Witness Name: Katherine Victoria Burt
Statement No: WITN6392001
Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

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1998 ISSUE 2

THE BULLETIN

Magazine of the Haemophilia Society

Campaign Update

Moves to put the hepatitis C campaign back onto the Government's political agenda have had some success.

The Society's attempts to put the campaign into higher gear have been boosted by two developments: an all-party meeting of MPs in the House in April and a debate in the House of Lords at the beginning of June.

At the all-party meeting, which was well-attended by MPs, it was agreed that a delegation of MPs would ask to meet with Secretary of State for Health Frank Dobson, to impress upon him the urgency of the need for Government action. The MPs, led by Roger Godsiff, have now written to Mr Dobson and are awaiting a date for the meeting.

The debate in the House of Lords, called by Lord Alf Morris, was on the subject of haemophilia and hepatitis C. Among the speakers were eminent members of the medical profession, Lord Winston, Lord Alderdice and Lord McColl of Dulwich. All had points to make in favour of the campaign. Replying for the Government was Baroness Ramsay. Unfortunately, she had no news to give the House, but merely said that the Government was still considering the situation.

The Society will continue to put pressure on the Government. The next planned event will be a lobby of Parliament, which is due to take place on July 22. If you would like to take part in the lobby, please contact the Society's national office.

Dame Catherine Cookson, OBE, MA

It is with regret that the Society has heard of the sad death of its President, Dame Catherine Cookson. She has been a staunch supporter of the Society for many years and will be greatly missed.

A full tribute to Dame Catherine Cookson will appear in the next edition of The Bulletin.

Royal Visitor

Three year old GRO-A and his father, GRO-A chat with HRH the Duke of Kent at the official opening of the Osborne building at Leicester Royal Infirmary. GRO-A has severe haemophilia A and attends Leicester Haemophilia Comprehensive Care Centre which has moved to new accommodation within the Osborne building.


GRO-A

The Haemophilia Society

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

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Many thanks to:

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Editorial

By Bulletin Editor, Dr David Evans

On the agenda at the next AGM will be the subject of change to the constitution. We can choose to decide how we elect the Chairman and honorary officers, for how long the Trustees should serve, and how much time should pass before they are eligible for election as officers. We can reduce the number of Vice-Chairmen from two to one, and elect Trustees from outside. There are pros and cons for each of these options, but at present there appears to be little support from members for any great change. Although I am sure that the Society's organisation needs some fine tuning, many changes can be made without altering the constitution; but do write or 'phone in with your views, and make sure they are represented at the AGM.

In recent years, there has been a tendency for the Society to divide itself into different sub-groups, each with its own focus of interest. Let's hope that with new Trustees, a revised Constitution, and a new Chief Executive, the Society can turn over a new leaf so that we all work together for the benefit of all. Lastly, we have just heard that another Trustee, John Pepper is in the Royal Victoria Infirmary, Newcastle, with a heart attack. We send him and his family best wishes for a speedy recovery.

Publications available from the Society:

- Introduction to Haemophilia
- Haemophilia and Schools
- Haemophilia and Inhibitors
- Hepatitis C Factsheets
- Joint Care and Exercise
- Haemophilia Care in the UK
- Haemophilia Centres in the UK
- Passport – A guide to Haemophilia Centres Worldwide
- C Issues – a quarterly newsletter about Hepatitis C

Most of our publications are now available on-line via our web site. Click on the 'publications' icon on our home page.

We also have a variety of publications about haemophilia suitable for children and young people. Please request our comprehensive Publications List for fuller details or place an order via our web site.

Introducing Karin Pappenheim

Karin Pappenheim was appointed as Chief Executive of the Haemophilia Society earlier this year. Here the Bulletin tells you a little more about her history and how she sees the way ahead for the Society.

Karin Pappenheim has a strong background in public affairs and communications – previously having held posts as Director of the National Council for One Parent Families and Head of Publicity/Public Affairs for the UK Family Planning Association.

More recently, she has been acting as a consultant in public affairs and communications for a range of clients in both the private and not-for-profit sectors. She is very keen to get to grips with the problems faced by people with haemophilia.

Karin said: "Working with the Haemophilia Society will be a challenge, but one that I relish. I will be concentrating on the campaign for recompense for people with haemophilia infected with hepatitis C through their NHS treatment. It is a scandal that they have received no financial support from the Government."

She is also keen to address the issue of prescription by post code, where the availability of the best treatment depends on where you live rather than on clinical need.

She said: "The Society is already engaged in a dialogue with the Department of Health on the provision of haemophilia treatment. This is a very important issue for the haemophilia community, as it directly affects the quality of life. We will continue to press for the introduction of a fair commissioning system for health services that is of uniform high quality across the country."

Chris Hodgson, Chairman of the Haemophilia Society said: "We were delighted that we were able to persuade Karin to join us as Chief Executive. She brings with her a wealth of experience which is particularly appropriate for a campaigning charity such as ours."

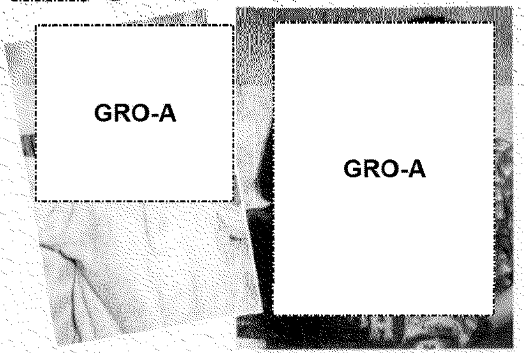
Section 64 Grant

The Society has been informed by the Department of Health that its Section 64 Grant for people with haemophilia and hepatitis C has been reduced by approximately £88,000 compared with last year. This is particularly disturbing at a time when the Government is apparently dragging its feet over a decision on whether to provide financial assistance to people with haemophilia infected with hepatitis C.

The Society has written to the Secretary of State for Health to protest at the reduction and urge Government to restore the funding. Karin Pappenheim, the Society's Chief Executive, said: "This is a blow for the Society and means that we will be extremely hard put to continue to provide the full range of services currently available for people with haemophilia. The previous Government recognised in our grant the additional pressure on our resources created by the need to respond to HIV and HCV infection. That need is no less urgent now than previously. In response we are launching a new fundraising drive. The fundraising efforts of all our members are now even more important than ever for the Society."

New Society Member

GRO-A was born at Leeds General Infirmary on GRO-A 1998. He weighed 8lb 8oz. Like his two brothers - GRO-A months - he has severe haemophilia. The photo shows the boys with their sister, GRO-A aged 13.



New Variant CJD - by Dr Steven Dealler

The Committee on the Safety of Medicines has decided that plasma for the production of blood products can now be sourced from the USA. The reason is the theoretical risk of new variant CJD from British blood. This article explains what new variant CJD is and some people may find it disturbing. If you have any queries or would like further information, please contact Joan at the national office.

Dr Steven Dealler is an authority on CJD. He is consultant microbiologist at Burnley General Hospital.

It's no good worrying about new variant CJD (nvCJD) without knowing whether it is actually a risk or not. At the moment the risk must be seen as minute; and the changes made by the Department of Health must have made the risks even smaller. However, it is possible that some people with haemophilia will have had injections of clotting factors made from the plasma of blood donors who were incubating these diseases, so it is worthwhile explaining the differences between these two disorders.

Creutzfeldt Jacob disease is a rare disorder of older adults. It has been known since the 1920s and is similar to a series of diseases in animals called transmissable spongiform encephalopathies (TSEs). These three long words mean that the disease can be spread from one animal to another, that it affects the brain, and makes it look like a sponge.

Bovine spongiform encephalopathy (BSE) is the best known, but the sheep disease, scrapie, has been around for longer, and is thought by many to have been the source of BSE in cattle and subsequently the cause of nvCJD in humans. A similar disease called kuru affected people in New Guinea who ate the brains of their conquered enemies. These TSEs share many features. The period between picking up the infection and showing the disease (the incubation period) is very long, and is often a large proportion of the animal's natural lifetime. They can be transmitted between animals and even between different species by inoculating tissue from one to the other. They are fatal. There is no cure. They seem to be involved with the build-up of a specific protein (called the prion protein) in the brain and other tissues.

The differences between nvCJD and sporadic CJD

	nvCJD	sporadic CJD
Laboratory tests		
Make-up of the prion protein	similar to BSE	different from BSE
Changes in mouse brain after injection	similar to BSE	different from BSE
Examination of tonsils of infected person	typical changes	not possible
Clinical features		
Age of onset	younger people (some under 20 yrs)	older people (usually 65 yrs or older)
Progress	long (years)	short (months)
Encephalogram (EEG) features	non-specific	specific

Different strains exist: they differ in the way they build up in different tissues. They seem to produce different symptoms in animals and patients and produce varying appearances in the laboratory, whether they are examined under the microscope or when the chemistry of the prion protein is analysed. The science is complex but it is a brave scientist who will not admit that BSE and nvCJD are closely related, whereas sporadic CJD is a different illness. The changes in the tonsils of people with nvCJD led to worries about blood transfusion. If the cells involved with immunity like those in the tonsils are affected, then blood could be a source of infection because these cells are also found in the blood.

The blood from people with sporadic CJD has always been a worry because experiments showed that blood could carry the disease to a small extent. However, the fact that the age of people showing the symptoms is high and the age of the people who give blood is generally low, suggested that these individuals would have donated blood early in the incubation period, or while they were not infective at all. This would not be true with nvCJD because the age of the cases is almost exactly the same as that of blood donors.

It has been calculated that about 1 in 20,000 people die of sporadic CJD and many of them would not be expected to have been infective when donating blood. This means that less than 1 in 20,000 blood donations would be from someone incubating the disease. When making clotting factors it would mean that infectivity in any one of these blood donors would be hugely diluted by the plasma made from non-infective donors. When this is done, it indicates that the risk from sporadic CJD to people with haemophilia must be minute. This is borne out by the fact that following-up recipients of blood donated by individuals who later succumbed to

turn to page 5

New Variant CJD – from page 4

sporadic CJD has not found anyone to have developed sporadic CJD.

The problem with nvCJD is different. We simply do not know how many people may be incubating it. A maximum of 80,000 has been suggested by one official group. Because of the age of blood donors, this could indicate that between 1 in 200 and 1 in 300 blood donors could be infectious and their plasma products may not be 100% safe, even after the dilution effect has been taken into account. Until we have some idea of the number of people who may be incubating the disease we cannot assume that a risk does not exist. The Department of Health has decided to act accordingly, by importing plasma from the USA where nvCJD is not known to be present and by recommending recombinant factor VIII.

With any new disease there is always the problem that at first it is difficult to know if the disease presents a major health risk or not. People with haemophilia have suffered repeatedly from inadequate action taken in the past, but this time it seems that the Haemophilia Centre Directors and the Department of Health are determined that, until the nvCJD risk is shown to be very low, the possibility of transmitting it through plasma-derived blood products will be eliminated.

Adventure Holiday - Craigower, Scotland.

Unfortunately, the holiday is not going ahead this year due to a poor response in 1997. The organisers are hoping to run it again in 1999. Contact GRO-D GRO-D at GRO-C GRO-C if you are interested.

Russian Visitors – Can you Help!!!

Two Russian boys, aged 16 years, are visiting the UK for two weeks around the end of September. We need families to look after them. We hope they can spend a week in the country and a week in the London area. So we need four families who can look after the boys for a week each.

Both boys have severe haemophilia A, speak a little English, are quite mature and can self infuse. This is a rare opportunity for them and we hope to ensure they have a good time. If you can help and would like more information please contact Joan or Julie at the Society.

Meet GRO-A

GRO-A

I am the GRO-A GRO-A for the Society and have been asked to write something about myself. I have severe haemophilia with the odd virus or two and am a social worker by profession.

I grew up in the Midlands, Gloucestershire and Somerset and have not really stopped moving since. I drifted into drugs work in Swansea where the staff seemed to find a volunteer with experience of putting needles in veins useful.

Thereafter, I moved around working here and there, ending up in a needle exchange in Berlin. I then decided I fancied a life of freedom, drink and not much work and so went to college to study social work. I even found a course in Hull that allowed me to study in Vienna which was excellent. I then got some work teaching English to immigrants from Yugoslavia at the end of the course. When that contract ran out I moved back to Britain and got a job working with homeless people in Brighton. A brief piece of research work in the same field and this post came up.

Alpha Therapeutic is now called Grifols UK Ltd

Alpha Therapeutic have recently changed their name to Grifols UK Ltd. The company would like to assure patients that the products and plasma sources will remain unchanged. The packaging and names of some of the products will change, and patients will be informed of this accordingly.

Hepatitis C Support Meetings

A personal report by GRO-A

The first two of the series of local evenings on hepatitis C took place recently in Newcastle and Lincoln. The first was poorly attended but the second was overflowing with people. In Newcastle the speaker was a Professor of Hepatology at a major transplant centre and at the second a consultant haematologist who had taken part in research on interferon treatment for haemophiliacs. The meetings were organised by the local groups in the two towns with a bit of help from me down in London, when needed.

It is a strange experience to help organise a meeting and worry that it will run smoothly, that the slide projector insists on pointing at the floor rather than the wall, that the food turns up on time and then to realise that it is about my illnesses as well. Why do the lights need to be turned off or the food arrive at the just the moment when the speaker starts to talk about drinking and hepatitis C when I probably should be paying most attention. On the other hand, since advice to enjoy a drink and not worry about it is rare, maybe it is better that my mind is somewhere else at the time. However it is not a good feeling to hear about the history of contaminants in blood products and then have to go back to a hotel room and put some more into your arm.

It is also interesting to visit the haemophilia centres and to be treated like a visiting professional rather than a waiting patient. Sadly the rooms behind the scenes are very much what you would expect. They are either the same as the other clinic rooms, boring laboratories with huge machines or American style walk-in fridges of clotting gunk and usually one room with staff grabbing a coffee between clinics. It will be even stranger at any of the half a dozen centres I used to go to. I can also get rid of my used gear rather than carry it home. I tend to pack light, so losing half a dozen empty bottles, assorted spikes and syringes before going home rather than have them rattle around in a plastic bag in my rucksack is very useful. I still feel embarrassed dropping bloody syringes on the floor of the train when I am wrestling a book out of my small rucksack, although it usually gets me a seat all to myself.

One aspect of the job that has surprised me so far is the number of people who assume I do not have haemophilia or hepatitis C because I am an employee of the Society. I would like to think this is because of the professional air that I radiate out to all. However, having been continuously mistaken by visitors for a client at the day centre for homeless people I used to work at, I have a feeling it is something else. I hope that if any of you have come to the hepatitis support evenings they have proved informative and useful. If any of you can suggest ways of improving them please write and let me know and I will ensure that when I finish in September I can outline some ways the society can improve.

Hepatitis Support Evenings

The Society's hepatitis C worker Lucy McGrath writes:

So far, we have had meetings in Newcastle, Hull, Lincoln, Bournemouth, Cornwall, Southampton and Liverpool. All had a very different feel. Some were packed out, and others were rather empty. We have been lucky enough to have a wide range of speakers and at the meetings there were lots of questions and informal discussions covering: latest treatments, feelings about living with HCV, co-infection with HIV, access to liver specialists, issues with mortgages, and lifestyle changes. There are four further meetings planned, as below. Please ring Lucy or GRO-D for details.

Personally I have found the meetings very useful. It has certainly helped me to meet more people who are living and dealing with hepatitis C and to hear the different concerns. I hope to use what I've learned to inform my ongoing work. Thank you to all those who have attended either as a speaker or a participant.

Thank you too to all the local group representatives (or others) who have been involved in organising from the other end!

Cardiff: 14th July. Northampton, 30th July. Bristol and Manchester: ***dates to be finalised.***

WANTED!

Parents of young people with hepatitis C. Can you help? We would be very interested to hear from any parent of a young person with hepatitis C who would be interested in taking part in a project to produce three booklets about hepatitis C, one for 12-16 year-olds who are infected, one for 16-21 year-olds, and one for parents. This would involve just talking over the telephone, or possibly meeting together in a group. Contact either Lucy McGrath or Pete Brown for details.

Birmingham Children's Hospital

Birmingham Children's Hospital, including the Haemophilia Unit, has moved to Steelhouse Lane, Birmingham, B4 6NH. The new hospital phone number is 0121 333 9999 and the new Haemophilia Unit number is 0121 333 9150.

Recombinant Factor IX

A recombinant factor IX product is due to be launched this summer by Baxter. This is good news for people with haemophilia B, but there are some doubts whether the Government will provide funding for children to use it as they do for recombinant factor VIII.

The Society is monitoring the situation and will report developments in the next Bulletin.

Video Delay

The Society would like to express sincere apologies for the long delay in the production of the video *Every Day A Milestone*. This has been due to a difference of opinion between the Society and the videos' producer that we regret could not be amicably resolved. We would like to apologise to the parents and children who took part in the video and to the members who expressed a need for a video about bringing up children with haemophilia. We hope the problem will be rectified in the not too distant future and will keep you informed.

London Marathon 1998

[redacted]

Three runners took part in the London Marathon to raise money for the Society - [redacted] [redacted] and [redacted] [redacted] All completed the course successfully, with Richard crossing the line in 3 hours 48 minutes, Philip taking 4 hours and 18 minutes and Joe coming in on 4 hours 30 minutes. Funds are still coming in from their run, but to date the total is a magnificent £1,000. A big thank you to all the runners and everyone who sponsored them in the Marathon.

Mild and Moderate Haemophilia

We have received a number of enquiries from parents of children with mild and moderate haemophilia who would like to be put in touch with other parents of mildly or moderately affected children. This may include the parents of recently diagnosed children who want to know from others what kind of issues are likely to be faced. If you are able to help, please call [redacted]

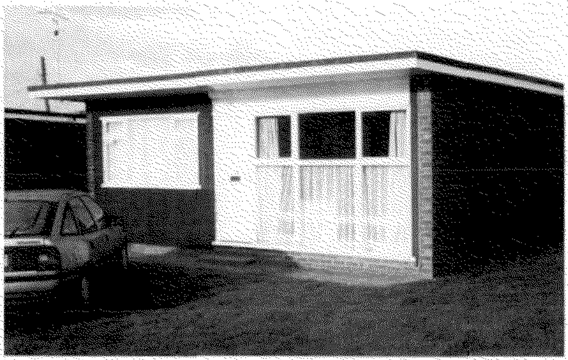
OBITUARY

[redacted]. We are sad to report the sudden death on January 18, 1998 of [redacted] [redacted] aged 32. [redacted] had a tremendous zest for life, despite his many health problems. He visited America seven times, enjoying a number of activities there. Among these were jet skiing off Malibu beach, flying over the Grand Canyon in a helicopter and snorkelling in Florida with the manatee. [redacted] was educated at [redacted] school in Carlisle and [redacted] in Hampshire. He later formed his own company, [redacted], which he ran very successfully until ill health forced him to retire. [redacted]s survived by his parents [redacted] [redacted] and niece [redacted] is deeply missed by all those who knew and loved him.

Haemophilia Society Holiday Bungalow at Hemsby in Norfolk

The holiday bungalow at Hemsby in Norfolk is now available for use by members. It has recently been redecorated, inside and out. New bed linen, duvets, pillow cases, bed settee, armchairs, colour TV, fridge and vacuum cleaner have also been provided.

The bungalow has a full size entrance door and only two shallow steps. The living area and kitchen are spacious and fully equipped. It sleeps six, in two bedrooms - one with a double bed, the other with two singles as well as a full-sized bed-settee in the living area. All rooms have oil filled electric radiators. There is no charge for electricity. Keys, bed linen and tea towels are collected from reception on arrival - so all you need to take are towels and food. For details, contact Keith Colthorpe, GRO-C Essex GRO-C Telephone GRO-C or mobile GRO-C



Child of Achievement Award

GRO-A

One of the prestigious Child of Achievement Awards has been won by GRO-A GRO-A was presented with the award at the Hilton Hotel in February by John and Norma Major in a ceremony which was watched by a host of celebrities, including children's TV presenters and stars of TV. He was one of only 150 children chosen from 30,000 nominations for the awards, and was selected for his positive attitude towards life and for helping others.

GRO-A has severe haemophilia A. He is not treated for his haemophilia prophylactically, instead he makes his way to school on his crutches when he has a bleed and carries on regardless. He helps the nursery children at the school with their reading during his lunch times and also helps older children who are having problems with their reading.

While he can't do so much on the sporting field, he certainly shines when it comes to swimming. He has won life-saving awards both in and out of the water and is vice captain of his school's life-saving team, which was placed first GRO-A and seventh in the British Isles last year.

SERVICE COMMISSIONING

The Government is looking into setting up new arrangements on the commissioning of specialist health care services, including haemophilia. The new arrangements, which will come into force from April 1999, will involve the setting up of regional specialised commissioning groups.

The Society's response to the Government's consultation document has been to highlight the problems of treatment by postcode and to point out that the level and quality of care for haemophilia varies in different areas of the country. Karin Pappenheim said: "We are hoping that the consultation will provide an opportunity to iron out inequity of treatment and ensure that all patients receive the same high quality of care. The Government has said that it wants to put patients needs and wishes at the top of its agenda, which includes consulting with patient groups. We would like to see people with haemophilia involved in the commissioning of haemophilia services and represented on the commissioning groups and that is part of the thrust of our response to the consultation document."

LIVING WILLS

by [redacted] HIV Worker

Several members have recently asked me about the whole subject of "Living Wills." These are specific instructions to doctors about what treatments or medical procedures people do or do not want to be given if they are no longer able to make those decisions themselves (e.g. if they are in a coma, or suffering severe dementia).

Although their use is advocated by a number of groups, including the Voluntary Euthanasia Society, they are not a way of enforcing euthanasia. A properly prepared Living Will is now recognised as a legal document. As such, it cannot order medical staff to do anything illegal.

The use of Living Wills has been recommended by the British Medical Association, the Law Commission, and Parliament. Although no specific legislation currently exists, it is widely accepted by legal and professional bodies that a Living Will, made by an adult of sound mind, in full awareness of the possible consequences of the choices outlined in the will, and making the decision without coercion or under duress, is a legally enforceable document. In other words, if you set out specific instructions about stopping (or starting) certain treatments if you become critically ill, the doctor must follow those instructions, even if he disagrees with your choice. It ensures that you retain control over your treatment, even when unconscious or incapacitated, a principle central in all British Law. The main reason for having such a will is to ensure that your doctors and family know what your wishes are if you become seriously ill and are no longer able to make decisions about what you want to happen to you. For that reason, any Living Will should be made in consultation with your Consultant, your family, and maybe other relevant professionals, such as your GP or other Haemophilia Centre staff.

Also, to ensure that everyone is able to follow your will, you should ensure your consultant, GP, family and any other relevant individuals or organisations have a copy of it. You can update it as often as you wish, but do make sure any old copies are destroyed, and new ones distributed to all parties as soon as possible.

In addition, you can appoint someone as a "Health Care Proxy". That is a family member or friend whom you trust is appointed by you to make decisions on your behalf if you are no longer able to. Although such a person does not have an automatic legal right to make decisions on your behalf, if the appointment of a Proxy is done in discussion with your doctor, it will usually be accepted.

If you want to set up a Living Will, the best thing to do is to discuss the idea with your family and your consultant first. The best way to write a Living Will is through a prepared form - this means you do not need the services of a solicit[redacted]don't want one. Forms are available fro[redacted] the national office or from the Terrence Higgins Trust [redacted] telephone [redacted] or over the Internet from the Voluntary Euthanasia Society at http://www.netlink.co.uk/users/vess/vh.html. Alternatively, if you want more information, or to discuss the issue of Living Wills in more detail, please contact Steve at the Society Office.

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Treatments and Alternatives Conference

The National Birchgrove Group, in co-operation with Macfarlane Trust and the Haemophilia Society has organised a National Conference on HIV Therapy, both conventional and complementary to be held at the Stakis Hotel in Bath from July 24th-26th. There will be sessions on the latest developments in combination therapy and other treatments, details on HCV/HIV co-infection issues, and the use of alternative and complementary medicine. In addition there will be plenty of time to relax and socialise. This is to be the first of a series of conferences organised by all three organisations for people affected by Haemophilia and HIV. Watch this space for details of more events in the coming months.

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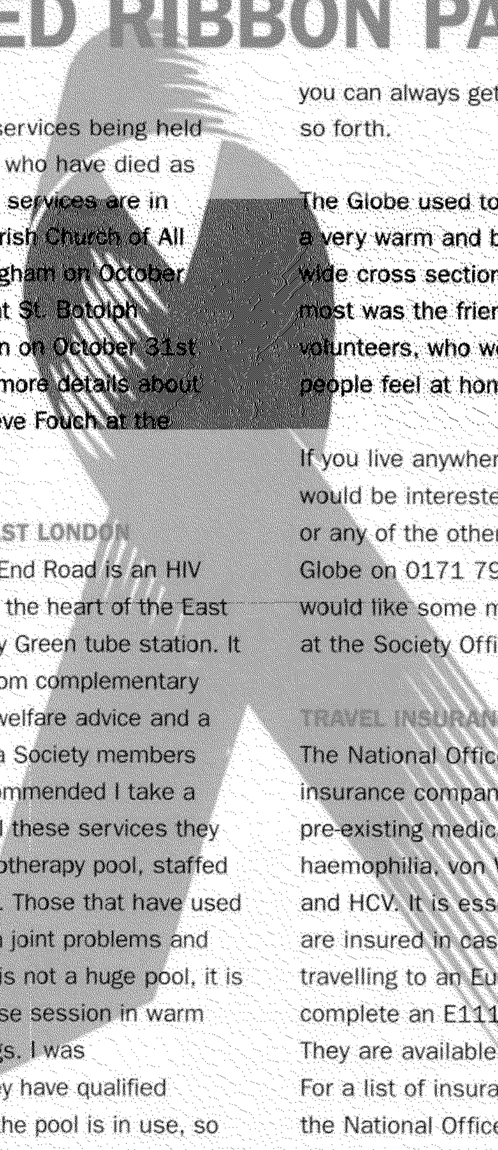


REMEMBRANCE SERVICES

There are two remembrance services being held this year, in memory of those who have died as a result of HIV infection. Both services are in October. The first is at the Parish Church of All Saints in Kings Heath, Birmingham on October 10th at 3pm. The second is at St. Botolph without Bishopsgate in London on October 31st also at 3pm. If you want any more details about either service, please call Steve Fouch at the national office.

HYDROTHERAPY POOL IN EAST LONDON

The Globe Centre on the Mile End Road is an HIV drop in and support service in the heart of the East End of London, just by Stepney Green tube station. It offers a number of services from complementary therapies and counselling, to welfare advice and a GP service. Some Haemophilia Society members have used the centre and recommended I take a look, because in addition to all these services they have a gymnasium and a hydrotherapy pool, staffed with qualified physiotherapists. Those that have used the pool say it has helped with joint problems and stress immensely. Although it is not a huge pool, it is a good size for a gentle exercise session in warm water and relaxing surroundings. I was particularly impressed that they have qualified therapists on-call at all times the pool is in use, so you can always get help and advice on exercises and so forth.

The Globe used to be a public baths, and still has a very warm and bright atmosphere. It is used by a wide cross section of people, and what struck me most was the friendly manner of the staff and volunteers, who went out of their way to make people feel at home and at ease.

If you live anywhere in London, or nearby, and you would be interested in using the hydrotherapy pool, or any of the other services on offer, just call the Globe on 0171 791 2855. Alternatively, if you would like some more information, please call me at the Society Office. *Steve Fouch, HIV Worker*

TRAVEL INSURANCE

The National Office has compiled a list of insurance companies which cover members with pre-existing medical conditions, including haemophilia, von Willebrands Disease, HIV and HCV. It is essential that when you travel you are insured in case of an emergency. If you are travelling to an European Union country, always complete an E111 form before you travel. They are available from the Post Office. For a list of insurance companies contact Tom at the National Office.

Society Council Meeting

The Society held its first Council meeting of the year this April at St Thomas' Hospital in London. The meeting was attended by about 30 representatives from the Society's local groups, national office and officers. It was chaired by the Society's Chairman, Chris Hodgson, who took the opportunity to introduce the new Chief Executive, Karin Pappenheim to all those present. Chris also updated the meeting on developments in the recombinant and hepatitis C campaigns, and informed them of the Government's decision to cut the Society's Section 64 Grant (see story on page 3)

Karin Pappenheim gave a brief talk on her role within the Society and said that among her priorities were the provision of the safest possible treatments for haemophilia and an added impetus to the hepatitis C campaign. She added that her campaigning background with other charities would help her in this and that it was a challenge she relished.

There were three other speakers at the meeting: GRO-A on the hepatitis C campaign; Dr David Evans on recombinant factor VIII and Mark Weaving on the Society's relationship with the media. All of the talks were well received, with a lively question and answer session before the meeting ended. The next Council meeting is scheduled for 31 October in London to coincide with the service of Remembrance.

The Parent Support Network – Two Years On

The Parent Support Network of The Haemophilia Society was launched two years ago. We thought it was time to ask some people who have used the service, what they thought of it.

[redacted] lives in north London and used the network shortly after her son, [redacted] was diagnosed. *"I found the network very useful and helpful because there was no history of haemophilia in the family at all and I didn't know what to expect. To talk to another parent who had a realistic view was very important. I think the service is essential for new parents."*

[redacted] lives in Cornwall with her three daughters. All have von Willebrand's disease. *"I always knew there was something wrong from a young age, but my diagnosis only came later in life. This was a relief and I phoned another parent and found out I wasn't alone with these problems. It's good to know that I can talk and know that my daughters can have access to information that I couldn't get at their age."*

[redacted] lives in [redacted] She used the network soon after [redacted] was diagnosed. *"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. I would definitely recommend the network."*

Next month, we plan to look at the Network in more detail.

Superstars Fundraising Event

[redacted]

This was organised by Mrs [redacted], with the encouragement of Society member, [redacted] who has two sons with haemophilia.

Over a number of weeks 12 contestants competed in 10 different sporting activities and at the end of the competition a presentation evening was arranged with the proceeds going to the Society. A total of £420 was raised. A big thank you to all those who took part in the event and helped to make it a success.

Charity Fun Casino Evening

A Charity Casino evening organised by [redacted] [redacted] [redacted] and Hepworth Minerals and Chemicals Ltd has successfully raised more than £1,500 for the Society. The event, which was held in March at Whiston in Staffordshire, was a great night for all who attended, including Melissa Watson from the Society's national office.

Thanks go out to all those who helped to organise the event and to those who put their money on the gambling tables. If you have any ideas for a fundraising event, please call Melissa at the Society and she will be pleased to help.

[redacted]

[redacted] *and The Buccaneers*

CONTACT LIST FOR GROUPS

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

ENGLAND
CAMBRIDGESHIRE & DISTRICT • CORNWALL • HAMPSHIRE • 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

NORTHERN IRELAND

SPECIAL INTEREST
BIRCHGROVE GROUP • MANOR HOUSE GROUP

Services available from the Society

The Haemophilia Society works to help people with haemophilia and related bleeding disorders from its national office in central London and also via local groups.

Services:

- 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
- Centeon Call pager service
- 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
- Von Willebrands Support Network

For more information about any of the above services, please contact the National Office. Full details of our services are also available via our web site. **www.haemophilia-soc.demon.co.uk**

The Family Pages

The Family Pages are compiled by GRO-D Children and Families Worker GRO-D would like to hear from any parent, child or teenager who has any articles or ideas for inclusion on these pages.

Bristol Family Day

The Newcastle Family Day planned for 13th June has been cancelled as there was not the usual level of interest. Instead, some aspects of the day are to be incorporated into the Durham Family Weekend to be held 18-19th September. The weekend is run jointly by Newcastle Haemophilia Centre and the Northern Group of the Haemophilia Society and is a very popular annual event.

Bristol Family Day is due to take place on 3rd October. The Day will take place at the Grand Hotel, in the heart of Bristol. Built in the Victorian era, this hotel combines great splendour with its newly refurbished and excellent conference facilities. There is ample parking space next to the hotel. The day will include a presentation by Dr Peter Collins from Cardiff Comprehensive Care Centre and a series of workshops, including the topics of women who are carriers (women with low clotting levels, choices, pre-natal diagnosis etc), Sports and Activities, Schools, Siblings, von Willebrand's, home treatment and Fathers.

Continued on next page.

Bristol Family Day Saturday 3rd October 1998

For a programme and registration details please contact Pete or Julie on 0171 380 0600.

There will also be a drop-in surgery for advice on claiming Disability Living Allowance. Our family days provide a welcome opportunity for parents to hear about treatment developments and share experiences with other parents. As usual, there will be plenty on offer for the children including a creche for very young children and various activities arranged for older children and teenagers. These will probably include a visit to *The Exploratory* (a hands-on science centre), a visit up the River Avon to see the old steam ship, *SS Great Britain*, and some lively activities such as lazer-quest and ten pin bowling.

If you are interested in attending the day, please contact Julie at the national office. Julie will take your details and send you a programme and application form. The cost of the day will be £6 per adult. There is no charge for children. If you haven't been to one of our Family Days before and would like to know more, ring Pete at the national office who will be pleased to help with any queries.

[redacted] writes about his son [redacted]'s extraordinary sporting achievements

[redacted]

(9½ years)
Haemophilia B (Factor level 3%)

[redacted]ain sporting achievement is to have gained his black belt in the martial art of 'TAISUDO' (freestyle Korean Karate and kick boxing).

After discussion with his consultant, Dr Peter Jones, [redacted] took up the martial art of Taisudo in December 1994 when he was only 6 years old. Since that date he has progressed through his grades and is now a 1st Dan Black Belt.

[redacted] initially took up Taisudo as a means of building up his muscles around the major joints, which in turn would help to prevent bleeds and he has not looked back since. He is only the third person in the world who is known to have haemophilia that has achieved this ultimate level in any of the martial arts. [redacted]

[redacted]

[redacted] also excels in other sports, playing both football and cricket for his school team. He has also represented the school in athletics and is a keen swimmer who enjoys mountain biking and roller hockey. His sporting ambition in life is to be a professional ice hockey player and he constantly asks that if his haemophilia is cured can he play ice hockey. He is, in fact, a tremendous, highly competitive sportsman who refuses to allow his disability to get in the way of enjoying himself.

[redacted]

None of his activities have led to any serious bleeds, although he has required some treatment which he would not normally have needed.

When [redacted] found out that he had been successful in being selected to receive the [redacted]or Achievement in Sport he asked if his presentation could be made at an Ice Hockey game (both [redacted] and his father are season ticket holders for the Newcastle Cobras and members of the supporters club).

On Saturday 17th January 1998 [redacted] was officially presented with the Award at the conclusion of the Cobras v Cardiff Devils match by one of his favourite players, the Newcastle net-minder Stephen Foster (known as Fossy to his fans).

Living with GRO-A

GRO-A writes about her experiences living with her son who has severe haemophilia A.

GRO-A was diagnosed as having haemophilia when he was 6 months old. We were aware that it was in the family but even so it was still a shock to us all. One of the main decisions the family took was to insert a portacath and train to give Iwan his treatment. This stage was very difficult but we pulled through. He developed inhibitors which complicated things a bit. As time went by, with all the worries, progression was clearly to be seen. The inhibitor level disappeared and the amount of treatment was reduced. Iwan started school and is doing well. He leads a normal life and is given much care and support within the school environment.

The Centre at Ysbyty Gwynedd, Bangor has been a tower of strength throughout and has always supported us and encouraged us to see the positive side of haemophilia.

GRO-A

Here is a picture of GRO-A when he started at school.

The Centre's team are on call for us at all times and for this I will always be grateful. Alder Hey Children's Hospital have also played a vital part in his treatment and for this I am also grateful.

My family and friends and GRO-A two little cousins, who also have haemophilia, have been supportive and thank them all tremendously.

GRO-A is a very happy child and he himself has always been positive about his condition and seems to believe that he is no different from anyone else. He took to his treatment without any resentment and this has helped me enormously.

More Pen Friends Wanted

The Haemophilia Society is twinned with the Russian Association of Persons with Haemophilia. We have already set up some pen friend contacts between children in the UK and Moscow and now the Russian Association has found some children in St Petersburg who also want pen friends.

GRO-A aged 11 GRO-A is interested in humanitarian sciences. She has von Willebrand's disease and she would like to write to other children in English.

GRO-A aged 11 GRO-A is interested in computers. He has haemophilia A and wants to write in English.

GRO-A aged 9 GRO-A is interested in computers and music. He has von Willebrand's disease and wants to write in English.

GRO-A aged 16 GRO-A is interested in computers and cars. He has haemophilia A. He can write good English.

GRO-A aged 11 GRO-A has haemophilia A. His English needs working on so please write carefully.

GRO-A aged 12 GRO-A has haemophilia A. He wants to write in English.

If you want to write to any of the children please contact Pete at the national office.

FAMILY EXCHANGES - SPAIN AND FRANCE

GRO-A aged 13, lives in GRO-A France (a little village about 35 kms from Paris). GRO-A would like to stay with a British family for a week or two in June/July or February/March. In return, his parents would like a child from Britain to stay with them in August or April. GRO-A has severe haemophilia A and can self-infuse.

GRO-A aged 16, who is a carrier of haemophilia, would like to stay in Britain for 2 weeks in the summer as would GRO-A GRO-A aged 14, with severe haemophilia A. GRO-A can self infuse. Both live near Barcelona in Spain and would like to improve their English. In return, their families would like to arrange for children/ teenagers to go over at a later date.

For more details, please contact Pete a.s.a.p. on GRO-C

Adventure Weekend Report

Our first Adventure Weekend took place on 17-19th April at Marchants Hill, near Hindhead in Surrey. Fifteen children and teenagers between the ages of 8-15 took part in the weekend, which included a mixture of indoor and outdoor activities.

Indoor activities involved work on computers and included producing and printing a newspaper page, surfing the world wide web and a toy car race programmed by a computer. Outdoor activities included abseiling, archery and the ever-popular Go-Karts! The weekend was exciting for the children and teenagers (and a restful break for the parents!). A couple of younger children had a go at self-infusion under the guidance of nurses.

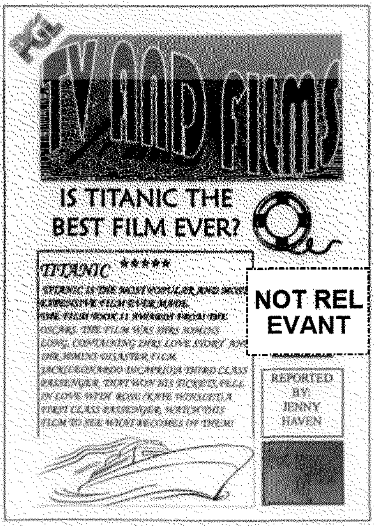
Staff at the centre were surprised at how active our group were and now have a more realistic idea that haemophilia doesn't usually mean that children cannot enjoy lively activities.

Pete would like to thank Sian and Louise, our haemophilia nurses; David, the physiotherapist and Stuart, who helped supervise the computer activities. John, our group leader at the PGL Holiday Centre also helped to make the weekend a great success. **Our second weekend will be at Boreatton Park, near Shrewsbury on 25th-27th September. Telephone Pete Brown at the National Office for details and a booking form.**

GRO-A

GRO-A

GRO-A



TV AND FILMS

IS TITANIC THE BEST FILM EVER?

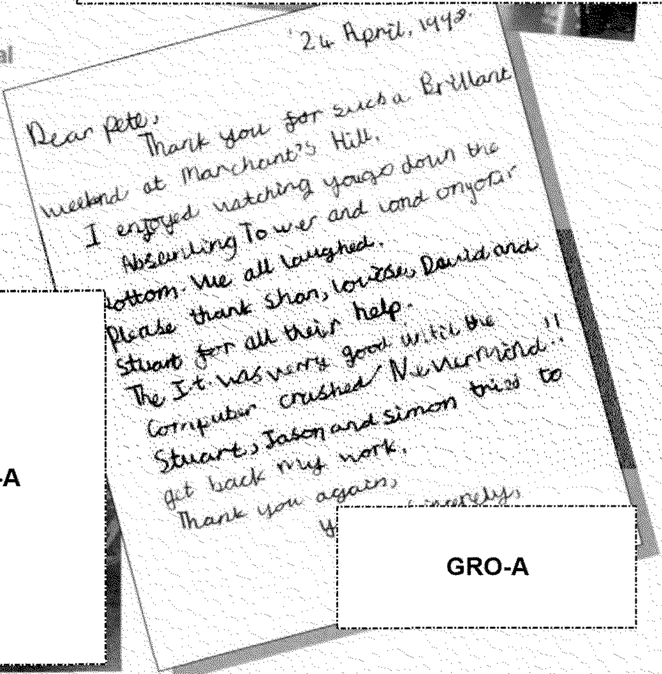
TITANIC *****

TITANIC IS THE MOST POPULAR AND MOST EXPENSIVE FILM EVER MADE. THE FILM TOOK 11 AWARDS FROM THE OSCARS. THE FILM WAS THIS YOUNG'S LONG, CONTAINING THIS LOVE STORY AND THE WOMEN'S DISASTER FILM. JACK(LEONARDO DICAPRIO)A THIRD CLASS PASSENGER, THAT WON HIS TICKETS, FELL IN LOVE WITH ROSE (KATE WINSLET) A FIRST CLASS PASSENGER. WATCH THIS FILM TO SEE WHAT BECOMES OF THEM!

REPORTED BY: JENNY HAVEN

NOT REL
EVANT

GRO-A



24 April, 1998.

Dear Pete,
Thank you for such a Brillant weekend at Marchant's Hill.
I enjoyed watching you go down the Abseiling Tower and land on your bottom. We all laughed.
Please thank Sian, Louise, David and Stuart for all their help.
The I.t. was very good until the Computer crushed Nevermind!!
Stuart, Jason and Simon tried to get back my work.
Thank you again,
Yours sincerely,

GRO-A

We haven't had room for competitions and jokes in this packed edition of the Bulletin, but look out for them in the next edition.

Report on the WFH Conference 1998

Society Chief Executive Karin Pappenheim writes: The World Federation bi-annual conference in Holland was attended by three UK Society staff members - Karin Pappenheim, Joan Doyle and GRO-A a member of the Northern Group, GRO-D and the Society's Chairman, Chris Hodgson.

The packed programme included information on the latest medical developments, nursing and psycho-social issues as well as the opportunity to meet representatives from haemophilia societies from around the world. Presentations took place simultaneously in ten different conference halls throughout each day. The delegates managed to attend around 70 of the sessions between them - showing the value of having a large delegation in attendance.

The delegation also took the opportunity to meet up with other haemophilia societies and exchange views and information on issues such as hepatitis C and the fight for financial recompense, HIV work, women and bleeding disorder projects. Among those present were representatives from our 'twins' in Russia and the opportunity was taken to talk through developments in the twinning process. The information that came out of these meetings was extremely valuable for the UK Society. It gave a strong sense of world-wide haemophilia issues, and the fact that 80% of people with haemophilia world-wide receive no treatment shows the importance of international work.

There were, however, some notable gaps in the programme - HIV/HCV co-infection treatment issues and new variant CJD on which very little was presented. These are of great importance in the UK and will doubtless become more high profile in other countries.

Another area that received little time was women and bleeding disorders. However, the presentations made on these topics implied that there are a large number of women with undiagnosed bleeding disorders worldwide, which suggests that this could become a more mainstream issue, and is one we are keen to address in the UK.

Haemophilia Society Chairman,Chris Hodgson writes: As I have haemophilia, I was most interested in attending the psychosocial programme. From the first session I realised that this was an aspect of haemophilia care that has changed for the better. Workers now listen to the patients and help them to come to terms with the feelings associated with living with haemophilia and to help them to deal with worry, guilt, anger and desperation.

However, much of the improved care has hardly touched the undeveloped nations and it was overwhelming to see so many young people from around the world with crippling joint damage because so little treatment was available.

I attended a talk by BPL on the impact of nvCJD on their business. They will be using American plasma for all concentrates from September of this year. In the meantime they are completely sterilising their plant and replacing many of the seals and components used in the process. It is perhaps comforting to know there has been only one new case of nvCJD in the UK this year.

On a more positive note, I learned from BPL's Export Manager to the East that they have just received a licence to export intermediate purity factor to the Moscow Children's Hospital and to assist with our twinning with Russia he will carry in as much factor VIII as he can by hand to supply the children's camp of the Russian Haemophilia Society in September.

I was proud to represent the UK at the General Assembly of the World Federation. The UK Society is held in high esteem by many countries for the services we are able to offer our members. I feel we have to work hard to continue to deserve that respect.

I found my first conference a terrific experience and look forward to the next conference in Montreal in the year 2000. Finally, I would like to thank Karin and our delegation for their enthusiasm and hard work.