Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392149

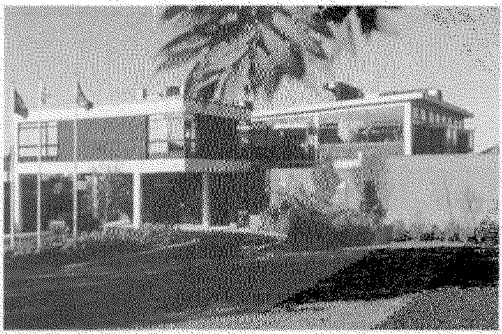
50TH ANNIVERSARY
1950 2000

THE BULLETIN

Magazine of the Haemophilia Society

SPRING 2000 ISSUE 1

50th Anniversary Day Seminar and AGM



The Haemophilia Society will be marking its 50th anniversary and AGM on Saturday 20 May with a day seminar at the Moat House Hotel, Oxford. Oxford has been chosen as the location because it was there that so much pioneering work took place in the early days of haemophilia treatment. This event will celebrate 50 years of the Haemophilia Society and look forward into the next 50 years of haemophilia care.

If you would like to join in the celebrations you will need to book early as places are limited. You can choose either to stay the night before the seminar, when there will be a wine reception and dinner, or just come for the day seminar. There is a full programme planned for Saturday 20 May, beginning with the AGM which all paid up members of the Society can attend. This will then be followed by speakers talking about the history of haemophilia, the Society and future treatments. Our special guest speaker is Laureen Kelley, an international ambassador for haemophilia and author of 'Raising a Child with Hemophilia'. (see p10)

The 50th anniversary seminar is open to everyone with haemophilia or a related bleeding disorder and their family. The registration fee for the day seminar is £6 and £25 for a residential place. We hope to see you there. Enclosed with this issue of ***the Bulletin*** is a provisional programme, a registration form and details about the event. If you have any queries please contact Joan Doyle on GRO-C or e-mail joan@ GRO-C

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Four sporting heroes!

On a windy day in January, four sporting heroes, all with haemophilia, made their way down to the Sports Café in Piccadilly, London, to receive a Duncan Goodhew Sport Award. The winners are pictured here with Duncan Goodhew and Karin Pappenheim. The boys all excel in a sport and each received a cheque for £100, presented by Duncan Goodhew the ex-Olympic swimmer. Well done to GRO-A GRO-A (discus thrower for his county and the SW of England) GRO-A (surfer supreme in the cold waters of the North Sea!) GRO-A (three star-kayaker and much more!) GRO-A (exceptional merit in football). More about the awards on page 14.

GRO-A

THE HAEMOPHILIA SOCIETY

Working for the best possible care for people with haemophilia and related bleeding disorders

Chesterfield House,
385 Euston Road, London NW1 3AU
Admin Tel: 0207 380 0600 Fax: 0207 387 8220

Thanks to sponsorship by MCI Worldcom the Society has a free information and advice helpline. The helpline number is

0800 018 6068

Monday to Friday 9am to 5pm

e-mail: info@haemophilia.org.uk
website: www.haemophilia.org.uk

Registered Charity No: 288260
Company Limited by Guarantee Reg. No: 1763614
Member of The World Federation of Hemophilia

SOCIETY STAFF

Chief Executive: Karin Pappenheim
Personal Assistant to the Chief Executive:
Sue Rocks
Benefits Advisor/Services Co-ordinator:
Info and Advice/Benefits Ruth Taylor
(Wednesday pm, Thursday, Friday 9am-5pm)
Info and Advice/Benefits Joan Doyle
(Mon, Tues, 10.30am - 5.30pm, Wednesday 9am – 2pm)
Children & Families Worker: Talia Barry
(Monday, Tuesday, Wednesday and Thursday 10am – 4pm)
Hepatitis Worker: Lucy McGrath
HIV Worker: Post Vacant
Communications Officer: Tom Bradley
Fundraising & Marketing Officer: GRO-A
Finance Officer: GRO-A
Membership & Administration Officer:
Julie Kershaw
Press Officer: Mark Weaving, Myriad PR,
Tel: GRO-C

Thanks go to the following pharmaceutical companies who are providing valuable support in 2000.
**Aventis Behring · Baxter · Bayer · BPI
Grifols · Roche · Schering Plough ·
Wyeth/Genetics Institute**
Copies of the Haemophilia Society's commercial funding guidelines are available upon request.

CONTACT LIST FOR GROUPS

In order to establish contact with your local Group you should write in the first instance to the national office. We have Groups in the following areas:

ENGLAND

BRISTOL & SOUTHWEST • CAMBRIDGESHIRE & DISTRICT
CORNWALL • HAMPSHIRE • HULL • KENT
LEICESTERSHIRE & RUTLAND • LINCOLN & DISTRICT
NORFOLK & NORWICH • NORTHAMPTON • NORTHERN
NORTH WEST • NOTTINGHAM • OXFORD
SOUTHERN • SOUTH ESSEX • YORKSHIRE

WALES

NORTH WALES • SOUTH WALES

SCOTLAND

PERTH • GRAMPIAN • TAYSIDE
WEST OF SCOTLAND • SOUTH EAST SCOTLAND

NORTHERN IRELAND

NORTHERN IRELAND GROUP

SPECIAL INTEREST

BIRCHGROVE GROUP

SERVICES AVAILABLE FROM THE SOCIETY

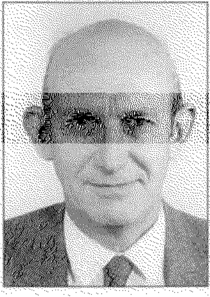
- General information about haemophilia and related bleeding disorders
- Information about Social Security benefits
- Information, advice and support on hepatitis and HIV
- Information for parents of newly-diagnosed children
- Parent support network
- Hardship grants
- Aventis Alert pager service (previously called Centeon Call)
- Caravan holidays in the UK
- Adventure holidays and weekends for children
- Fundraising support
- Assistance with media enquiries
- Information on treatments
- Travel advice and travel insurance advice
- Haemophilia Days and Family Days
- One-off meetings on specific issues, such as hepatitis
- Hepatitis C Support Network
- C. Issues
- Von Willebrands Support Network
- Mild and moderate haemophilia support contacts

For more information about any of the above services, please contact the national office.

Full details of our services are also available on our web site: www.haemophilia.org.uk

Editorial

by Dr David Evans



There has been a lot of discussion in the media about the problems of the NHS - long waiting lists, a lack of doctors, nurses, and most recently laboratory staff and no money for drugs and treatments.

Nearly everyone agrees that we need to spend more money on our health services to bring them up to the level expected in a modern world; but there is no easy way to do it.

The two main options are to increase taxes, or to raise money through some sort of health insurance. Few politicians of any party like the former, and Labour politicians are opposed to the second, with its implications of encouraging private medicine. So there does not appear to be any way forward.

How does this affect haemophilia? We want more money so that everyone can have recombinant products in adequate amounts, so that the best treatments can be provided for all with HIV or hepatitis, so that new joints can be provided as soon as people need them, and so on.

Would health care financed by insurance be any help for haemophilia? Any extension of our present schemes of private medical insurance is unlikely to be helpful: the insurers are not interested in long term illnesses, particularly those as expensive as haemophilia. However, in many other European countries health care is financed by some sort of insurance scheme, with varying degrees of state control. People with haemophilia still receive proper treatment in these countries. Many doctors including myself believe that some similar scheme could work here. As a minimum, the authorities should be looking at new ways of financing health care in the UK, because we are not getting what we need.

One remarkable fact brought out by our recombinant survey, which was summarised in the last edition of ***the Bulletin***, is that over half the health authorities who replied had no details about all their patients with haemophilia.

Bearing in mind the cost of treatment and the fact that there is a well-established system of haemophilia centres across the country, it seems remarkable that they do not have this information. How can we expect those who look after us to do their job properly when the people who draw up the policies do not have all the information to do it?

The management of inhibitors is a particular problem. For the patient, treatment is difficult and worrying. For the staff, it is a big demand on their skills and knowledge. For the administration, it is a heavy expense. Many authorities do not have the resources in skill or finance to cope.

In the coming months, we in the Haemophilia Society must put out heads together and come up with some sensible ideas about this worrying complication.

Retirement of Dr Peter Jones

One of our best medical friends, Dr Peter Jones, retires from the NHS in March. He has always been a stalwart supporter of the Society, which we acknowledged by giving him the Macfarlane Award in 1981. He is Director of the Newcastle Haemophilia Centre which he set up in 1972 and which was one of the first to offer comprehensive care.

He is probably best known for his books *Haemophilia Home Therapy* and particularly for *Living with Haemophilia* which was first published in 1974. It is now due for its fifth English edition and has now been translated into over seven different foreign languages. He is an Executive Member of the World Federation of Hemophilia and has written several of their publications too.

We wish him and his wife Brigitte a happy retirement. However, he is not stopping his work for haemophilia as he and his wife are going to Palestine later this year on a voluntary basis on behalf of the World Federation of Hemophilia to set up a Haemophilia Centre there.

Annual Draw 1999

Winning Ticket Numbers

1st prize	113513	GRO-A	Belfast
2nd prize	006316	GRO-A	Herts
3rd prize	218776	GRO-A	West Sussex
4th prize	064968	GRO-A	Lancs
5th prize	010633	GRO-A	Aberdeenshire
6th prize	218296	GRO-A	Carlisle

Membership renewals - a reminder

Please remember that you may not receive future issues of ***the Bulletin*** unless you are a fully paid up member of the Society. The Society normally issues two reminders before removing an individual from the membership mailing list. As a paid up member you will receive four issues of ***the Bulletin*** per year, and a range of special discounts; you are also entitled to vote in elections and at general meetings. If you are a new reader, why not join the Society. For full details of membership contact Tom Bradley or Sue Rocks at the national office on GRO-C

Treatment Update

Compiled by Dr David Evans

Blood Transfusion Safety

Blood Transfusion Centres all met their targets for removing white cells from blood donations by the end of October last. This was introduced to reduce the admittedly remote chance of transmitting CJD with blood transfusion. It was also confirmed that the supply of blood products from imported plasma remained secure. New techniques for screening for hepatitis B are under discussion.

Management of Inhibitors

Dr Hann of Great Ormond Street Hospital for Children, who is a member of our Health Sub-Committee, has drawn our attention to the massive expense of treating someone with an inhibitor, either for managing a serious bleed, or for attempting to eliminate the inhibitor. Such treatment may cost as much as £200,000 to £500,000. Not only do local health authorities not have such sums available, but many are quite unaware that they may be asked to find them. Our survey showed that many authorities do not know how many patients with haemophilia they are treating. Dr Hann thinks that the Department of Health should be providing central funds and advice, but so far they have not been willing.

The Health Sub-Committee will be discussing the matter at their next meeting.

Supply of BPL Products

Marc Greenwood, Senior Product Manager, BPL

BPL has achieved continuity of supply to all patients treated at centres who provided volume predictions for 8Y, Replenate, and Replenine-VF. Negotiations with centres throughout the country are now underway to ensure this commitment is maintained for the next contract period.

Correction

We apologise for the following errors in the winter 1999 issue of The Bulletin. Fandhi was incorrectly spelt. Grifols is not a subsidiary of Alpha and they do not make 200 unit phials of factor VIII.

Recombinant Survey

Following an article in the winter issue of ***the Bulletin*** "Recombinant Survey" Dr Ludlum has pointed out that there is no national consortium for haemophilia care or treatment in Scotland. There is a National Consortium of Health Authorities which arranges contracts for recombinant factor VIII and IX and also agrees national criteria for patients who receive these concentrates.

Measuring Factor VIII

Measuring the amount of factor VIII and other clotting factors is a complicated business. Professor Carol Kasper, a well-known haemophilia expert from Los Angeles, USA, has recently pointed out some problems. The 100% level was originally set as the standard amount of factor VIII in the plasma of a pool of normal donors. More recently the standard has been made from a standard concentrate, using newer assay techniques, with the result that doctors find that the levels they get after infusion do not always tally with the result they expected.

Most of the plasma used to calculate the normal level of factor VIII comes from working adults in the developed world. Normal children and old people may not have quite the same levels. Nor may people from other parts of the world. So the levels that we think of as "normal" may not be normal for lots of individuals who are tested.

Blood tests and von Willebrand's

Blood group 0 carriers of severe type 3 vW have about 40% vWF antigen, and group A carriers have about 66%. If someone has only 40% vWF Ag, do they have a disease or not? Based on blood tests alone, many centres used to believe that one in 100 of the population has vW; but many of these people have no symptoms so how can it be said that they have a disease? Professor Carol, a well-known haemophilia expert from the USA thinks that the true incidence of people with vWD who actually bleed abnormally is more like one in 10,000.

HIV Services in Southampton

A new drop-in centre called the Ribbons Centre has opened in central Southampton. The Centre, which is a project of two local charities, is open twice weekly and offers a range of services. These include: complementary therapies, an up to date resource library, access to the Internet for research purposes, refreshments and social events. The Centre welcomes anyone living with or affected by HIV.

For details about opening times and location telephone: 023 8022 5511

Email: info@ribbon99.freeserve.co.uk

The pros and cons of genetic therapy

by David Evans

Darwin's theory of natural selection was based on the idea that spontaneous mutations (which are, after all, only genetic modifications which occur naturally and by chance) result in some sort of benefit for the plant or animal concerned, so that they are passed on to successive generations and give them an advantage over others. The reason why Asian 'flu affects so many people is that every few years the 'flu virus undergoes a genetic modification, and although we are resistant to all the different types of 'flu that we have met before, each time a new strain comes along, we lack immunity to it and consequently get infected.

Genetically modified foods are causing a lot of anxiety. However, there is nothing wrong with genetic modification itself. Mother Nature has been doing it since the beginning of time. The problem with GM foods is more to do with the way that the large international corporations have tried to force their new GM products (which may or may not be improvements on existing products) on the market without proper discussion and agreement.

Recombinant clotting factors are produced by methods using genetic manipulation, and we think that they are an improvement. All of us involved with haemophilia have a keen interest in seeing how genetic modification can produce not just new treatments, but also a permanent cure. So we must not let anxiety about the possible dangers of GM foods give the impression that everything to do with GM is bad.

Nevertheless, there are problems. Last year, GRO-A GRO-A an 18-year-old American with a congenital liver disorder due to an enzyme defect died as a result of an experiment in genetic manipulation. The gene his body lacked was attached to a modified virus of the type which causes a common cold, and injected into him. It has now been reported that the Pennsylvania Institute for Gene Therapy where he was treated had deliberately flouted the safety regulations. The Institute has been accused of giving too high a dose of the virus, leading to a reaction which fatally damaged his liver and other organs (which were already damaged by the disease for which he was being treated). All similar experiments at the Institute have now been suspended by the US food and drug administration (FDA).

In the UK, such experiments, including any similar ones which might be tried for haemophilia, are licenced by the Government's Genetic Therapy Advisory Committee (GTAC). No similar trials are under way in the UK, but the possibility of a similar treatment has been discussed as a way of curing haemophilia. The problem with all treatment aimed at giving someone the normal gene which they lack is that their body recognises the new gene as "foreign" and reacts against it to destroy it. It was the reaction against the new gene injected into GRO-A which led to his death.

The Institute in Pennsylvania did not inform volunteers of the possible risks. Consent forms were altered to omit reference to the monkeys which had died. The fact that this research in Pennsylvania was dishonestly conducted should not act as a brake on other research of a similar type conducted by honest and conscientious scientists. Gene therapy studies involving modified cold viruses are under way in the UK for a variety of diseases. None at present involves haemophilia, and none involves injecting the cold virus. Such research is very costly, and the researchers, particularly those in the USA, are under pressure to produce results by the people who have provided the funds, who are often commercial companies. In the UK, permission for such research must be obtained from the Gene Therapy Advisory Committee, to whom adverse effects must be reported, and the Medicines Control Agency. British scientists insist that what happened in the USA is not happening here.

All new treatments carry an element of risk, and there has to be one man or woman who is the first to receive any new treatment. The first man to receive a genetic treatment for haemophilia may or may not survive; but we hope that such research will be conducted openly and frankly, as well as successfully. Our old friend, Queen Victoria, the world's most famous haemophilia carrier, was one of the earliest women to have chloroform as an anaesthetic in childbirth. It was successful, but think how the development of anesthesia would have been set back if it had failed.

Events Diary

Art Exhibition
Location: Petersfield, Hampshire
Date: Saturday 8 April *Contact:* GRO-A

Hepatitis Evenings
Location: Various
Contact: Lucy McGrath

50th Anniversary Children's Party
Location: Great Ormond St, London
Date: Friday 19 May *Contact:* Talia Barry

50th Anniversary & AGM Seminar
Location: Moat House Hotel, Oxford
Date: Saturday 20 May

Living with HCV - a weekend for young people and parents
Location: Manchester
Date: Saturday17 & Sunday 18 June
Contact: Lucy McGrath

Action on Pain Campaign

By GRO-A

One in four people living in chronic pain is driven to contemplate suicide as a result, according to research findings published in support of No Pain Day which was held on November 15 1999. Startlingly, this number rises to one in three for people aged between 20-29 years of age.

These findings have been compiled from a questionnaire carried out last year by Action on Pain to investigate patients' perspectives on pain and pain management. Although modern treatments for haemophilia are extremely effective, pain remains an issue for many people living with haemophilia.

The findings confirm that chronic pain is experienced by young and old alike and affects both men and women. No matter what the cause, common to all who experience pain is that they are unlikely to talk about it or ask for help. Two out of three respondents say that they suffer in silence.

Chronic pain affects as many as one in 14 adults in Britain today and is a problem that is increasing. Fifty six per cent of those affected are between 25 and 65 years old. The Haemophilia Society has been working with Action on Pain, an awareness campaign run by the Patients Association, Arthritis Care and The Pain Society, to increase awareness amongst the general public and health professionals that millions of people are living in unnecessary chronic pain.

The campaign aims to encourage people to speak up as their pain can be managed successfully and their quality of life vastly improved. The Action on Pain PainLine constantly receives calls about the problems facing people in chronic pain and No Pain Day highlighted the need and value of such services. The helpline offers practical advice about pain management including a booklet "About Living in Chronic Pain".

Many people and clinicians agree that the ideal way for pain to be managed successfully is by a specialist who adopts a holistic approach and offers individual and expert advice.

With six out of 10 respondents reporting that their pain has put close relationships under stress, it is not surprising that many people feel isolated as a result of their pain. Pain may be caused by acute injury or may result from a chronic condition such as arthritis. Whatever the cause, people face similar difficulties learning to live and cope with it.

If you would like to know more about Action on Pain please contact The Patients Association, PO Box 2106, London, W1A 3DZ or call the PainLine on 0116 269 5568.

For further information about pain management and haemophilia, please contact your Haemophilia Centre.

Help for Carers

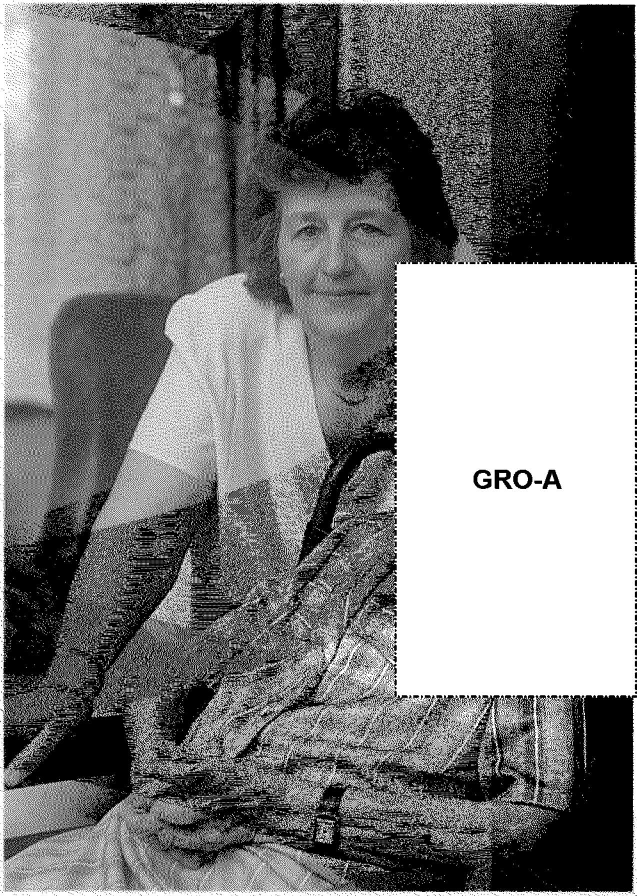
by GRO-A *Press Officer*

The Carers National Association (CNA) aims to support and campaign for the 5.7 million people across the UK who look after a relative, partner or friend who have a long term illness, is disabled or elderly and frail. It is estimated there are 51,000 carers under 18 years helping to look after a parent, sibling or other relative. Some people care through choice, but others do so because there are no suitable alternatives.

GRO-A

Support groups and branches

CNA has developed a range of advice networks, branches and support groups across the country to reach as many carers as possible. The importance of accessing information and services at the right time can really help a carer to manage their situation better. Our advice line for carers deals with queries from people asking for information on benefits and other financial help, getting help in the home, respite care centres, taking a break from caring, to making adaptations to the home and buying special equipment.



GRO-A

All CNA branches give carers the chance to get out and meet people in similar circumstances, to benefit from their experience, offer each other support and share local information about resources and help. Because they draw carers together from a range of caring backgrounds, the branches also act as a local carer's voice.

Campaigning

The government has allocated £140 million in the National Strategy for Carers to guarantee more respite breaks for carers and their families. This money will enable Social Services departments in England and Wales to develop new short term break schemes over the next three years.

Under the Employment Relations Act 1999, carers are now legally entitled to take time off from work for family emergencies.

CNA will continue to campaign throughout 2000. Our main priorities will be to get a better financial deal for carers. This will be the main focus of this year's Carers Week, to be held between June 12 - 18. It is a UK wide platform raising awareness among the general public, Government, health and social services of what carers do.

Too many carers tell us they are just not getting the help they need. We will continue to campaign to persuade all those who take decisions which affect carers to adopt policies and practices which will deliver: real choices, a decent and sustainable income and a quality of life which is acceptable to carers and those they care for.

For further information on the CNA please call Carers Line on: freephone 0808 808 7777 or write to us at: 20-25 Glasshouse Yard, London, EC1A 4JT

Note: If you or someone you know is a carer, the Haemophilia Society would like to hear your experiences and to know what support would help you as a carer. Contact Joan Doyle at the national office.

RED RIBBON PAGE

Most people with Hep C not developing liver toxicity on Highly Active Antiretroviral Therapy (HAART)

By Keith Alcorn, Editor, Aidsmap.com

Although people with hepatitis C have a four-fold higher risk of developing liver toxicity on HAART, almost 90% do not suffer any significant liver problems as a result of their anti-HIV treatment, according to a new US study from Johns Hopkins School of Medicine. The findings challenge the view amongst many doctors and people with HIV that protease inhibitors are especially difficult to tolerate if you are co-infected with hepatitis C. However, the study also confirms the view that ritonavir is responsible for a much higher rate of liver toxicity among all patients.

Researchers looked at 298 patients who had started a new regimen between January 1996 and January 1998, 71% of whom received protease inhibitors. 52% had hepatitis C infection. 10.4% of all individuals developed serious liver toxicity (defined as grade 3 or 4 elevation of ALT and AST, adopted from ACTG standard measures) after a median of 188 days, but 30% of ritonavir users developed severe toxicity. Ritonavir accounted for half of all severe toxicity cases although only 50 of 298 patients were receiving the drug. Rates of severe toxicity were similar in those who used saquinavir in combination with ritonavir.

Co-infection with hepatitis C made no difference to the rate of severe toxicity in ritonavir users, but severe toxicity in people taking non-PI containing regimens (usually two NAs) only occurred in individuals co-infected with hepatitis C (p=0.06). Individuals with hepatitis C taking PIs other than ritonavir were 60% more likely to develop severe toxicity than those without hepatitis C, but this trend was not statistically significant and only 8.1% of HIV/HCV co-infected individuals experienced severe toxicity on PIs other than ritonavir.

A CD4 increase of more than 50 cells after starting PI therapy or a baseline CD4 count below 200 were also associated with an increased risk of severe toxicity regardless of HCV status. These findings suggest either an immune restoration effect or that CD4 increase in this context is a surrogate for superior drug absorption and hence increased risk of liver toxicity.

Severe hyperbilirubinemia (another marker of liver toxicity) was seen in 10 (3.4%) individuals, and was associated with indinavir treatment (RR 2.3, non-significant). All but two cases occurred in individuals with hepatitis C or B.

Twenty-five out of 31 individuals with severe toxicity stopped therapy, but six continued with no significant consequences, and there were no deaths attributed to drug-related liver toxicity.

References

Sulkowski MS et al. Hepatotoxicity associated with antiretroviral therapy in adults infected with human immunodeficiency virus and the role of hepatitis C or B virus infection. Journal of the American Medical Association 283 (1), January 5 2000.

http://www.aidsmap.com/news/story

We thank the National Aids Manual (NAM) for supplying this article

Goodbye to Steve Fouch

Karin Pappenheim, Chief Executive, writes

All at the Society were very sad to say goodbye to Steve Fouch, our HIV development worker for the last two years, just before Christmas. Steve has gone on to a new job as director of Healthserve, an initiative of the Medical Missionary Association, which will provide a health information resource centre to serve Christian churches and healthcare professionals. Since joining the Society Steve had built up strong relationships with both the Birchgrove Group and the Macfarlane Trust, where he played a key role in the strategic review. In his first year he also carried out an important survey of the services available across the UK for people with haemophilia and HIV. More recently, Steve co-ordinated a new project to meet the needs of young people with HIV and haemophilia funded by the Pilgrim Trust and the Elton John Foundation. Steve will be much missed and we wish him well in his new post.

Questions about HIV Treatment?

Find out your options at aidsmap.com

Booklet: HIV Treatment Information on the World Wide Web.

A practical guide to help you get to grips with the growing range of HIV-related treatment information on the World Wide Web.

Make the most of the wealth of resources available on NAM's acclaimed website www.aidsmap.com by ordering your free booklet.

Telephone 0207 627 3200, e-mail info@nam.org.uk, or write to:

NAM Publications, FREEPOST LON277, London SW4 7YY

Hepatitis Update

Compiled by Lucy McGrath, Hepatitis Worker

Hepatitis C (HCV) study

Original article by Jennifer Roberts, London school of Hygeine & Tropical Medicine Reader in Economics of Public Health

Summary Written by Lucy McGrath, Hepatitis Worker

The Haemophilia Society has commissioned a pilot study into the social and economic impact of hepatitis C and haemophilia. This study involved telephone interviews with about 20 people affected by haemophilia and HCV and was carried out by Dr Jennifer Roberts at the London School of Hygiene and Tropical Medicine, with her assistant Sarah Bond. The full study findings will be available soon, but here are some of the key conclusions of the research:

- Hepatitis C has not been handled well in the care of haemophilia in many parts of the country.
- There appeared to have been no national strategy to inform staff about the appropriate way of dealing with the issue with respect to testing, informing people about the illness or conveying information about treatment options.
- Provision of information was largely left to voluntary agencies.
- Health care professionals in many cases have not appeared to be fully aware of the disease or its implications.
- Counselling facilities are not available generally and there is a particular need for help with young people and their families.
- Access to treatment has been patchy and information about treatments is not routinely available.
- Some reported stigmatising comparable to early HIV sufferers.
- Uncertainties about likely progress of the illness were causing deep anxiety to many with the disease and to the parents of those with the infection.
- A comprehensive strategy that addresses the health and social needs of these people is required at national level.

Hepatitis C- mortgages and life assurance

We have a new hepatitis C fact sheet called 'Financial Issues' which looks at life assurance, mortgages and saving for the future for people infected with HCV and/or HIV. If you would like a copy, give us a ring at the Society.

Irish Tribunal of Inquiry

Brian O'Mahoney of the Irish Haemophilia Society

In Ireland a Tribunal of Inquiry which is looking into how people with haemophilia were infected with HIV and hepatitis C has just been set up. In June the Terms of Reference for the Inquiry were passed by the Irish Parliament, and the first preliminary hearing was held at the end of September. This was a hearing to allow interested parties to seek formal legal representation before the tribunal. The tribunal is due to examine how blood products contaminated with HIV and hepatitis C were given to people with haemophilia and related bleeding disorders. There is currently ongoing discussion between the interested parties about the interpretation of the Terms of Reference for the inquiry. It is hoped that full hearings will commence in the Spring. For regular updates on the outcome of this tribunal, please contact the Society and ask to go on the mailing list for C Issues.

LIVING WITH HEPATITIS C

Date: 17-18 JUNE 2000

Sheffield Swallow Hotel

A weekend for young people and young adults (14-30) with HCV

and

parents, partners, friends or siblings

There will be a small registration fee

- *Separate events for 15-17s, 18-30s & parents/guardians*
- *Luxury hotel with gym & pool- set in beautiful grounds*
- *Videos, information sessions*
- *Issues covered: health, careers, relationships, feelings, sex.....*

For more information and a registration from, contact: Lucy McGrath, Hepatitis Worker on GRO-C

Free Helpline 0800 018 6068 Monday - Friday 9am - 5pm

Reviews

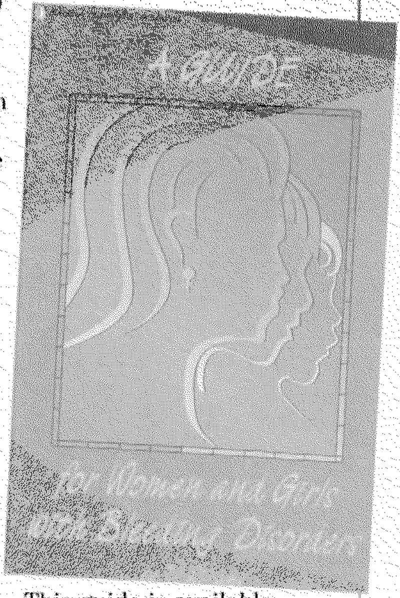
'Raising a Child with Hemophilia' by GRO-A -

Review by Chris Hodgson

A new edition of GRO-A book 'Raising a Child with Hemophilia - a practical guide for parents', has recently been revised and updated. She has a son with haemophilia. As well as the medical problems involved for a person and their family living with haemophilia, the book covers the feelings and the psychological issues which we all have to deal with at various times throughout our lives. It is a book I would recommend. It is available direct from your Haemophilia Centre free of charge. If your Centre has no stocks it is also available from Diane Whitewood at Aventis Behring (formerly Centeon) GRO-C GRO-C but ask your Centre to obtain the book for you. Any other difficulties obtaining a copy, please contact Tom at the Society.

GRO-A

'A Guide for Women and Girls with Bleeding Disorders'



The National Hemophilia Foundation (NHF) has published a booklet called 'A Guide for Women and Girls with Bleeding Disorders'. It describes the issues which arise for women and girls who are affected by bleeding disorders. The guide answers many questions about a variety of bleeding disorders, treatment consideration and obstetric and gynaecologic concerns. This guide is available from the Haemophilia Society. To receive a copy contact Tom on GRO-C If you have any queries about women and bleeding disorders contact Joan on the above number or e-mail joan@ GRO-C

Letters

I have been a patient at the Hampshire Haemophilia Comprehensive Care Centre since its inception as the Southampton Haemophilia Centre. I cannot speak too highly of the treatment and care I have received.

At the beginning of December my wife and I attended a meeting at the centre. We had a very interesting evening, the highlight being the tour of the laboratory where we were shown how blood samples were received and dispatched, what happens to the samples and how blood products were stored.

Unfortunately attendance was not high so the staff would like to repeat the evening at a future date. I was asked if I would write to you to give a "patient's eye view" of the evening and to ask if you would be prepared to mention the forthcoming meeting in any literature you may send to members of the Haemophilia Society.

I am sure Mrs Kath Yates from the centre would be pleased to discuss any future plans of the centre with you.

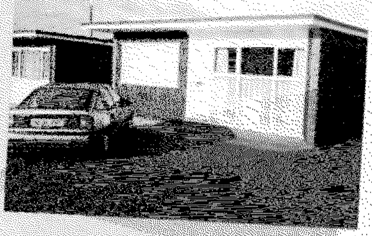
Thank you,

GRO-A Southampton

E-mail Friends

If anyone wishes to communicate with others by e-mail, contact Talia Barry (*talia@* GRO-C

My name is GRO-A
I am a 30-year-old haemophiliac living in the southern part of India. I am a software engineer and my hobbies are ham radio, short wave listening, amateur astronomy, bird watching, reading and learning foreign languages (at present French and Esperanto).
I also practice "Reiki".
My e-mail is: GRO-A



The Hemsby Bungalow is becoming increasingly popular for holidays and has had yet more improvements for the year 2000. Also available this year are mini breaks for £70. (Friday to Monday and Monday to Friday). A microwave oven was installed at the end of 1999, and many of the curtains will be replaced before this season starts.

Full details can be obtained from the national office or from Keith Colthorpe GRO-C

Benefit Changes

By Ruth Taylor, Benefits Advisor

The new deadlines for appealing against benefits decisions are now in place. You have one month in which to request a revision of a decision or appeal. If the letter notifying you of the decision does not give reasons for the decision you can request the reasons and ask to see the evidence on which the decision was based. This will give you a further two weeks.

Disabled Persons Tax Credit (DPTC) and Working Families Tax Credit (WFTC) have now replaced Disability Working Allowance and Family Credit. The new benefits are much more generous. Anyone who was refused the old benefits because their income was too high would be well advised to apply again. If you could apply either for DPTC because you get Disability Living Allowance or WFTC because you have children, DPTC is more generous.

Since October 4 1999 disabled people and lone parents returning to work are entitled to continue claiming Housing Benefit and Council Tax Benefit at their existing rate for the first four weeks after they return to work. Ask for form NHB 1EP as soon as you know you will be starting work. You have eight days after your income support or job-seekers allowance stops to claim the run-on. This time limit cannot be extended.

The Welfare Reform and Pensions Act 1999 which abolishes the Severe Disablement Allowance and makes changes to Incapacity Benefit and Disability Living Allowance does not come into force until April 2001. We will deal with it in more detail in the Autumn Issue.

Obituary

Kenneth Moore 1927 - 2000

Kenneth Moore who lived in [redacted] Cornwall sadly passed away on the [redacted] this year. He leaves his devoted wife [redacted] their son [redacted] and daughter [redacted] and two little grand daughters.

As a child Ken lived in [redacted] Somerset with his five brothers, [redacted] There was little known about haemophilia when Ken was a boy and no form of treatment would have been around, which meant days or sometimes weeks of pain and bedrest. Early types of treatment became available during the 1950s. Having cheated death many times, it was his courage and the love he had for his family that gave him the determination and the will to fight for life. Ken was probably the oldest severe haemophiliac, at 72 years, in the U.K. As a young man he moved to London. Life changed for the better when he met [redacted] They were so happy and in love and married in 1955, and lived in [redacted] He worked for a pharmaceutical company and retired in 1972. Ken and [redacted] had many friends in Oxfordshire. Ken was on the committee of the local Oxford group for some time. Together with two professors at Oxford Ken was instrumental in the design of the first "Home Treatment Kit" which was contained in a portable case. Indeed this was the forerunner of today's DIY treatment. A sample of Ken's blood was sent up into space during the shuttle programme of the early 1980s for medical research. During his retirement he became a local Councillor and a Governor of three schools - and when time permitted would spend many hours fishing. Ken and [redacted] returned to the West Country, [redacted] in Cornwall to continue their retirement in 1985. They are well known in their little village. There was a large congregation at his funeral service which was held at the Wesley Rock Methodist Church, [redacted] Ken will be missed by his family, many friends and fellow patients and hospital staff.

By [redacted] Cornwall Group.

The Alan Tanner Hardship Fund

This fund was set up to assist people affected by haemophilia or related bleeding disorders with the cost of essential items which they cannot afford themselves. The items we give funding towards are usually a fridge for treatment or household items to ensure safety or comfort for a child or adult. Our budget is limited and we receive more applications than we can fund.

It is therefore necessary for us to give grants to those in priority need which are directly linked with haemophilia.

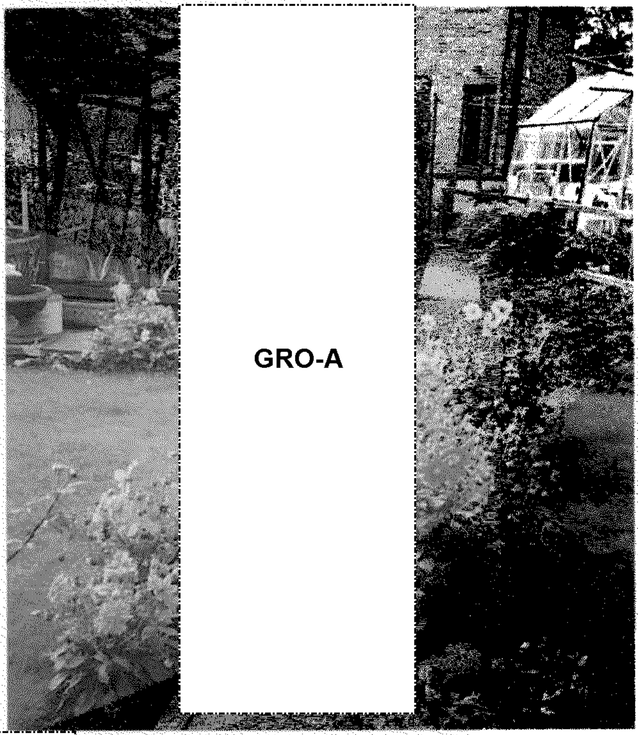
There are items we are unable to provide funding towards and these are listed in our 'Guidelines for the Hardship Fund' which is available from the Society. These guidelines will give you detailed information about applying to the fund, how we assess applications and how we make payments to successful applicants.

The Haemophilia Society will endeavour to assist all applicants and where we are unable to help with funding directly, we will provide advice on other possible sources.

If you require any information about the Alan Tanner Hardship Fund contact Joan Doyle on [redacted] or e-mail joan@[redacted]

Karen Pappenheim, CEO, receives a cheque for £15,000 from Stephen Redgrave & Matthew Pinsent from The Hospital Saving Association (HSA)

Fundraising



GRO-A *proudly shows his certificate*

GRO-A personal best in Junior Great North Run

GRO-A GRO-A aged 13 and who has von Willebrand's, took part in the Junior Great North Run last year to raise much needed funds for the Haemophilia Society. He raised the grand total of £492.60, with many donations coming from the Directors and staff at UniChem Ltd.

GRO-A completed the three mile course in 16 minutes 30 seconds, which was just three minutes behind the winner and a personal best fo GRO-A We would like to congratulate GRO-A for doing so well in the run, and being an excellent fundraiser for the Society. Keep up the good work!

A successful year for the GRO-A

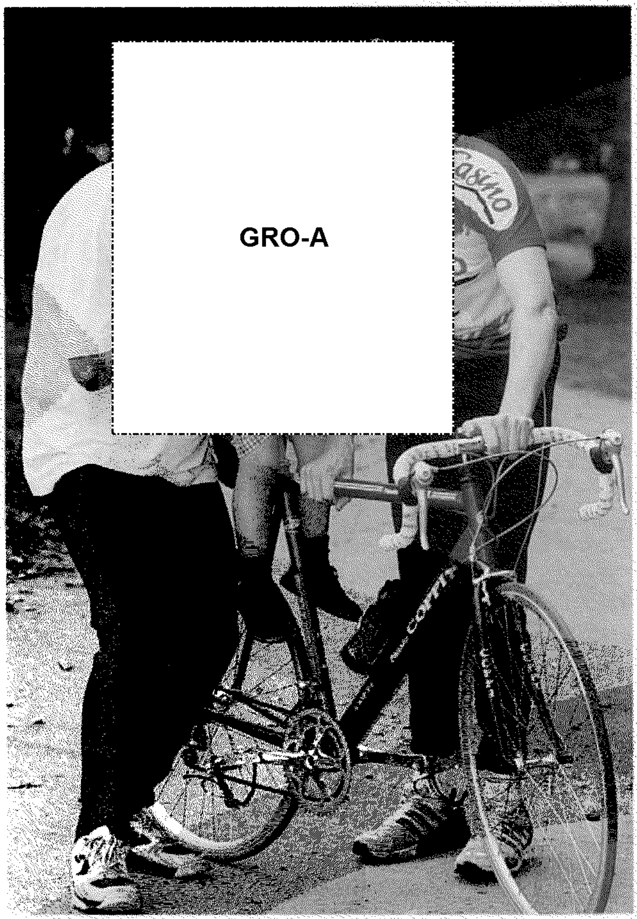
GRO-A GRO-A have again shown their commitment and support to the haemophilia community through raising £6,000 in 1999 for the Society's services. Trustee Keith Colthorpe attended their Christmas Dance to receive the cheque. A big thank you goes out to GRO-A and the fundraising Committee for all the hard work they have put into raising this magnificent sum for the haemophilia community. They do a wonderful job!

Christmas Appeal

We have had a successful Christmas Appeal in 1999 which raised the Grand Total of £25,184.96 for the Society. This includes Annual Draw ticket sales, Christmas Cards and donations. We would like to thank all our supporters who generously supported the appeal. The winning ticket numbers are on page 3.

GRO-A inspires Charity Bike Marathon to raise £2,810

Top fundraiser GRO-A and friend GRO-A embarked upon a mammoth cycle ride from John O'Groats to Land's End in September last year to raise money for the Haemophilia Society. As well as raising sponsorship mone GRO-A worked tirelessly in organising a charity auction and gained the support of the Pirelli Club in Carlisle, and raised the grand total of £2,810. They were helped by their friend GRO-A who followed them in a van which contained two weeks worth of supplies for their trek across the UK. GRO-A was inspired to undertake the journey through knowing his friend's little boy, GRO-A (pictured) who has Factor V deficiency.



GRO-A

Help with Insurance

By Richard Bryant, Bryant Kesek & Partners

March 2000 sees the launch of two new insurance schemes which will be available to all members of The Haemophilia Society, offering Home and Motor insurance with excellent cover and very competitive premiums.

Both schemes are being underwritten by CGU Insurance plc and are available exclusively through Bryant Kesek & Partners who are Registered Insurance Brokers based in Cranleigh, Surrey. CGU is the new name for the recently merged General Accident and Commercial Union.

HOME

Choice of cover - "Standard" or "Wider"
"New for Old" cover
Buildings or Contents - or both
No Claim Discount
Choice of excess
24 hour Helpline

MOTOR

Choice of cover - Comprehensive
Third Party Fire and Theft or Third party only
"No Claim Discount Protection" option
Courtesy car option *
Approved Repairers *
Uninsured Loss Recovery Option
24 hour Helpline
*if Comprehensive cover

CGU will not be able to accept each and every proposal put to them. However, in those circumstances, Bryant Kesek & Partners, being Registered Insurance Brokers, will be able to obtain quotations from other Insurers. However it is anticipated that CGU will be able to offer cover for the Home and Motor insurance of the vast majority of members.

Bryant Kesek & Partners was formed 15 years ago and has built up a reputation for providing a insurance broking service based on a very personal service to clients backed up by high technology.

They specialise in the arrangement of Life Assurance and have many years' experience in financial planning from life assurance through to mortgages, pensions and investments. They can also advise on immediate and long-term care, raising additional income in retirement and many other important areas. Part of their service to members of The Haemophilia Society is to remove the strain of finding a suitable Life Assurance Plan.

A full financial review is available to all clients but they are equally happy to discuss specific areas in isolation. All advice is, of course, impartial, confidential and obligation-free.

Bryant Kesek Financial Services Ltd is a member of Countrywide Independent Advisers Ltd which is regulated by the Personal Investment Authority for life assurance, pensions and investment business only. The PIA does not regulate general insurance.

They can also arrange Travel insurance with a "Top Ten" Insurer at competitive rates. An article about travel insurance will be published in the next issue of ***the Bulletin***.

For information about travel insurance provided by Bryant Kesek & Partners contact them on: 01483 274792
or by e-mail at insurance@bryantkesek.demon.co.uk

World Federation of Hemophilia Congress

Montreal July 16-21 2000

Six representatives of the Haemophilia Society will be attending the XXIV international congress in Montreal this summer: Society Chairman and Vice Chairman Chris Hodgson and Philip Dolan, Trustee Keith Colthorpe and Chief Executive Karin Pappenheim together with two local group representatives of the Society.

Look out for a full report in the September issue of ***the Bulletin***.

50th Anniversary Celebrations

This year the Haemophilia Society is half a century old. That means for the last 50 years we have been working to secure the best possible care, treatment and support for people with haemophilia and related bleeding disorders. That is a good reason to celebrate.

Has your local group or Haemophilia Centre any functions i.e. party or event planned to celebrate the 50th anniversary of the Haemophilia Society? If there are any events planned, let us know and we will promote them in ***the Bulletin***.

Contact Joan Doyle at the National Office, and don't forget to let Mark Weaving know on GRO-C

Congratulations

The Society's Finance Officer GRO-A had a baby girl. Baby GRO-A was born on GRO-A Mother and daughter are doing well.

Society News

Elections 2000

The Trustee election process gets underway this month. The call for nominations goes out to Society members in this mailing. Nominations are invited for the three Trustee places which come up for election this year, representing a third of the nine elected Trustees. Two current Trustees, Carolyn McGimpsey and Alex Susman Shaw will be standing for re-election; whilst Dr David Evans will be retiring after six years as a board member.

The position of Chairman also comes up for election this year. Chris Hodgson, the Society's chairman for the last three years will be standing for re-election. Members may also choose to submit other nominations. Please remember that you must be a fully paid up member to make a nomination, which should be submitted on the official form available from Tom Bradley at national office. Nominations must be returned to the office by **12 noon on Wednesday April 12**. Results of the election will be announced at the AGM on Saturday May 20.

Achievement Awards

We are now calling for nominations for the 2000 Achievement Awards. Below are some of the winners for the awards in 1999. Anyone in the haemophilia community can be nominated for an achievement award. Candidates may either be nominated or can apply personally. The letter should state the name, address and age of the candidate, together with details of their achievement, educational establishment (if appropriate), accompanying letter from their Centre Director and any other supporting documentation.

For enquiries and sending nominations please contact GRO-A at the Society. **Deadline for all nominations is May 8.**

Duncan Goodhew Sports Award: there are two awards of a cash prize and certificate given annually and are for children up to 18 years old. The award is given to children who have excelled or achieved in sport.

GRO-A ***Art Award:*** this is a cash prize and certificate and is open to students with haemophilia or a related bleeding disorder studying the arts. Preference will be given to a student studying music, as a reflection of GRO-A love of music developed in later life.

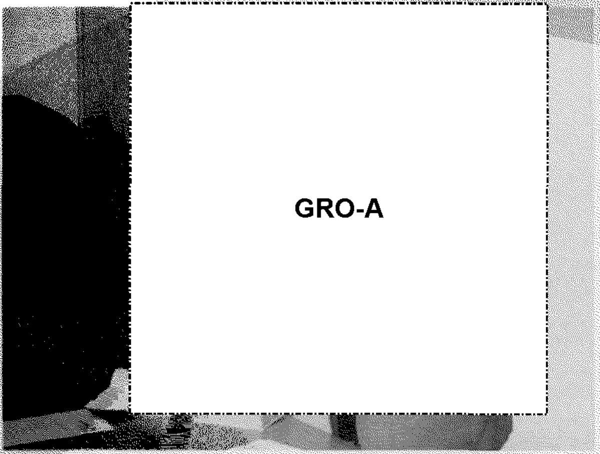
GRO-A

The Haemophilia Society Award: this award is presented to an individual who has made a significant contribution to the well-being of people with haemophilia in the United Kingdom.

Catherine Cookson Awards

Following the death of Dame Catherine Cookson, we have been unable to give the Catherine Cookson Awards for educational achievement. However it is hoped that the executors of her estate will be able to continue the awards in her name, and we are awaiting their reply.

The Haemophilia Society Award 1999



GRO-A

The Haemophilia Society Award was presented last year to GRO-A (photo,left) at the Local Groups Forum in London on the November 20. GRO-A has been involved with the voluntary sector for the past 20 years, initially helping the elderly and disabled in Wales. Soon after the realisation that people with haemophilia were becoming infected with the HIV virus, GRO-A with GRO-A founded the Birchgrove group (named after the Birchgrove pub in Cardiff). Sadly, GRO-A has now died and much of this award is also an acknowledgement of GRO-A work with GRO-A

The group has expanded from its two founder members to over 40, providing not only mutual support to those infected, but also to the families affected. GRO-A gives much of his time to the bereaved and their children.

With his tremendous commitment and passion he also spent time fundraising for the group. This enabled the group to have weekends away, conferences and give much needed breaks to those having the constant worry of HIV. In 1992 the group went national. Even seven years after the diagnosis of HIV there was no national support, and GRO-A raised the money for the first national conference in 1993.

As the chair of the National Birchgrove Group he has been a powerful force, expressing the needs of people with haemophilia and HIV to various funders, but also to the Haemophilia Society and the Macfarlane Trust.

By his enthusiasm and his ability to motivate others, the younger people with haemophilia and HIV have now been encouraged and helped to form mutually supporting groups.

Not content with these achievements he has recently handed over the Chair of National Birchgrove Group, but has now taken over the chair of the South Wales group of the Haemophilia Society.

Our best wishes go to him and his family.
Chris Hodgson

The Family Pages

Compiled by Talia Barry, Children & Families Worker

PARTY, PARTY, PARTY!!!

Celebrating the Society's 50th Anniversary

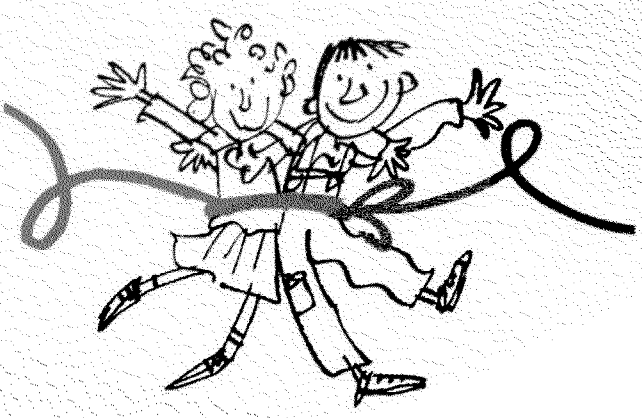
The Haemophilia Society has been given the Quentin Blake Award 1999 in recognition of our work undertaken with children and families. The award will enable us to produce party packs for every Haemophilia Centre in the UK and the local groups. This award will help children and families to get together and share their experiences of having a child with a bleeding disorder and kids can have fun!

The party packs will contain lots of goodies and will be illustrated by Quentin Blake, the illustrator of Roald Dahl books. Each lot of party packs sent out will include an organisers pack so that whoever is hosting the party can have a checklist of what to do, suggestions of games to play and basically, how to make the party a success.

Every Haemophilia Centre will receive a number of party packs in the next few months, meanwhile if you have any queries, don't hesitate to contact Talia Barry at the Society. If you are part of a local group and are interested in the party packs please contact Talia and she will arrange to have some packs sent out to you.

The first party will be at Great Ormond Street Hospital on May 19 2000, we can't wait!

Lastly, a big thank you to Quentin Blake for the Roald Dahl Association award, we hope the parties will be enjoyed by many children and parents.



"We would like to say a big thank you to BBC Children in Need, Baxter, Bayer, Centeon, Wyeth/Genetics Institute and other trust and corporate donors who support our children and families work."

A Brave Young Boy

GRO-A

GRO-A GRO-A is five years old and is quite honestly one of the bravest young people that I have come across. He has severe haemophilia A and is on home treatment. Ever since he started to receive treatment he has been exceptionally brave and never lets his haemophilia get him down GRO-A mum often gets upset because she doesn't like to cause him pain when she treats him but GRO-A wipes her tears away and tells her it is going to be OK.

GRO-A is a lesson to us all that you don't have to let haemophilia rule your life and that you can try and smile at everything even if you are sometimes feeling very sad inside. Sometimes it can very difficult to be a young person with haemophilia. Don't let it get you down!

Well done GRO-A

GRO-A

"The Factor Fusers" was the name that GRO-A came up with when he was asked to suggest a name for a group of boys with haemophilia GRO-A is four years old and is pictured receiving his sports voucher for his efforts from Baxter Hyland Immuno.

Urgently Seeking Willing Bodies...

Are you a nurse/doctor/physiotherapist who would like to come away on an adventure weekend for young people with haemophilia? If you are interested there will be weekends where we need you on May 12 - 14 and September 22 - 24 and September 1 - 4 in Scotland.

The weekends are great fun, you can get as wet as you like (or you can stay dry) and there is always time made available for socialising with the other adults. All expenses are paid.

Please give me a call or email me at the Society at the address/telephone number below:

Talia Barry on GRO-C
Email: talia@ GRO-C

The Oxford Haemophilia Centre go on a trip of a lifetime to Disney World

By Lara Oyesiku, Haemophilia Nurse, Churchill Hospital, Oxford

GRO-A

Fourteen children with haemophilia took an all expenses paid holiday of a lifetime to Disney World Orlando, made possible with £20,500 raised from a three year fund-raising campaign by staff, friends and families from the Oxford Group of the Haemophilia Society.

The boys ranging from nine to 17 years were accompanied on the trip by a specialist medical team It comprised Dr Helen Eagleton and Dr Randall Jones myself Clinical Nurse Specialist Lara Oyesiku, and tw secretaries from the Oxford Haemophilia Centre, Sharon Osborne and Catherine Rugg.

We were given concessions to the action-packed adventure parks including Universal Studios, Sea World, Magic Kingdom, Wet 'N' Wild and a spine chilling Alligator tour on air boats, to name but a few A barbecue organised for us on Coco Beach by the Haemophilia Chapter in Florida, was good fun! One o the boys said "It was the best adventure holiday I've ever had, making new friends on the trip was great a the roller coasters at Busch Gardens were just brillia

The trip was organised to give these children a drea come true experience, positively helping to develop a enhance their self esteem in a safe and caring environment, albeit action packed at times, where th medical needs could be met.

Thanks to the prophylactic treatment with recombina factor VIII/IX given daily the boys were able to participate fully on the holiday.

Although the majority of the boys could treat themselves, those unable to were assisted and encouraged to learn for themselves. One boy, who initially could not treat himself, learnt to do so, meaning less journeys and long waits at his local hospital! He came away from the trip with his newly learnt skill and fun filled memories.

Would you like to know how other families are living with haemophilia?

Has your son recently been diagnosed with haemophilia? A video has just been released called 'Every Day A Milestone' which can give you basic information about what it can be like to have a child with haemophilia. It talks the viewer through various scenarios such as 'the first bleed' and 'going on holiday' and shows children having treatment and doing sports. The video is designed for parents of newly diagnosed children and for teachers and any other people who would like some information about haemophilia. If you would like a copy, please call the society and we will send one out to you. The video is free to members and an administration charge of £10 will be charged for anyone else who would like a copy.

DO YOU WANT SOME ADVENTURE?

DO YOU WANT TO GET AWAY FROM YOUR PARENTS FOR A WEEKEND?

PARENTS, DO YOU WANT A CHILD-FREE WEEKEND? LOOK NO FURTHER:

We are running three adventure holidays this year for young people. The dates are as follows;

May 12 - 14 Ross-on-Wye PGL ages 8-13 years

September 1 - 4 Dunfield, Perth ages 8-16 years

September 22 - 24 Ross-on-Wye PGL ages 8-13 years

The weekends are great fun and involve getting wet and muddy but having lots of fun! There is a small cover charge for the holidays and for low income families the holiday is free. All holidays are also open to siblings if there is enough space, so just ask! Holidays are open to children from all over the UK and we can often assist with transport.

If you have a child or know of a child/young person with a bleeding disorder who would like to come on one of these weekends, please contact Talia Barry at the Society and she will send out an application form.