates an informal network through which people with the virus are put in touch with each other. She also works closely with the Manor House Group, an active self help group whose members meet regularly and offer mutual support at difficult times such as bereavement or undergoing a liver transplant.

Campaigning for improved care



GRO-A is given prophylactic treatment in the comfort of his own home from Liz Waters, Haemophilia Community Sister of St Thomas' Hospital

GRO-A

When the Society was founded by a small group of haemophilia patients in 1950 there was no effective treatment for their condition. Haemophilia meant pain, disability and short life expectancy. From the start, therefore, the objective was to secure better treatment, and perhaps eventually a cure.

Patients then might not have dreamed of the highly specialised, and effective treatment now available. The advent of clotting factor treatment, originally derived from blood, and recently synthetically produced, has revolutionised haemophilia care. We now have a whole system within the NHS of haemophilia centres for diagnosis and treatment. Research is going on into gene therapy which may one day take the place of clotting factor injections.

All this progress has taken place within a lifetime, but there is still a long way to go. Treatment for haemophilia is very expensive, and funding problems have led to wide national variations in the standard and level of care. Cost has been a barrier to the uptake of the newer synthetic 'recombinant' treatment products, developed to minimise the risks of blood borne viruses. Unfortunately, despite medical advances, treatment by postcode is a reality. People with haemophilia have long become used to moving house to be near the best treatment centres, but still find it hard to accept that where you live should determine the quality of care received.

The Society has campaigned hard for patient choice to ensure that no one should be denied access to the safest treatment products on grounds of cost. With the tragedy of HIV and HCV infection in the haemophilia community still with us, the Society has been a powerful voice for people with haemophilia and their families who want the safest possible treatment.

The Society therefore strongly welcomed the Government's decision to instruct health authorities in March 1998 to provide recombinant factor VIII for children under 16. In 1999 the same instruction will apply to recombinant factor IX. This is a breakthrough, and already health authorities in some parts of the UK are moving towards provision of recombinant for adults as well as children.

In seeking to improve treatment the Society works very closely with the medical field, particularly the UK Haemophilia Centre Directors Organisation and the Haemophilia Nurses Forum of the Royal College of Nursing. Partnership between patients and clinicians is becoming ever more a part of the health service, and the Society is keen to follow this principle.

In 1999, we will maintain our focus on improving treatment and care, using every opportunity to influence health policy and practice, locally and nationally. The Society hopes to play a leading role in producing a new National Framework for Haemophilia to set standards and establish a blueprint for high quality care in the 21st century.

International work

1998 has been a busy year for the Society with a broadening of its international activities. The society has been represented at a European level through Trustee, Gordon Clarke, being elected to sit on the European Haemophilia Consortium Steering Group. Representatives from the Society also attended the World Federation of Haemophilia Conference at the Hague where links and contacts were established with other Societies around the world.

Over 80% of haemophilia patients globally are not given adequate treatment, making such links and exchanges of information vitally important. We made great strides with our Russion Twinning programme through establishing a Russian Pen Pal scheme between children in Russia and the UK, as well as sending Children's Books for children who have difficulties attending school. Our priority for 1999 is to fund a Russian visit to the UK, and help their Haemophilia Association form an organisational strategy and provide a skills exchange.

Treasurer's report

The Haemophilia Society has faced a financially challenging year in 1998 with severe reductions in Government Section 64 funding and in corporate sponsorship, following changes in the blood product industry. Despite these setbacks early on in the year it has been the Society's aim to maintain its level of service commitment to the haemophilia community.

To achieve this stringent controls were placed on all areas of expenditure whilst fundraising activity was increased with a new focus on project appeals and collaboration with other organisations. The Trustees also agreed to draw down on reserves to ensure that existing services were maintained for 1998.

Fundraising efforts were a special priority during the year in the light of the reduction in Section 64 funding. The impact of that reduction, combined with shortfalls in corporate funding and donations, is seen in the year end deficit even though expenditure was tightly controlled and was lower than in the previous year. This is in contrast to 1997 when, due to substantial legacy income and higher level of Government grant, there was a year end surplus of £71,363.

These shortfalls in income will continue to impose financial pressure on the organisation in the coming years, hence the Trustees, having reviewed the reserves policy in 1998, concluded that it remains prudent to seek to maintain reserves at no less than six months' running costs. Financial planning for 1999 and beyond assumes it will be necessary to draw on these reserves to maintain and develop the Society's services in the next three years.

Simon Taylor
Treasurer

Summarised Accounts

For the year ended 31 December 1998

	1998 £	1997 £
Total income	541,061	675,121
Total expenditure	580,190	603,758
Net (outgoing)/incoming resources	(39,129)	71,363
Gain on disposal of caravan	1,700	—
Net movement in funds	(37,429)	71,363
Funds brought forward	559,935	488,572
Funds carried forward	522,506	559,935
Being:		
Unrestricted funds	378,215	417,071
Restricted funds	16,821	13,500
Designated funds	33,864	53,107
Local Group funds	93,606	76,257
	522,506	559,935
Represented by:		
Fixed assets	45,720	49,893
Current assets	556,344	541,865
Creditors	(79,558)	(31,823)
	522,506	559,935

Statement of the Auditors

In our opinion the summarised accounts of the charity for the year 31 December 1998 are consistent with the full annual accounts on which we have given an unqualified opinion.

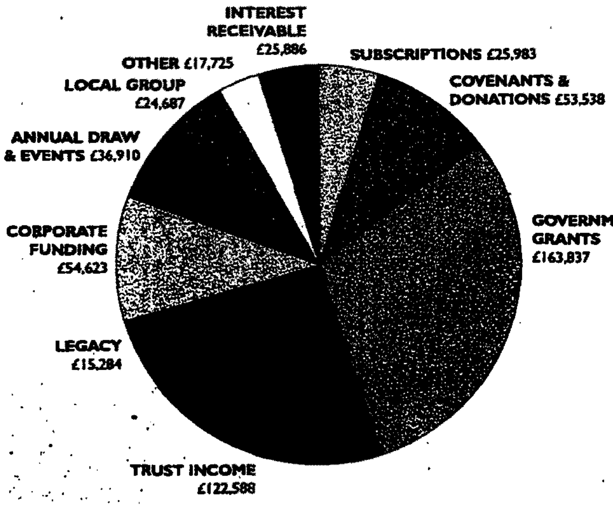
Dodson Lifford Hall
Chartered Certified
Accountants
87 Pickwick Road
Corsham
Wiltshire
SN13 9BY

14 April 1999

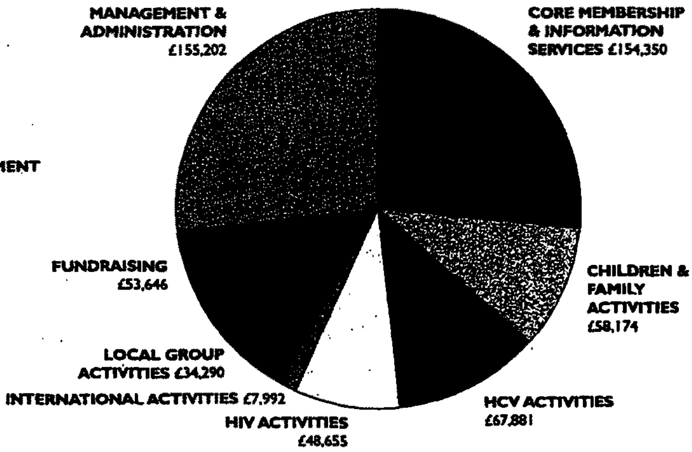
Full audited accounts are available on request from the Society.

Income and Expenditure 1998

Income | Total £541,061



Expenditure | Total £580,190



Fundraising

Killer Pool Competition: This successful event was organised by the friends of Brian Newman and raised £600 for the Society

Tim Dorey's Four Corners Cycle Ride: Tim cycled around the four corners of the British mainland in aid of the Society. He cycled a total of 3120 miles and raised over £2,300.

1998 has been a challenging year for fundraising. It has been our goal to raise over £500,000 to ensure the continued delivery of the Society's services for people living with haemophilia.

We have been very grateful for the continued and new support of donors, which include charitable trusts, companies, local self-help groups, volunteers and individuals living with haemophilia or a related bleeding disorder. The kindness and generosity behind in memoriam and legacy donations have also been welcome as an important source of funds.

Outlined within this Annual Report are the many areas for which we are seeking funding in 1999 and beyond. Long-term financial stability is essential if the Haemophilia Society is to continue responding effectively to the needs of people living with haemophilia. It is becoming increasingly difficult to attract new sources of funding, particularly as haemophilia is such a very rare condition – can you help us to meet this challenge in 1999?

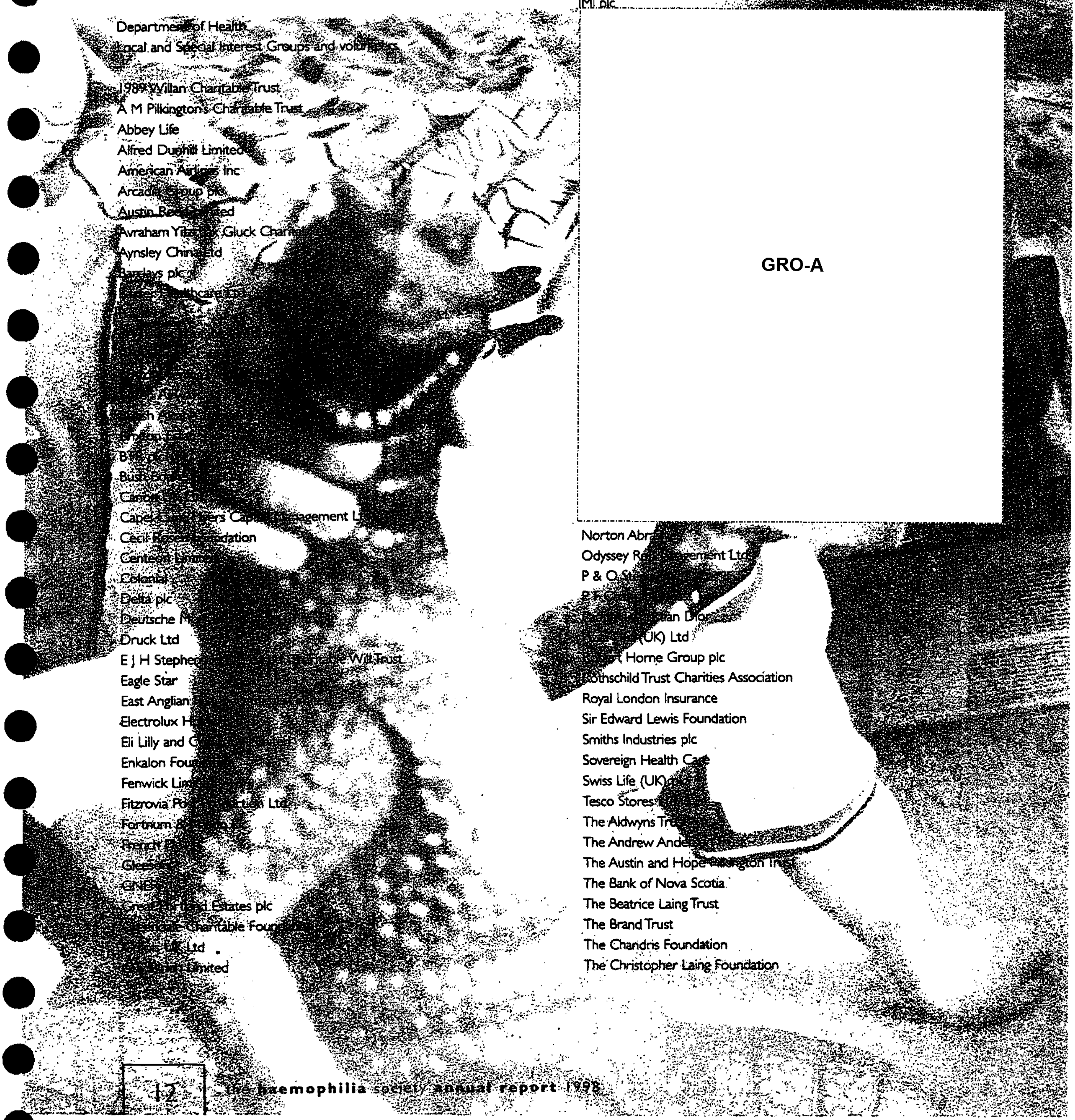
Become a Corporate Supporter – the Society believes in partnership with its corporate supporters. This can be in the form of direct sponsorship, employee giving scheme, or a simple donation – if you would like to offer your support please contact Melissa Watson at the Haemophilia Society.

Join our Friend's scheme – to become part of this scheme we ask for a minimum donation per year. Please write to the Society to find out more.

Become a member! – if you have an interest in haemophilia or other bleeding disorders, do become a member of the Society. Your membership subscription will help support the charity and, in return, we will keep you in touch with news and information.

Donors and supporters 1998

The Haemophilia Society would like to thank the many individual, trust and corporate supporters in 1998 for their commitment and support.



The Holden Family
Don Bratt and Allen McDougall
London Marathon Runners, Paul Carter, Joe Hall and Richard Morris

Department of Health
Local and Special Interest Groups and volunteers

1989 Willan Charitable Trust
A M Pilkington's Charitable Trust
Abbey Life
Alfred Dunhill Limited
American Airlines inc
Arcadia Group plc
Austin Reed [illegible]
Avraham Yitzchak Gluck Charit[illegible]
Aynsley China Ltd
Barclays plc
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Harris & Sheldon Group Ltd
Henderson Investors
Hepworth Minerals and Chemicals
IMI plc

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Norton Abr[illegible]
Odyssey Re[illegible]ement Ltd
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Robert Horne Group plc
Rothschild Trust Charities Association
Royal London Insurance
Sir Edward Lewis Foundation
Smiths Industries plc
Sovereign Health Care
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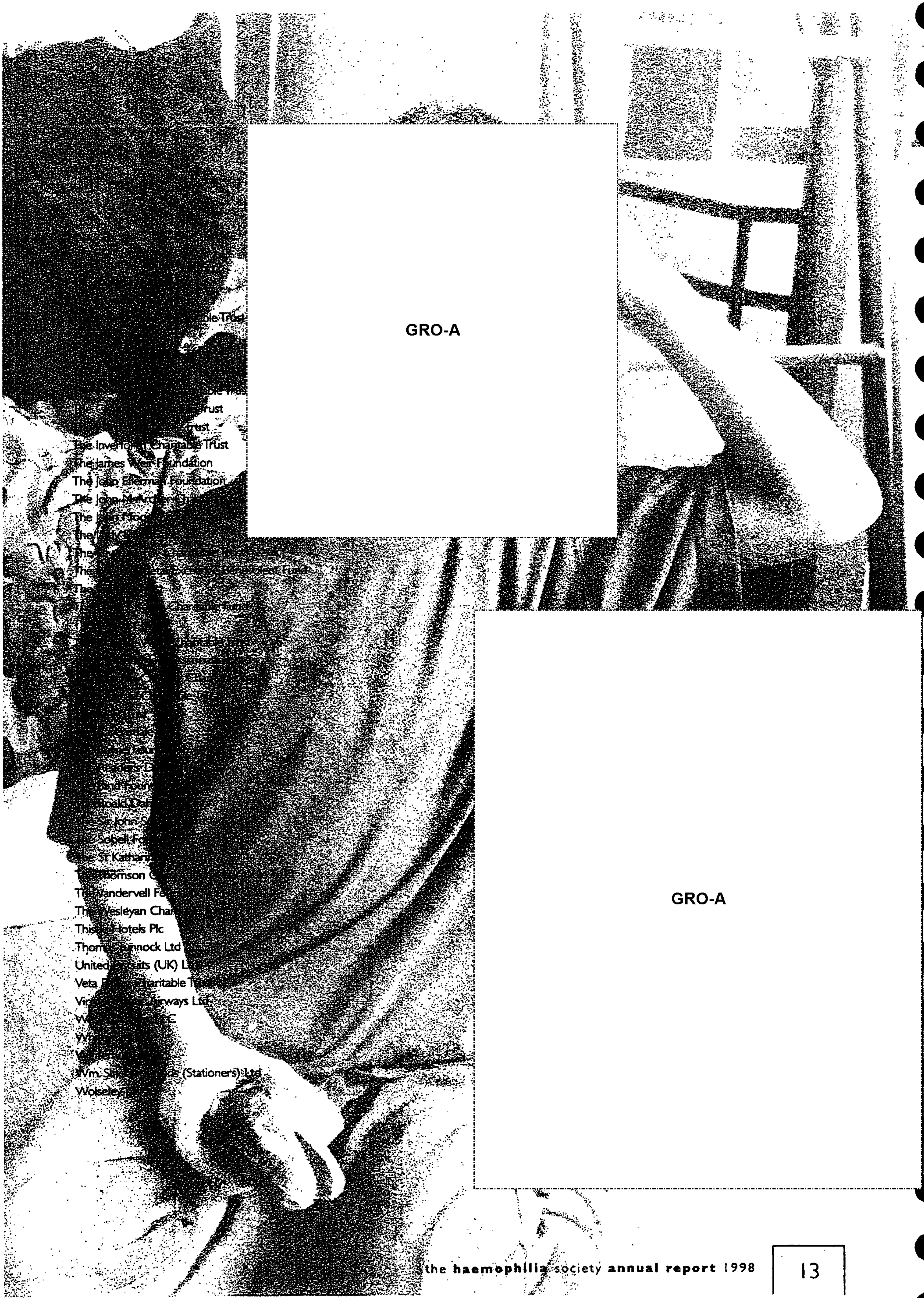
The Aldwyns Tr[illegible]
The Andrew Ande[illegible]
The Austin and Hope Pilkington Trust
The Bank of Nova Scotia
The Beatrice Laing Trust
The Brand Trust
The Chandris Foundation
The Christopher Laing Foundation



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GRO-A

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