Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

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THE BULLETIN

Magazine for the Haemophilia Society

1998 ISSUE 3

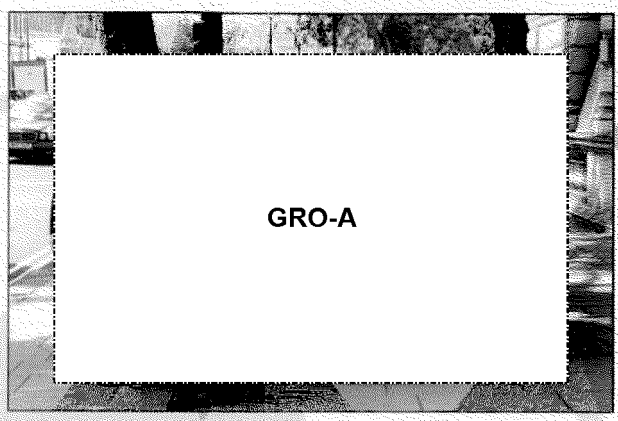
NO GOVERNMENT HELP FOR PEOPLE WITH HAEMOPHILIA AND HEPATITIS C

In a shock letter to Society Chairman Chris Hodgson at the end of July, Health Secretary Frank Dobson announced that the Government will not be providing financial help to people with haemophilia and hepatitis C.

The news was met with anger and disbelief. Society Chief Executive Karin Pappenheim said: "The Government's arguments are very thin, and don't take fully into account the circumstances of people with haemophilia and hepatitis C. We have written to Mr Dobson, telling him and requesting a further meeting.

"It was particularly upsetting that he has offered nothing - not even a hardship fund for people in dire need. All that has been offered is funding towards a young people's project. While this will be useful, it must surely leave older people with haemophilia and hepatitis C feeling that the Government thinks that they are a lost cause.

"We will continue to fight this campaign. We have a just cause and many strong supporters. Most importantly, people are suffering and dying, they need help and we will not stop until they receive it."



The delegation preparing to hand in the petition to 10 Downing Street during the day of action in July

Mr Dobson's announcement came just over a week after the Society and Manor House Group had held a day of action at Westminster. The event consisted of a press conference followed by the handing over of a petition and 90 white lilies, symbolising those who have died, to 10 Downing Street in the morning and a mass lobby of Parliament in the afternoon. •

New Vice Presidents

The Society is delighted that Lord Alf Morris of Manchester and Dr Peter Jones, director of the Newcastle comprehensive care centre, have agreed to become vice presidents.

Both have made many distinguished contributions to the haemophilia world within their own sphere. Lord Morris, as an outstanding Parliamentarian and more recently as a member of the House of Lords, has been one of the Society's most staunch supporters in the HIV campaign and latterly has been instrumental in the campaign for recompense for people with haemophilia and hepatitis C.

Dr Peter Jones has been centre director of the Newcastle Haemophilia Centre since the early 1970s. He is the author of the book 'Living with Haemophilia' which is currently in its fourth edition, with a fifth planned for the millennium. The book has been translated into seven languages to date. He is also a member of the executive committee of the World Federation of Haemophilia and is chairman of its strategic planning and fundraising committees. He has three children, one of whom is a surgeon, and five grandchildren.

They take over from retiring vice presidents Dr Rosemary Biggs, who stands down this year, and Dr JF Wilkinson who, sadly, died recently (see obituary on page 11). Both have served many years in office and they deserve grateful thanks for their commitment and dedication. •

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The Haemophilia Society

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

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Chairman: Chris Hodgson

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Many thanks to:

Grifols • Bayer • Baxter Healthcare • Centeon • Ipsen

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

Northern Ireland Group

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.org.uk

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CHIEF EXECUTIVE'S COLUMN

As I near the six months mark since joining the Society I reflect on how quickly that time has flown by. It has been a steep learning curve, and I still have many more people to meet and places to visit before my induction into the field of haemophilia is complete. Of course, work in an organisation such as ours never stands still and to borrow a phrase from the newly appointed Opposition spokeswoman on health, Ann Widdecombe, I have had to 'get stuck in' straight away to many important issues.

Not least among these is the campaign for financial assistance for those infected with hepatitis C, which culminated in our Lobby of Parliament on 22 July. A tremendous amount of work went into organising the event and the sustained lobbying efforts during the months before it. This involved not only staff and volunteers at the national office, but Trustees and members of our local groups and the Manor House special interest group for those infected with hepatitis C. Literally hundreds of Peers and MPs were written to and briefed, and we won widespread cross-party support for our campaign.

This makes the response from Government all the more disappointing. But we know the decision was not taken by the Health Secretary Frank Dobson alone. The Cabinet and Prime Minister were consulted as well. Hence, we know that in terms of taking our case to the highest level we could not have done more. Clearly, the Society cannot accept this decision as fair or just. But having now been turned down by both a Conservative and Labour Government, the Board will be reviewing in the autumn the future direction of the campaign.

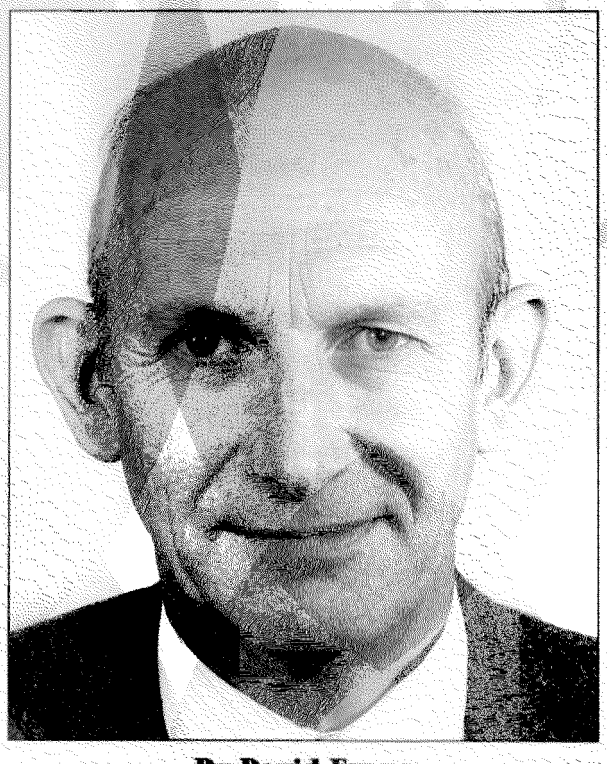
Karin Pappenheim

Meanwhile there are other pressing concerns on which we must be active. The battle for equal access to best quality, safest treatment goes on. Having won the right to recombinant factor VIII for under 16s and new patients, we want to see this extended to adults. And with the impending launch of recombinant factor IX, the question of costs and funding for this will be with us soon. As recent press and media coverage shows (see page 10) the safety of our blood supply and products continues to be a major public health concern. The Society still has much campaigning to do to achieve our mission of securing the best possible treatment and care for people with bleeding disorders.

Editorial by Bulletin editor Dr David Evans

The campaign for financial aid for people with hepatitis C has failed to touch the hearts of two Governments. The Society cannot accept this as a right or just decision by Government, but justice on this issue may finally be won in the courts. However, our campaign also highlighted the need for better services for hepatitis treatment and management, so we must do our utmost to ensure that proper medical care is available throughout the country. For this we shall need to join forces with other charities interested in liver disease.

As has already been reported, the income of the Haemophilia Society has fallen substantially, so economies are necessary. We hope to be able to continue to provide a full range of services from the office in Chesterfield House, but we have had to reduce the cost of the Bulletin. This edition has had to cut down the use of colour. We have managed to maintain the same number of pages, but the pictures inside are now black and white. We shall have to see how things go.



Dr David Evans

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ANTE-NATAL TESTS - BY GRO-A

GRO-A has a girl and three boys with haemophilia. There was a picture of her children in the last Bulletin. She describes the problems she had with the pregnancies and afterwards.

I have four children, GRO-A 14) and GRO-A (11) to my first husband and GRO-A (22 months) and GRO-A (4 months) to my second husband. I am a pharmacist working in the NHS. When GRO-A was born in 1984, there was little done about ante-natal tests, and we did not have a family history of haemophilia. When GRO-A was born, he cried a lot and slept fretfully. His skin was very sensitive and blistered easily. He also bruised for no apparent reason. When I voiced my concerns to my GP, I was told that I was being over-protective.

When he was 17 months old, he was diagnosed with severe haemophilia A. Blood tests on 18 members of the family followed and showed no evidence of carriers or problems with the blood.

I remarried in 1994 and another baby came along. This time I was offered amniocentesis and chorionic villus sampling as I was 40 years old. It was decided not to take the tests, as there was a risk of the foetus bleeding, particularly if it should have haemophilia. The only test I had was screening of the foetus to check the sex, which was inconclusive. The notion of haemophilia was only mentioned vaguely, almost in passing, so I felt that this was not a problem. In 1996 I gave birth to GRO-A. Much to our dismay he too had severe haemophilia. Fortunately, by then, treatment and care at St James's Hospital had spectacularly improved.

Both my daughter GRO-A and I have now been diagnosed as carriers. My previous result was explained by there being more sophisticated and refined tests now available.

I decided to be sterilised but, by the time I got my appointment, I realised that I might be pregnant again. The option changed from sterilisation only to sterilisation PLUS termination. I was distressed and extremely upset. I realised that I could not go through with it. Nursing staff advised me to take a little longer to come to a decision. The consultant observed that at eight weeks CVS was risky. Amniocentesis could be carried out at about 16 to 18 weeks but was risky too and was not necessarily accurate. I was also firmly assured that the baby was female.

The baby was born in 1998 and was a bonny BOY. He was diagnosed with severe haemophilia A within 24 hours. All my sons have the same diagnosis.

Our fragile world came crashing down about us again.

The shock of all three sons being affected and the effort of caring is overwhelming. I am desperately seeking support and back-up. I am the wage-earner in our family and must go back to work as Pharmaceutical Advisor for Barnsley Health Authority. I also need extra work to ensure sufficient money for my four children to have a good quality of life. Before GRO-A was born I had three part-time jobs covering all seven days of the week. Flexible but very arduous.

GRO-A

The back-up from St James's Hospital is encouraging, but having to justify the needs of my children to the benefits agencies, education authorities and care committees are extra strains for hard-working, loving, caring parents who themselves need support, affection and understanding.

When GRO-A arrived, we were totally unprepared for haemophilia. We knew nothing about it. It was only when I returned to Yorkshire that GRO-A was diagnosed and the long hard struggle to bring him up sound in physique, mind and emotion began. Love and kindness were top requisites. This desperate situation is now trebled. My dear daughter also needs our love and care. My marriage is under unbelievable strain. My own strength, stability and ability are being stretched wafer thin.

The tests are there for every woman, but the decision whether to take the formidable risks they entail for a POSSIBLE foetus with haemophilia is truly overwhelming.

I can only quote Lorenzo Dow (1777-1834) who wrote in 'Reflections on the Love of God' - "You will be damned if you do - And you will be damned if you don't."

GUIDELINES FOR HARDSHIP FUND GRANTS

By Joan Doyle, Services Co-ordinator & Benefits Advisor

The Alan Tanner Hardship Fund was set up to assist people affected by haemophilia with the cost of essential items which they cannot afford themselves. The budget is limited and we receive more applications than we can give funding for. It is therefore necessary for us to prioritise applications and give grants for those in priority need which are directly linked to haemophilia. 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 would like a copy of the guidelines for financial assistance, contact Julie or Tom at the national office and information will be sent to you.

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FINAL HEPATITIS SUPPORT MEETINGS

By Robert James, Hepatitis Project Worker

The series of meetings has now finished because it is holiday time and there is no more money in the kitty to keep me on. In the past few months I have got to know the insides of Virgin, South West and Connex trains very well. Amazingly only one got in late and that was only going as far as Northampton.

The meetings all happened without any major disasters, all the speakers turned up as did their slide projectors and OHPs. The display stand and accompanying literature was delivered to all the correct locations. Pity the couriers forgot to bring it back from one of the venues but the hotel seemed happy to look after our books and leaflets for an extra week at no cost. I managed to leave my own stuff behind in a hotel room once and was late for one meeting, but only a little. One evening even finished early, with all the tidying up done by quarter to ten. (I love you, people with haemophilia of South Wales).

The evenings themselves seemed to go quite well too. It is strange how an issue comes up at a meeting and appears to be of paramount importance in that town but at the next is not mentioned and a completely different one is the major talking point. Mind you I got to hear views on all the subjects. The feedback has all been very positive with loads more people ticking the boxes marked Yes rather than No. You are all too polite.

A report by Robert James on the hepatitis C project will be available shortly from the Haemophilia Society.

MEMBERSHIP SURVEY ATTRACTS BIG RESPONSE

The Society's first survey of members for some years has attracted a sizeable response with well over 700 returning the questionnaire sent out earlier this year. Our aim in carrying out the survey is to find out more about how members use the Society's services, and to learn from you where there may be gaps or needs not being met by our current services. We also wanted to know a good deal more about the circumstances of our members in order to better represent your interests, hence questions were included on employment, uptake of benefits and age.

Initial results have proved very interesting, and we are continuing to analyse the full response. Some early findings are worth reporting now. Out of those members who returned questionnaires, the majority are people with haemophilia or parent or guardian to someone with haemophilia. Most are long standing members, with 22 years being the average length of time in membership. Only a very small number of respondents (under 4%) are members of one of the Society's two special interest groups, while just 20% are members of local groups.

The survey has provided useful feedback on the Bulletin, which the overwhelming majority of respondents said they read themselves and passed on to others in their household. This is very good news for the Bulletin, underlining what an essential means of communication the publication is with our members. Also encouraging were the very positive comments about style and content. At the same time we take careful note of the fact, that of those who answered our question about whether the Bulletin could be improved, over half replied 'yes'.

The other important message from the survey concerns the uptake of the Society's services. Overall, the members responding appear to be infrequent users of the Society's services. This may be a reflection on the characteristics of that particular group of members who actually completed the questionnaire. But among the responses many commented that they did not know what the full range of the Society's services were until they received the questionnaire. This points to a need for more effective publicity about what is on offer. As a first practical step we are now listing all of our services in the Bulletin so that readers are regularly reminded of the wide range of ways in which the Society can help.

Look out for more detailed information on the survey in the Winter issue of the Bulletin.

BELFAST HAEMOPHILIA DAY

By Lucy McGrath, Hepatitis Worker

This event has been organised in conjunction with the local Northern Ireland Haemophilia Society, and will take place on Saturday 14th November 1998 at the Stakis Park Hotel, Templepatrick. We are very grateful to Bayer who are sponsoring this event.

On the day there will be workshops on a variety of subjects, including: von Willebrand's disease; haemophilia treatments; family issues; latest medical knowledge about hepatitis C; haemophilia and schools, and living with hepatitis C. There will also be an address by Karin Pappenheim, and a chance to ask questions, and express views about the work of the Society. Joan Doyle will be available throughout the day to discuss benefits queries, including Disability Living Allowance claims.

The day should provide a good opportunity both to hear about some of the latest developments affecting people with bleeding disorders, and to allow the sharing of experiences with people in a similar situation. There will also be plenty to do for the children, with activities for the older ones and a creche for the younger ones.

For more details and a registration form, please contact Julie Kershaw or Lucy McGrath at the Society. The charge for the day will be £6 for adults and free for children.

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ARE YOU CONSIDERING THERAPY FOR HEPATITIS C?

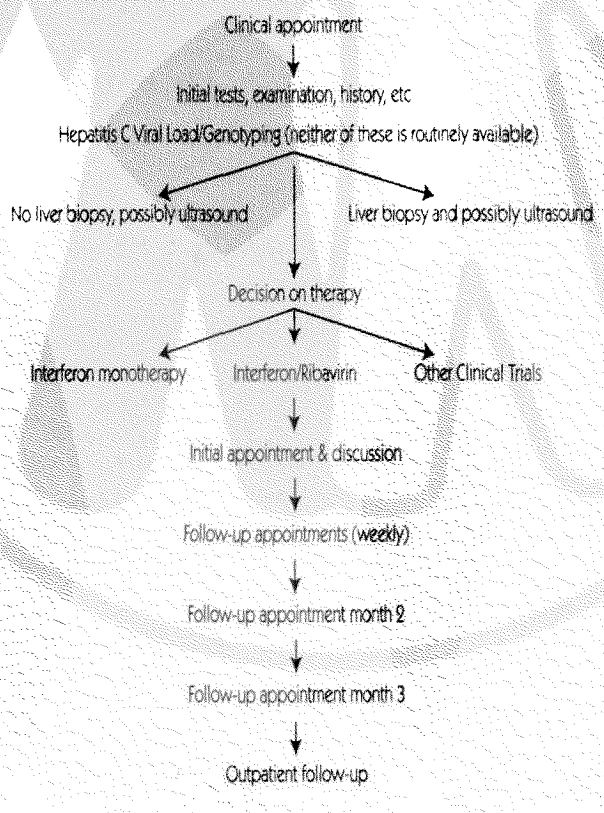
by Nigel Hughes, Clinical Nurse Specialist HIV & Virology, MidKent Healthcare NHS Trust

The following article is a revised extract from an article by Nigel Hughes, a Clinical Nurse Specialist in HIV and virology who works with many people with hepatitis C, some of whom are co-infected with HIV. Nigel has a special interest in hepatitis C, and will be presenting a workshop on latest developments in this field at the Belfast Haemophilia Day. This article first appeared in the Mainliners Newsletter in July 1998.

Hepatitis C: The Gold Standard in Therapy - Choice

There continues to be much debate about the best options for people living with chronic hepatitis C viral (HCV) infection and I hope that I can discuss most of these issues in this article. I am going to concentrate on the orthodox therapies as this is what I know best, but this is not meant to be in any way dismissive of other forms of therapy, whether Western or Eastern complementary therapies.

If you elect to look into the possibility of orthodox treatments you need to consider various possible steps. Possible routes may be:



This is a suggested follow-up process which may vary between centres. What is essential is the need for adequate time to discuss the various issues, particularly the tests required, therapies, side-effects and how to manage them, the goals of therapy and the end results you can expect to be achieved.

It is unfortunate that the liver biopsy is still the best diagnostic method for assessing liver damage. Many doctors will offer interferon therapy to those with haemophilia without the need for a biopsy first. However, if a biopsy is performed on someone with haemophilia, it is necessary to give the appropriate factor concentrate before the operation to raise the factor level and the biopsy should be performed by a skilled practitioner, with adequate pain relief.

If you elect to have a biopsy, a scoring system is used to measure the amount of inflammation, cell death and/or cirrhosis. This grades the severity of liver disease so a decision can be made on the need for therapy.

If you elect not to have a biopsy because of a bleeding disorder, many doctors will still offer Interferon.

(If you are considering whether or not to have a biopsy, please see the Liver Biopsies fact sheet)

Okay, but what therapy?

Interferon used by itself, monotherapy, may be useful in inducing HCV remission in 15-25% of clients treated, possibly lower in people with haemophilia. Combination therapy, using Interferon and the oral antiviral Ribavirin (Rebetron or IFN/RBV) may work in 40-50% of clients after 12 months therapy. These are very general figures, as responses in various communities and client groups will vary dependent on viral, host and behavioural factors.

For instance, responses to Interferon Alpha therapy in clients with HIV/HCV co-infection are less likely to progress to HCV remission (undetectable HCV via viral load). The new AMFAR trial commencing in the US in up to 200 such individuals may provide more information in the near future.

There has also been much discussion about the possible poor response in HCV+ clients with genotypes 1a, 1b or 4, but this may be as a result of the longevity of these individuals' infections compared to more recently introduced genotypes such as types 2 and 3. If you are concerned about this, discuss it. Some centres can offer genotype testing, but these are not and should not be generally viewed as ways of rationing therapy based on resistant genotypes.

At present many centres in the UK are offering Interferon monotherapy to clients with chronic HCV and increased risk of liver disease as evidenced by their liver biopsy and possibly by their viral load. A few may now be offering combination therapy to new clients, but remember that, although this was licensed in the US on June 3 1998, it will not be licensed in the UK for some months. The majority of centres offering monotherapy may offer combination therapy to clients when monotherapy has failed at three months (HCV still detectable) or when clients relapse after a year of therapy at six months post-therapy.

Interferon Alpha is administered by injection subcutaneously in a 3 million-unit dose three times a week for up to 12 months. Some centres may give more or for longer, but as a rule increasing the dose will

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increase your risk of side effects. Ribavirin in combination is given as a capsule orally twice a day, either 1000mgs or 1200mgs if you are less than or more than 75kgs respectively. Combination therapy is given for either six or twelve months, dependent on the centre, but increasingly it may be given for the longer duration. Recent studies have suggested a response rate of 33% after six months, compared to 41% after twelve months.

Am I eligible for therapy and what about side effects?

It is extremely important to remember that both monotherapy and combination therapy do not suit everyone and that they will not work for everyone. There are side effects, which you should be informed about, including the ways you can manage or reduce them.

There are a number of side effects with Interferon, (mostly reversible when therapy is stopped) among them flu-like symptoms, fatigue, depression and irritability, platelet and neutrophil (bone marrow) depression, skin dryness, hair thinning, loss of libido, nausea, loss of appetite, disturbed sleep pattern and thyroid disease (which may not reverse).

The main side effects for Ribavirin are haemolytic anaemia – a particular concern for patients with a low haemoglobin or heart problems – irritability, depression, rashes and nausea. There is also a risk of Ribavirin causing defects in the unborn child (teratogenesis), so clients using this therapy must be on adequate contraception during therapy and for at least six months after therapy stops.

These may all sound very concerning, and I would reinforce that they should not be viewed without caution, but many of these side effects are at least comparable if not as common as side effects in anti-HIV combination therapy. HCV is like any viral infection in terms of orthodox therapy. Unfortunately antiviral agents used by Western medicine are usually potent and cause side effects in varying numbers of clients. It is important this is fully discussed, especially as there are various ways to manage them and take appropriate actions to reduce them (including complementary therapies). Because of them clients may not be eligible for therapy, or some may have to cease. For some clients the side effects are minimal or can be effectively managed.

Some people are not eligible for therapy because of an increased risk of side effects or worsening of previous health problems. They include:

Mental health problems such as clinical depression or psychosis and/or personality disorders; lung or heart diseases, particularly if considering the use of Ribavirin and if you are anaemic; some autoimmune diseases, which will need to be investigated as Interferon may make some worse.

It should also be noted that the amount of support involved in deciding on and using therapy is significant in your response. Medical care needs to be a partnership between the client, the physician and centre.

In conclusion

If you decide on a course of action that uses Interferon or combination therapy with Ribavirin then make sure you are in control as much as possible. For the future when protease, helicase and other therapies are developed in HCV we may see some much more promising approaches after the millennium, hopefully with a vaccine as well. Until then, find the therapy that is most available to you and likely to be of most benefit. The only person that can decide that is you, but make sure you have the information, support and if needs be an advocate to ensure you can make a choice, whether it is Interferon, with or without Ribavirin or Western or Eastern Complementary Therapies.

References:
1. Hughes N; Patients and their treatment: Clinical Guidelines for the management of Hepatitis C with alpha interferon (workshop); Royal College of Physicians: London, 1997 (unpublished)
2. Hughes N; Hepatitis C - no longer an infant: Recent developments in 1998; Mainliners Newsletter 1998; May: 6-7
3. Galmiche JP, et al; French consensus conference on hepatitis C: screening and treatment; Gut 1998; 42: 892-898
4. James JS; Hepatitis C Important Treatment Advance: Interview with Douglas Dieterich, MD; AIDS Treatment News 1998; 295: 1-5
5. Shiffman ML; Management of Hepatitis C; Clinical Perspectives in Gastroenterology 1998; May:6-19

If you want to discuss the issues raised in this article, please contact Lucy McGrath at the Haemophilia Society.

IMPORTANT...

...do you or someone you know have hepatitis C ?

By Lucy McGrath, Hepatitis Worker.

A recent study by a group in Vancouver shows that people with hepatitis C, who contract hepatitis A, have a severe risk of liver failure. In this study 432 patients with hepatitis C, together with 595 with hepatitis B, were studied over a seven year period from 1990 to 1997. Of the patients with hepatitis C, 17 of the patients contracted hepatitis A, and of these 7 developed severe liver failure and 6 died. Of the patients with hepatitis B, 10 contracted hepatitis A, and although one of these had some liver function abnormalities, they all recovered.

Most people who contract hepatitis A do not develop liver failure, but the conclusion of this study is that people with hepatitis C have a substantial risk of liver failure and death if they contract hepatitis A.

This data suggests that everyone with hepatitis C should be vaccinated against hepatitis A. Most people with haemophilia will have been vaccinated, but if you are in any doubt about your immunity to hepatitis A, you should contact your centre to have it checked.

Reference: 'Fulminant hepatitis associated with hepatitis A virus superinfection in patients with chronic hepatitis'. Vento et al; New England Journal of Medicine: January 1998

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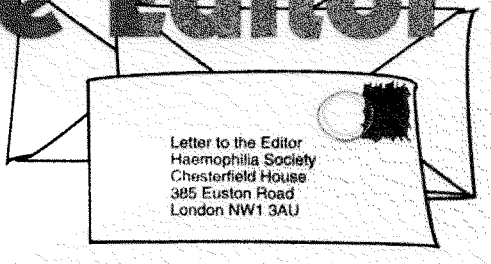
Letters to the Editor



We would love to hear your stories or responses to the letters printed. Please share your experiences, good or bad. Your story may help someone else. Please state if your name can be printed.

U.S. Plasma Concerns

Sir,

It is with some trepidation that I have discovered that blood products are to be imported once again from the US. Unless I am very much mistaken, which I don't think I am, this is where previously infected blood was derived from. Many people with bleeding disorders were infected, and sadly died. Since then a definitive test for HIV has been developed and no further cases have been reported since 1986. We now seem to be heading back to square one again. Frank Dobson has decided that the minute risk of nvCJD, which may or may not be transmissible in this way, outweighs the risk of importing what may be highly suspect supplies from the US.

What seems to have been ignored along the way is the 'window period', where a person may have become infected with HIV, but the tests will be 'negative' for up to three months before seroconversion occurs.

As there is still a much bigger problem with HIV in the US than here in the UK, I feel we may be opening another Pandora's Box with possibly fatal results. Does anyone else share my worries over this hastily thought out plan by Mr Dobson and the Department of Health or am I the lone voice in the wilderness? I would be interested to know.

Yours sincerely,

LG.

Editor's Reply

Everyone is concerned about this . However, the days when plasma in the United States was collected from 'skid row' donors have long gone. Most US plasma is collected from plasmapheresis donors, who give plasma, and whose blood is tested every two weeks or so. They are seen very regularly and live in areas where HIV and other viruses are less common than in the big cities like Los Angeles and New York. The enormous sums of dollars that might be claimed in negligence by a US citizen who became infected from US plasma or plasma product gives the plasma producers the incentive to produce as clean a product as possible.

Notice: Lost & Found

A jacket was found after the lobby at Westminster. If you think it's yours, give Sue at the national office a call.

The Future *by* GRO-A - *Hampshire Group Chairperson*

In my very privileged role as Chairperson, I am aware of the many problems people with haemophilia have endured over the last ten to fifteen years. Sadly, many are no longer with us and their families, quite understandably, have left the scene. We are still living with and encountering problems. These will not go away, but many of us in our group feel that we have accepted and learned to live with these cruel burdens that we and our families are forced to confront.

In our particular group we have always encouraged unity and friendship and supported each other through some of the most terribly painful times. What I am really trying to say is that we feel there is light at the end of the tunnel no matter how distressing the circumstances may be. People with haemophilia and their families are a pretty tough and resilient bunch, we need to be! At the end of the day life goes on.

There must be a whole bunch of people who do not have any viruses, and we are pleased and thankful that they have not been exposed to any infections. We would hate to be separated from our friends and fellow members because of problems personal to us. We have discussed this as a group and we feel that it's time the Society thinks about other issues and does not get bogged down with current concerns, worthy as they are. There are so many people whose needs are important, with diverse and complex difficulties. Is the Society catering for these people?

My opinion and concern is that if we do not move forward as a Society, and we remain fixed in our present situation, we could produce a divided group of people being singled out because of their particular circumstances and having a 'them and us' Society.

I by no means wish to appear callous, unsympathetic, or to trivialise anything. However, I feel the Society must find a balance and work together across a united front for all people with haemophilia.

There are so many issues at stake, with babies and young children, recombinant factor, nvCJD, DLA, HIV, HCV and Mobility/Disability. The list is endless. We as a community of people have had our fair share of fighting and it seems we will always have to fight to get the best sort of treatment and services.

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RED RIBBON PAGE

UPDATE ON PROTEASE INHIBITORS

By Steve Fouch, HIV Worker

Since 1996, there has been some concern that people with HIV and haemophilia being treated with the new class of anti-HIV drugs known as Protease Inhibitors (PIs) Indinavir (Crixivan), Ritonvir (Norvir), Saquinavir (Invirase) and Nelfinavir (Viracept) have been at risk of increased bleeds. Until recently this was entirely based on anecdotal reports, but at the World Federation of Haemophilia Congress at the Hague this May, a number of studies were presented on the subject.

Some points were common from all the papers presented:

1. Increased bleeding occurs in some, but not all people with haemophilia on PIs.
2. Some of these people have had to increase their clotting factor prophylaxis.
3. As many as about 1 in 10 people have such severe side effects that they had to stop treatment, but everyone else was managing to control the bleeding to some extent on increased prophylaxis.
4. No-one has any idea what causes this side effect, and indeed if it is directly caused by Protease Inhibitors.
5. Increased bleeding seems to occur equally in people with haemophilia A, B or von Willebrand's disease.
6. Bleeds can vary from an increase into target joints to bleeds into muscles, knuckles and toes, nose bleeds, blood in urine and stools, and heavy periods in women.
7. These side effects are not seen in people without haemophilia on PI therapy.
8. These side effects do not seem to occur in people with haemophilia treated on other classes of anti-HIV drug.
9. These side effects seem to be equally common to all four of the PIs in current use.

What is not clear is how many people are affected - studies vary from 59% of people with haemophilia on HIV combination therapy in the Birmingham study, to 12% in the Dublin study. Nor is it clear how or why this happens, nor who is most likely to develop these side effects.There is obviously a lot that is not understood about these side effects at this time.

WHAT SHOULD I DO?

If you are on, or considering going on to a drug regime that includes protease inhibitors, there are some questions to ask your doctor:

- How have other people at your centre managed on PIs?
- How often will you be monitoring me to see if there is any change in my bleeding?
- What steps can I take to minimise any abnormal bleeding?
- What are the other side effects I may experience on combination therapy?
- What alternatives are there if I cannot manage on PIs?

It is important to be aware that most people with HIV (around 80%) show a marked improvement in health on drug regimes that include PIs. The problems related to bleeding seem to be managed by most people reasonably well. These side effects are not a reason to avoid treatment, nor a reason to be refused it by your centre, but they should be talked over with your doctor before you start combination therapy.

Additionally, there are a number of national help lines that can keep you up to date on treatment issues, and help you to make an informed choice. These include:

The AIDS Treatment Project on 0645 470047

The Terrence Higgins Health Promotion Unit (Alison Gray) on GRO-C

Body Positive (London) - Treatments Information Centre (Robert Fieldhouse) on GRO-C

The new National AIDS Manual & British HIV Association Website at http://www.aidsmap.com which has up-to-the-minute treatment information on-line.

The Terrence Higgins Trust and Body Positive both have extensive libraries and information resources (including Internet links) that you can book in to visit as well.

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Supply and Demand Problems

By Joan Doyle, Services Co-ordinator & Benefits Advisor

In February, Frank Dobson, Secretary of State for Health, announced that all children with haemophilia under the age of 16 years would receive recombinant factor VIII (rfVIII) treatment. This announcement was a great relief for the parents of children with haemophilia. However, the Society has received a number of telephone calls from members whose children have not yet begun to receive rfVIII.

I have been in contact with pharmaceutical companies who produce rfVIII who have explained the problems with supply and demand. To begin with, Frank Dobson's February announcement was a complete surprise which none of the companies were expecting. Allocations for the supply of rfVIII for 1998 had already been agreed. Haemophilia centres and the pharmaceutical companies had gauged demand based on the previous year and what would have been normal growth in demand for 1998. When haemophilia centres throughout the country received guidelines for provision of rfVIII, there was a surge in demand for this product.

Production of rfVIII has been increased but the demand cannot be met at this time. The reasons for this are, firstly, there is no way to rush (and no one would want to) the production of treatment. RfVIII has to go through several processes to ensure safety and standards are at the highest level. Haemophilia centre directors have to ensure a secure supply of rfVIII for those people who have been in receipt of this treatment before the announcement. There must be rfVIII available for all eventualities for these individuals as there is no question of them having to return to a plasma derived product. Before a child can begin receiving rfVIII treatment, the consultant has to be sure that the supply is consistent so there is no danger of running out of the product and the child having to be treated with a plasma derived product.

The pharmaceutical companies and the Haemophilia centre directors are looking at all possible solutions to this problem. The supply of rfVIII to other countries has been kept to the minimum required so that more product is available for children in the UK. The pharmaceutical companies hope to be able to meet demand by the middle of next year. On a more positive note, Baxter are hoping to open their new production plant in September this year which will increase the level of production and more rfVIII will become available.

If you have any queries or information regarding the provision of rfVIII, please contact Joan Doyle at the national office.

BLOOD PRODUCTS IN THE MEDIA

Over the summer, newspaper and media reports have highlighted concerns relating to safety of blood supplies and products. In July it was reported that Ministers were considering banning blood transfusions from British donors due to fears of new variant CJD transmission. This turned out to be very alarmist reporting of the deliberations of the Spongiform Encephalopathy Advisory Committee.(SEAC) which has been looking into the possible risks of new variant CJD transmission via blood donors based on current research findings.

SEAC's previous recommendation in February, that British plasma should no longer be used in treatment products to avoid any possible risk of infection, has already been accepted by Government. Following SEAC's latest advice to Government, all blood supplies are to be put through the leucodepletion process to remove white blood cells which are theoretically the likeliest part of blood in which infection might exist. In taking this step the Department of Health stressed again that the risks are theoretical. Deputy Chief Medical Officer Jeremy Meters said: "This is a purely precautionary measure. Blood in the UK remains very safe and leucodepletion will make it even safer."

However, Oxford haemophilia centre director Paul Giangrande commented: "I don't think this will totally eliminate the risk and we desperately need a proper screening test." The Haemophilia Society responded by welcoming the new move to reduce any potential risks, while underlining the importance of moving towards synthetic treatment products for people with bleeding disorders.

Within the same month further concerns were raised when the British Medical Journal reported a study of treatment with human albumin for burns victims. The study, which examined evidence of treatment over 50 years, suggested the albumin treatment was associated with increased numbers of deaths, but was unclear as to why. The Department of Health is looking into the study, and researchers have emphasised that findings should be interpreted with caution.

As clotting factor products contain small amounts of human albumin, the Haemophilia Society is aware that members might be concerned. Clearly the study looked purely into albumin treatment for burns victims and drew no conclusions about other treatment uses of albumin.

BPL NEWS

Following the Department of Health announcement in May, BPL is now moving to supply products made from US plasma.

The company is producing booklets and information sheets in consultation with the Society aimed to answer some of the questions patients may have regarding this move, and some of the wider issues surrounding nvCJD.

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Christmas Appeal

It is now the time of year when the Society looks to you for much needed support with our Christmas Appeal. Following the reduction in our Government funding, we are relying heavily on the income from this year's Christmas Appeal and hope that you can help.

Enclosed with this issue of the Bulletin you will find the Society's new 1998 Christmas Card Catalogue and the chance to win exciting prizes with our 1998 Annual Draw.

The Christmas card catalogue contains many new festive designs that we hope you will like. We also offer an overprinting service if you would like to personalise your cards. This is available through a separate brochure which can be requested from Tom Bradley at the national office.

Do you know anyone else who may be interested in buying the Society's Christmas Cards or Draw tickets such as family, friends or a local business? If you would like additional catalogues or tickets please call Tom at the national office. Thank you for your support.

Thank You to Atlas Dies Ltd

The Society is in the process of upgrading its computer equipment and would like to say THANK YOU to Dennis Huxtable and Steve Jupp of Atlas Dies Ltd., who have kindly donated the necessary hardware to get three PCs up and running.

With other generous donations (details to follow in the next edition) we hope to have an efficient and up-to-date IT system in place very soon.

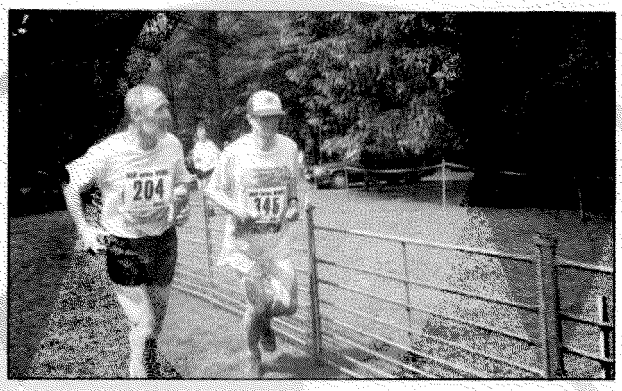
Southern Group Donation

The Society would like to thank the Southern Group for generously donating £5,000 to the national office this year. On behalf of the Trustees and staff we would also like to send our sincere best wishes and thanks to Mr GRO-A who has been actively involved in the local group for many years, and has recently had to give up his position due to ill health. His commitment to the haemophilia community is to be highly commended.

Man v Horse race

Well done to Bryn Davies, who raised £160 for the Haemophilia Society

Bryn Davies, a local headmaster, ran in the Man vs. Horse race in Llanwrtyd Wells on Saturday 13 June on behalf of the Haemophilia Society and for another charity which helps people with medical problems. The race is a cross country event of 22 miles where the runners compete against a number of horses, with cash prizes for those who beat a horse to the finishing line. Bryn completed the race in 3 hrs 37 mins. A big thank-you also goes out to Mrs GRO-A who is a member of the Society, and everyone who supported Bryn.



Can You Help?

Do you have any fundraising ideas you would like to make a reality, or want to help the Society in another way such as through volunteering? If you do please give Melissa a call at the national office to discuss your ideas.

GRO-A

It is with much sadness that we report the death of GRO-A on GRO-A 1998, aged 44. GRO-A was a member of the Society for many years and had haemophilia.

He will be much missed by his family and friends. In special memory of GRO-A his friends at his local pub, The Cricketers Arms in GRO-A organised a charity event involving a pool competition and mammoth raffle. The event was organised by GRO-A with his brother GRO-A also taking part in the event. They successfully raised the wonderful sum of £600 for the Haemophilia Society. We would like to offer our warm thanks to GRO-A friends and family who have remembered him through supporting this event.

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The Family Pages

A LETTER FROM MOSCOW

Hi! My unknown English friend!

I am writing to you from Moscow. My name is GRO-A GRO-A I am 16. I learn at Moscow school in 9th form. We learn many subjects, such as History (it's my favourite subject), Maths, English, French, Russian, Literature, History of England in English, Physics, Geography, Chemistry. If you like you can graduate only 1 classes or 11. I'd like to learn 11 classes. There are 2,000 pupils in our school and 33 pupils in our class (boys and girls) . I like my classmates and teachers. Teacher of History is our class manager. I visit to the museums, theatres and exhibitions.

We have 4 terms during our school year. After every term we have holidays which are not more than 10 days and after the fourth term we have the longest vacation - 3 months (June, July, August). But sometimes I can't go to school because of bleedings. I have very often bleeding into my knee. In such cases my mother 'phones to urgent medical service '03' and we are carried by car to the Children's Haematological Centre in the hospital.

The haematologist examines me and nurse makes me injections of cryoprecipitate. Usually it takes the whole day, that's why I can't go to school. Sometimes the Children's Haematological centre supply me with factor and I can do injections myself. In such cases I don't miss school.

This summer vacations was great! I was in camp 'Vympel' not far from Klin in Moscow region. I did special exercises, played volleyball, table tennis, swam in the pool, danced. It was for the first time in my life to be in the camp. I took part in all sport camp competitions.

We made video. The Secret of the Lost Factor. I played role of the captain of the ship. It was in July and in August I was lucky to be in another camp in Anapa at the Black Sea.

Anapa's resort is famous for sandy beaches, shallows, mud and water cure. I did special exercises for my joints, cured with mineral water.

I have the big collections of coins, stamps and badges. There are coins of many European, African and American countries (157 countries) in my collection.

I'd like to have a pen friend in Great Britain. I am waiting for your reply. Sorry for my poor English.

If you'd like to be put in touch with GRO-A contact Pete Brown at the national office.

The Haemophilia Society is planning to bring two Russian teenagers with haemophilia to the UK in 1999 for two weeks, GRO-A We need families to offer a home to the boys for one of the two weeks while they are in the UK. Could you or someone you know accommodate the boys?
If you would like more information about this project please contact Joan Doyle on 0171 380 0600.

JOKE CORNER

Some more doctor jokes!

Doctor to patient: "Why did you run out of the operating theatre just as you were about to have your operation?"
Patient: "Because the nurse said to be brave and that there was nothing to worry about as it was just a minor operation."
Doctor: "So? That should have put you at your ease."
Patient: "Yes, but she was talking to the surgeon!"

"Doctor, doctor I'm an incurable thief."
"I've got something you can take."

"Doctor, doctor I feel like a pair of curtains."
"Don't be so stupid - pull yourself together."

Tell us your jokes, doctor ones or otherwise. Space permitting, we'll print them in the next issue.

COMPETITION TIME

Who am I?

- My first is in injection but not in a jab
- My second is in butterfly but not in a stab
- My third is in tourniquet and also in plaster
- My fourth is in swab as well as disaster
- My fifth is in muscle and also in bleed
- The whole is a person who comes to your need
- To give you your factor and help you to mend
- To help out the doctor and to also be your friend!

Write into Pete at the national office with your answers. The first three correct entries will win a prize

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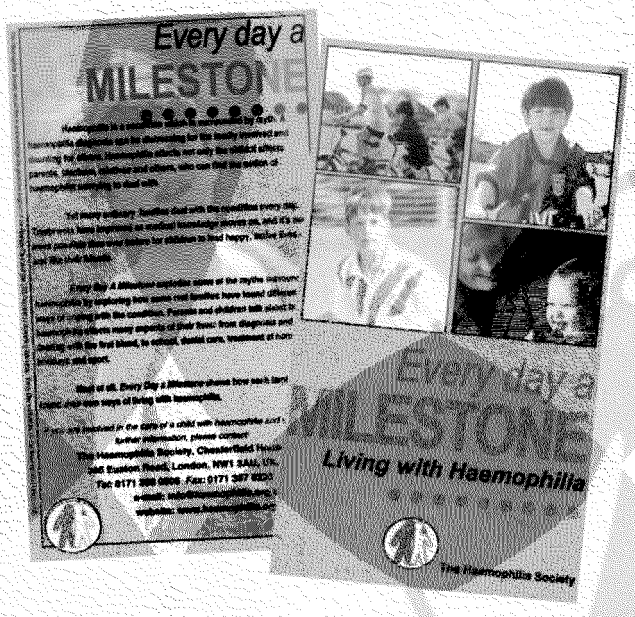
EVERY DAY A MILESTONE

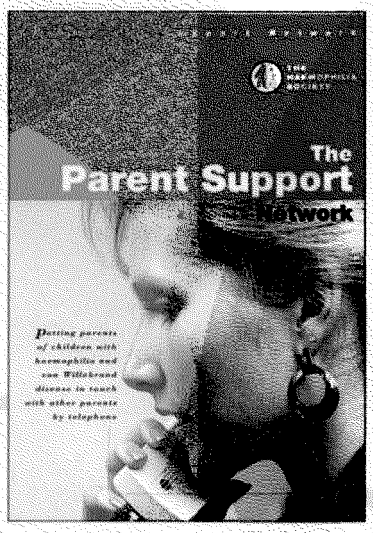
This video is now available from the Society. Parents of children with haemophilia talk about their experiences in a helpful and illuminating way that will be a welcome source of support to all parents. Areas covered include First Bleed, Schools, Holidays, Sport, Home Treatment, Dental Care and Support. Running time 30 minutes approx.

The Society is grateful to the Persula Foundation and the Lloyds TSB Foundation for their support.

To request your copy please call Tom at the national office on GRO-C



THE PARENT SUPPORT NETWORK



Don't forget, if you are a parent and would like to speak with another parent about your child's haemophilia or von Willebrand's disease you may benefit from contacting the Society's Parent Support Network.

The network exists as an additional source of support to existing services that are available from your Centre and the Society.

All of the parents in the network have varied experiences of living with haemophilia and the various hurdles and milestones one goes through.

This includes coping with a new or recent diagnosis, talking with the playgroup or school, home treatment, sports, siblings, feeling isolated etc.

If you would like to use the network, please give Pete a call on 0 GRO-C He will then arrange for a parent to contact you.

Three parents gave their views on using the Parent Support Network in the last edition of the Bulletin (Issue 2 1998).

Further details about the network can be found on our web site: www.haemophilia.org/support.html

KELLEY COMMUNICATIONS PUBLICATIONS

Parents may like to know that we receive limited supplies of three interesting magazines from Kelley Communications in the US. These are: THE PARENT EXCHANGE NEWSLETTER - a newsletter for families affected by haemophilia that promotes an exchange of information and support; FACTOR FRIENDS – an activity magazine for children aged 7-13 and FACTOR FUN – an activity magazine for children aged 3-7.

If you are interested in receiving regular copies of these publications please call Pete on GRO-C

FACTOR XI DEFICIENCY - CAN YOU HELP?

We have had a request from a parent of a boy with FACTOR XI DEFICIENCY who would like to talk to another parent of a child with the same condition. Please call Pete on GRO-C if you are able to help.

MILD AND MODERATE HAEMOPHILIA

Pete would like to thank the parents of children with mild and moderate haemophilia who phoned to say they would be willing to talk to other parents, especially of recently diagnosed children, who want to know from others what kind of issues are likely to be faced. We have already linked some parents together. If you want to be added to the list or want to contact another family (or both) please give Pete a call on GRO-C

Good Luck Message from the Society

Good luck to GRO-A who will be completing the final part of his Four Corners Cycle Ride. GRO-A whose three brothers were born with haemophilia, has been cycling the four corners of Britain this year to raise much-needed funds for the Haemophilia Society.

BRISTOL FAMILY DAY

This will take place on Saturday 3 October 1998 from 9.30 am - 5pm at the Grand Hotel in the centre of Bristol. There are still a few places available. To book your place, 'phone Julie at the national office as soon as possible.

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2nd European Haemophilia Consortium (EHC) Summer Camp, Greece, June 19 - 27, 1999

The EHC is arranging a summer camp sailing in the Greek Archipelago for young people (18 - 30 years) with haemophilia.

The route begins and ends in Athens. You do not need any sailing skills, but everyone on board will have to be willing to actively participate in the sailing and in the daily running of the boat. The whole week except one day will be spent on the boat. The day on shore will be spent on an island where small sailing boats can be rented. Short stops will be made on other islands where various water activities can be tried. The purpose of the trip: **Try to experience as much as possible.**

It costs DM 250 (at time of print $80) per person. The fee covers accommodation, meals and activities for the whole week. It does not include travel to and from Athens.

Selection may be necessary if there is a large number of applications for the trip. The criteria for selecting participants is:

Date of receipt of application form. Closing date for applications is March 5, 1999. Applicants that have not participated in previous camps will be given priority.

Geographical spread: As wide spreading as possible among European nationals.

Are you interested in participating ?? Would you like more information ??

Contact: Jesper Grand, The European Haemophilia Consortium, The Danish Haemophilia Society, Frederiksholms Kanal 2, 3rd Floor DK, 1220 K, Copenhagen, Denmark Tel: (Denmark) GRO-C

Bon Voyage !!

Society News

AGM

The Society's AGM was held in July at St Thomas's Hospital in London, attended by some 30-40 members. At the meeting Society chairman Chris Hodgson reviewed the activities of the past year, while Chief Executive Karin Pappenheim presented future plans for the organisation's work. The results of the nomination process for the Board were announced, with three new members being welcomed: Simon Taylor as Treasurer, GRO-A and Keith Colthorpe as Trustees.

Outgoing treasurer Nick Lawson was thanked for his hard work and achievements in improving the finances of the organisation, and thanks also went to GRO-A who stood down as a Trustee this year. Chris Hodgson sent the Society's best wishes to John Pepper GRO-A GRO-A

The question of further reform to the Constitution was discussed. After thorough consultation with the membership, and considerable debate the board has decided that additional constitutional reform is not a priority at the present, and has accepted the Chief Executive's recommendation that this should be looked at again next year. One of the key issues examined in the consultation was that of whether members should continue to elect their chairman or whether the Trustees would appoint the chairman from among themselves. The majority view in the consultation exercise was that members want to go on electing the chairman, and value the postal election system introduced in 1996.

Society Council Meeting

The Society will be holding its second Council meeting at **St. Botoloph's Church without Bishopsgate on 31 October 1998**, from 11am to 1pm followed by a light buffet. This meeting will take place before the Remembrance Service for people with haemophilia who have died from HIV and HCV. For further information about the Council Meeting, please contact Julie Kershaw or Sue Rocks at the national office.

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