

Witness Name: Katherine Victoria Burt

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INFECTED BLOOD INQUIRY

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1995 - No 2

The Bulletin

HAEMOPHILIA RESOURCE PACK NOW AVAILABLE

A new haemophilia resource pack is now available for parents of children newly diagnosed with haemophilia.

The packs, which include everything that you would need to know about haemophilia, have been produced by Bayer in cooperation with the Haemophilia Society. They will be given out at centres to new parents of children with haemophilia.

The resource packs are very user-friendly and include quotes from parents who are already living with a child with haemophilia. The information in the binders is very comprehensive, covering the subject right through from the causes of haemophilia to routine diagnosis and care, treatment and growing up with haemophilia. They come in the form of a loose leaf binder so that individual pages can be photocopied and handed out to relatives, teachers or child minders who need to know more about haemophilia.

Graham Barker, Director of Services for the Society commented on the new resource packs: "One of the most stressful times for families is when

they discover that they have a child with haemophilia. The new packs provide detailed and easy-to-understand information about the condition at the time when families need it most. We are very grateful to Bayer and Maxim Medical for producing the packs, which are a significant step forward in helping the families of newly diagnosed children with haemophilia."

GRO-D

The first pack was presented recently at Great Ormond Street Hospital for Children NHS Trust to new parents **GRO-D** and their 3 month old son **GRO-D**. Pictured with the **GRO-D** from the left at the presentation are: Haemophilia Nurse Specialist Kate Khair, Deborah Williams of Bayer and Graham Barker (right).

HEPATITIS C CAMPAIGN UPDATE

There have been a number of developments in the hepatitis C campaign since the last edition of the Bulletin.

An all-party meeting of MPs was held at the House of Commons 26 April, jointly chaired by MPs Sir Geoffrey Johnson Smith (conservative) and Alf Morris (labour). Around 20 MPs attended the meeting and were very supportive of the Society's position.

As a result of this an Early Day Motion (number 1219) has now been put down in the House calling for the Government to recognise the plight of people with haemophilia infected with hepatitis C, and to consider providing help in a similar way to that already given to people who are HIV positive. Currently 191 MPs of all parties, have put their names to the Motion and it is hoped that more will come on board in future. The more support shown by

members of parliament, the more likely it is that the Government will take action.

This is where Society members can be very useful. If you haven't yet written to your MP about hepatitis C, please do so. If MPs know that hepatitis C is a problem that is affecting their constituency then they are more likely to support the campaign and sign the Early Day Motion.



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EDITORIAL by Bulletin editor Andy Cowe

A glance through this edition of the Bulletin gives an instant picture of the work of the Haemophilia Society. Regular readers will notice two new features. Service Shorts will keep readers informed about aspects of our work which sometimes go on unseen but are the heart of our service to members. The Red Ribbon page will reflect our activities and support for people with haemophilia and HIV.

The articles on the hepatitis C campaign and liver biopsy show our concern over hepatitis. News of staff changes and the column from the Manor House Group demonstrate some of our responses to this threat.

We also have a number of good news stories. Our AGM report highlights

this year's awards to people with haemophilia who have achieved excellence in education, music and sport. The stories about **GRO-A** and **GRO-A** show that haemophilia, when properly treated, need not be a bar to a full and active life.

Letting parents know that haemophilia can be overcome is one of the most important jobs this Society can do. We bring news of a range of parent's support activities and publications which can help. The launch of the Haemophilia Resource Pack (our headline story) adds to the resources we have at hand to achieve our objective – improving the quality of life for people with haemophilia and their families.

Publications and Services available from the Haemophilia Society

Publications

The Society produces the range of books, booklets and leaflets listed below to help people with haemophilia.

- ★ Introduction to Haemophilia
- ★ Joint Care and Exercises
- ★ Hepatitis
- ★ The Essentials of Haemophilia Care
- ★ Teaching Children with Bleeding Disorders
- ★ Children's Haemophilia Book
- ★ Will making guide
- ★ NHSME Patient Perspective Booklet
- ★ Past copies of the Bulletin

Services

The Society works to help people with haemophilia from its national office and also via the local Groups. The services currently available from the national office are:

- ★ Support to children and families affected by HIV and haemophilia
- ★ Information and help with benefits, in particular Disability Living Allowance
- ★ Hardship grants
- ★ Armourpage service
- ★ Caravan Holidays
- ★ Adventure Holidays for children
- ★ Fund-raising support
- ★ Assistance with media enquiries
- ★ Information on treatments and blood products
- ★ Travel insurance advice
- ★ Information on travel regulations/restrictions
- ★ Haemophilia Days
- ★ One-off meetings on specific issues, such as hepatitis.

For further information about the above services, or to check on the availability of Society publications, please contact the national office.



We extend our grateful thanks to the Bio Products Laboratory who have kindly donated a sum to pay for the publication of this edition of the Bulletin.

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HEPATITIS WORKER APPOINTED

The Society has appointed a hepatitis research worker on a six month contract to explore the needs of people with haemophilia and hepatitis C.

Mandy Cheetham started work at the Society on June 7. She will be based at the Society national office, but will also travel to Centres up and down the country. She will be interviewing people with haemophilia and hepatitis C, their families and health care

professionals about the implications of the virus.

She will also be monitoring the services offered by Haemophilia Centres to see how closely they comply with the UK Haemophilia Centre Directors' Organisation Guidelines.

Mandy is a qualified social worker and joins the Society from the St Giles Trust, where she was working with homeless and vulnerable people in London. In this

work she has encountered many people who are HCV positive.

"I will be investigating the special problems that the combination of haemophilia and HCV cause," she said. "My job will involve talking to as many people as possible in the six month period to find this out. If people have difficulties or experiences they would like to share about how the virus has affected them they are very welcome to call me at the Society national office in complete confidence."

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LIVER BIOPSIES By Dr Chris Ludlam Centre Director, The Royal Infirmary of Edinburgh

The procedure for obtaining a small sample, or biopsy of the liver is a well established technique that has been used for many years. Most biopsies are performed by first anaesthetising a small area of skin over the liver in the upper part of the abdomen and then passing a special biopsy needle through the skin into the liver. On withdrawing the needle a small piece of liver about 1-2mm in diameter and perhaps 10mm long is retained within it. This is sent to the pathology department where it is processed and examined under the microscope.

There are many disorders that can affect the liver and some of these can be diagnosed by specific blood test, e.g. different forms of viral hepatitis, but sometimes this is not possible and a biopsy is suggested. In the case of hepatitis C infection this can be diagnosed by a simple virological blood test. The blood "liver function tests" sometimes provide a measure of its inflammation but they do not reflect how severely it is affected by a disease process. Neither of these blood investigations, however, reveal the extent to which the liver is damaged by cirrhosis or scarring. One way in which this can be measured is by performing a liver biopsy. As well as revealing the extent of scarring, under the microscope, it is also possible to visualise the degree of inflammation. If there is any doubt about the cause of a liver problem then a biopsy may help the diagnosis.

Thus in individuals with hepatitis C infection it provides information about the degree of liver damage as this may be considered important by some doctors in helping to decide whether interferon should be offered. In people without haemophilia a liver biopsy is considered advisable by many doctors before prescribing interferon. In those with haemophilia who have hepatitis C it is not a prerequisite to interferon therapy. Many doctors will offer interferon to those with haemophilia without a biopsy.

Is a biopsy safe? Liver biopsies 10 to 20 years ago were associated with more side effects. Biopsies today are performed using safer needles and are usually undertaken with the help of ultrasound which can visualise the liver on television screen thus ensuring that the doctor can guide the needle into the

liver. Some centres use a laparoscope which is a tiny telescope which can be inserted through a small incision in the abdominal wall and can be used to visualise the liver to ensure that the biopsy needle enters it safely. Using a laparoscope it is also possible to see the degree of inflammation and cirrhosis.

Before a biopsy it is necessary to give factor VIII or IX concentrate to raise the level. After the biopsy this should be continued with further infusions for about 3 days. A biopsy would not normally be performed in an individual with an inhibitor because it would be harder to raise the factor VIII or IX level to prevent bleeding. There is a small risk of bleeding after a biopsy and this may need to be treated by a blood transfusion. Very occasionally the bleeding will be problematic and an operation will be required.

If your doctor suggests that you have a liver biopsy you should ensure that you receive a full explanation as to why it is considered necessary and exactly how it will be performed. With this information you should be able to make a decision that is reasonable for your circumstances.

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THE RED RIBBON PAGE

The Red Ribbon

You may well by now be familiar with the Red Ribbon badge, worn by many. The red ribbon was chosen as a simple symbol, enabling people to show their support for people living with HIV and AIDS and as a recognition of the family and friends who have died. It started about five years ago in the USA, and is now in widespread use all over the world.

The haemophilia community has been particularly badly affected by HIV and AIDS, with over 1,200 people with haemophilia in the UK infected, more than 600 of whom have now died. The HIV epidemic is the most serious event ever to have affected the haemophilia community. Over the years, the Society has sought to help those affected, more recently working with groups such as the Macfarlane Trust and the Birchgrove Group.

The good news is, that ten - fifteen years after **GRO-C** infected, many are still alive and with advances in treatment, many people are leading a very good quality of life. This page is to help everyone with haemophilia who is affected by HIV by giving information and news on issues that concern people with HIV.

The other good news is that of course most people with haemophilia in the UK have not been infected with HIV. We must always be alert to the problems of blood safety to ensure that such a tragedy can never happen again. The haemophilia community is a very strong, close one and we all need help, support and understanding, and we hope that this page, will over the years help us all to work together in facing this great challenge.

If you would like to wear a red ribbon as an expression of support for people with HIV, very smart enamel badges are available from the Birchgrove Group, address details below.

Simon Taylor - Vice Chairman

The Haemophilia Society and HIV

The Society Executive passed a resolution last year on Haemophilia and HIV, some

highlights of this are outlined below, but the full text is available from the office.

The Haemophilia Society will demonstrate its support for people with haemophilia and HIV by undertaking a range of activities. The society will support self help initiatives for people with haemophilia and HIV and their families and seek to gain access to services provided by other agencies that are of benefit to people with haemophilia and HIV.

To achieve these objectives the Society will endeavour to do the following:-

- encourage the Birchgrove Group to continue its work in developing regional networks of self help by providing practical and financial support; work with other HIV agencies to discuss common concerns and if appropriate share platforms with them;
- work with haemophilia centres and individual staff to ensure that funding for HIV work is maintained and encourage their support for local self help initiatives as part of a national network;
- encourage the Society's local Groups to become more "HIV friendly" and provide more support to those who have haemophilia and HIV, and their families;
- give greater prominence to HIV issues in the Society's publications.

Getting the best Treatment

It is sometimes very difficult to make sure that you are getting access to the best and latest treatments, particularly if you are being treated at a small centre with little experience of HIV. Three pieces of advice which may help:

- Go to a different centre for your HIV care. This is worth considering if another hospital has a much larger HIV patient base. There, you will have access to more trials of new treatments and possibly a greater range of services. Talk about it with your centre, your family and

friends, but don't be afraid to consider it. Treatment guidelines for HIV and Haemophilia are under preparation which may help the situation.

- Get as much information as you can on the options that are available. AIDS Treatment Update, available free from NAM, is an excellent, highly regarded publication giving the latest information. On-line information is available from POSNet and the Cruisaid information exchange in London can help as well.
- Get involved. Join you local Society or Birchgrove Group, meet others in the same situation, share advice and stories.

Plans in the Pipeline

A number of activities are under consideration by the society, Birchgrove and the Macfarlane Trust, more details nearer the time.

- A joint Birchgrove/Society weekend for people affected by HIV.
- A Women's Weekend for women affected by haemophilia and HIV.
- A Coping with Bereavement Conference.
- A Specialist newsletter, giving details of news of new treatments. We need volunteers to help with this, please let us know if you would like to assist.

Contacts

The Macfarlane Trust:
Tel: 0171 233 0342
PO Box 627, London SW1H 0QG

The Birchgrove Group:
Tel: 0345 697231 Lo Call
PO Box 313, Canterbury, Kent CT1 1GL

NAM Publications:
52 The Eurolink Centre, 49 Effra Road, London SW2 1BZ
Tel: 0171 737 1846

Cruisaid Information Exchange:
369 Fulham Road, London SW10 9TR
Tel: 0171 746 5929

PosNet:
Tel: 0181 695 6113

SERVICE SHORTS

The Society's Services Committee is the group that is responsible for overseeing on a day to day basis, the work of the Society in terms of the services that the Society makes available to our members. These range from the adventure holidays, to help with benefits and grants, to publications and lobbying the Department of Health and Haemophilia Centres for the best possible treatment and care. Future Bulletins will include a round up of some of the issues that we have been looking at over the last few months. In many cases you will read more about them elsewhere in the Bulletin, but we hope you will find this page useful.

Hepatitis Worker Joins Staff

In view of the new workload that hepatitis has placed upon the Society, we have employed a new member of staff Mandy Cheetham, initially on a six month contract, to make a detailed assessment of the needs of people with haemophilia and hepatitis. We can then press centres and the government to provide the help that we need.

Hepatitis Campaign continues

Letters to MPs are still needed! The more pressure that can be applied the better. So if you feel able, carry on writing and pestering your MP, so that they bring pressure on the government. We also need people who have suffered illness as a result of their hepatitis, who are willing to speak to the press. if you wish to help in this way, please contact Graham Barker at the office.

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Blood Products policy

The Society is looking at reviewing its policy on blood products in the light of new advances and new products that are becoming available. As a general principle, safety is of course paramount to all of us. Great steps forward have been taken in the last ten years, but we must be constantly on our guard. Frankly, we don't know what might be out there in the blood supply that may cause us problems in the future. The lessons of HIV and Hepatitis are only too clear for all of us.

We believe that everyone in the UK should have access to the safest possible products, which are also the purest products. We shall be examining whether the time has come for old "intermediate" purity products such as BPL 8Y to be phased out in favour of higher purity products that are now being produced by BPL, SNBTS and the commercial sector. We would welcome all views on this important issue.

THE ANNUAL GENERAL MEETING

This year's Annual general Meeting of the Haemophilia Society was held at the Prideaux Theatre, St Thomas' Hospital on Saturday 13 May.

The meeting was opened by the Chairman, the Rev Preb Alan Tanner with a moment's silence to remember those who had died in the past year.

The Chairman said that the Annual Report largely covered a year of consolidation for the Society after a large number of significant changes last year. He said that all concerned should be congratulated that all difficulties had been resolved.

Two special reports were made to the meeting - one on the constitutional review, and one on the hepatitis C campaign.

CONSTITUTIONAL REVIEW

Andy Cowe spoke on the results of the Constitutional Review of the Society. He reported that the working party had brought a number of reports to Council and received their views, and by April of this year had their broad agreement for a series of recommendations.

Items of interest among the recommendations were:

- The Memorandum of Association objects clause of the Society needs to be updated in line with modern practice and brought before the Charity Commission.
- Executive committee members are to be renamed as Trustees. There should be 11 Trustees, and the term of office should run for two years with no person being able to serve more than three consecutive terms of office.
- The Chairman should have a vote in the meetings instead of the current position of only having a casting vote.
- Postal ballots of members for the election of the Executive committee and officers of the Society should be held instead of members having to attend the AGM in person.
- Members of the Society need to be better defined in the Memorandum and Articles. There should be differentiation between voting members and mailing list members - for example libraries who are on

the Society mailing list do not need to have voting rights.

The proposals will be brought before an Extraordinary General Meeting of the Society in November of this year and the new system be running by 1996.

HEPATITIS C CAMPAIGN

Simon Taylor reported on the hepatitis C campaign.

He reported that the Society had been working to ensure that as much information is passed on to members about hepatitis C as quickly as possible. A prime channel for this is the Bulletin. The Society is also producing a new booklet on Hepatitis C.

The campaign itself is going well, but is not as easy as the HIV campaign in the '80s as there is not the same public appeal. He reported that the Society had contacted its friends in Parliament and that Ministers had already received over 150 letters from MPs interested in the situation. There has also been an all party meeting in the House of Commons with supportive MPs. Mr Taylor said that the Society is currently working towards a motion in the House, which would be followed by a meeting with the Minister and then perhaps with the Prime Minister.

ELECTION OF OFFICERS AND EXECUTIVE

The Chairman was elected unopposed, but he took the opportunity to say that he intends to continue in office only for a further two years. He said that this would allow him to see through the HCV campaign and the constitutional review.

The treasurer Nicholas Lawson was re-elected unopposed.

There were three candidates for the post of Vice Chairmen. Standing were Simon Taylor, Chris Hodgson and John Pepper. Elected were Simon Taylor and Chris Hodgson.

For the Executive committee it was reported that Julian Lander and Carol Holliday were standing down. The

Chairman thanked both of them for their services to the Society and made particular reference to Julian Lander. He said that Julian had been on the Executive committee for many years and had held almost every office in the Society. He applauded his sustained service to the Society and remarked that it could not have taken place without a considerable cost in Julian's time and energy.

As there was one vacant seat all of those standing for the Executive committee were elected unopposed.

They were: Gordon Clarke, Keith Colthorpe, Andy Cowe, Philip Dolan, David Evans, Norma Guy and John Pepper.

The President remains Dame Catherine Cookson OBE.

The Chairman reported that Dr Elizabeth Mayne was standing down from the Medical Advisory Panel. He thanked her for the immense amount of guidance that she had given to the Society over the years and to himself

NOT RELEVANT

personally. Dr Paula Bolton Maggs was elected to the panel in her place. The other members of the medical advisory panel remain unchanged.

The Chairman then thanked all those people who have helped the Society. He singled out those people who served on the local Groups and committees, the executive committee and vice presidents and Society staff. He also thanked those parliamentarians who have given support and paid especial thanks to the Society patron the Duchess of Kent GCVO.

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The afternoon session was taken up by an informative talk from Dr Mark Winter from the Canterbury Haemophilia Centre on prophylaxis and recombinant factor VIII products.

Speaking on prophylaxis, he pointed out that it was a well-established form of treatment that was aimed at keeping the level of factor VIII or IX in blood above 1%, so as to prevent any episodes of spontaneous bleeding. He stressed the benefits of this form of treatment, particularly for children, as it can prevent damage to the joints.

NOT RELEVANT

Once a joint has actually been damaged by bleeding, the most that prophylaxis could achieve was to prevent any further deterioration in the affected joint.

He also pointed out that prophylaxis is not only for children, but is frequently used for adults, such as when surgery is being performed or when the person experiences a series of bleeds into one particular joint.

He also made the point that prophylaxis does not necessarily need to be continuous but that it is tailor made to the needs of each patient with haemophilia. He gave the example of a child who tended to bleed in the summer holidays, but not when at school. Under these circumstances, Dr Winter said that he would treat the child prophylactically at the time when the bleeds were occurring - during the holidays - but would not use prophylaxis during term time.

He also discussed the issue of portacaths, which are used in some centres to gain venous access for very small children with haemophilia. He said that in his experience it was usually possible to gain access to even a very small vein by conventional means, particularly as it was often possible to make the vein larger by warming the patient's hands in a bowl of hot water. Furthermore, veins tended to get bigger the more that they were used. He tended to use portacaths only as a last resort when venous access by any other means was not possible.

He reminded members of the Society that as a patient group they had a great deal of political power and had the ability to influence the way in which they were receiving treatment. He said that his own local Group in Kent had

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SOCIETY AGM

been instrumental in persuading the commissioning agency that the highest standards of care should be given at all times. It was for this reason as much as any other that all severely affected children under his care were now being treated in a new centre with recombinant factor VIII, used prophylactically.

In the future Dr Winter expected to see better delivery systems for prophylactic treatment with factor VIII. This was likely to involve the use of a continuous infusion pump, attached to the skin which would deliver factor VIII into the vein at a slow and steady rate. This would make the factor VIII more effective and would also reduce the amount of factor VIII that needed to be injected overall.

Concerning recombinant factor VIII, Dr Winter said that he had been using this product in his centre for the past few months. The advantage of recombinant factor VIII is that it is not derived from human plasma although the genetic engineering process does involve the human factor VIII gene.

He believed that recombinant factor VIII is a genuine advance for people with haemophilia and that it is likely that in time it would replace factor VIII of plasma origin as the standard treatment for all patients with haemophilia. Although monoclonally purified factor VIII appeared to be safe there remained a theoretical possibility that viruses could be transmitted. The pattern of blood product treatment over the past twenty years had been for a new virus to be discovered every few years. On this ground alone he felt it likely that there might well be other viruses in the plasma supply that we had yet to learn about and that this was a concern for as long as patients with haemophilia were being treated with plasma-derived factor VIII.

In answer to a question from the audience on the relative effects of recombinant, high purity and intermediate purity factor VIII on the immune system he replied that he could not see any strong evidence for there being any significant impact from either recombinant factor VIII or high purity plasma factor VIII on the immune system, as they are both very pure. He commented that the use of intermediate purity factor VIII was no longer formally recommended by the Haemophilia Centre Directors' Organisation.

FACE LIFT FOR OXFORD

The Oxford Haemophilia Centre in Churchill Hospital has been refurbished.

The Centre has been in existence since 1968, and was the first to be opened in the UK. It has now been extended and completely refurbished. The Centre is in a single-storey building and also has separate clinical and laboratory wings. New automatic doors at the entrance have been paid for with money provided by the Haemophilia Society.

To mark the opening a meeting of 50 doctors involved in the care of people with haemophilia from around the country was held at the Centre in March. Guest speakers included Dr Charles Hay from Manchester who spoke about inhibitors and Professor Louis Aledort from New York who spoke about the benefits of prophylactic therapy.

The Oxford Centre has also recently appointed a new consultant



The new reception area.

haematologist to start in July. Dr David Keeling is currently a senior registrar at Addenbrookes Hospital in Cambridge. He did his general medical training at St Bartholomew's Hospital and went on to train in general haematology at the Royal Free and London Hospitals before spending three years in research at Middlesex Hospital. He has a particular interest in thrombosis. He is married with three children.

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NEWS FROM THE MANOR HOUSE GROUP

-The MHG give their view on hepatitis C

We are aware that the objectives of the Manor House Group (MHG) may cause some parents with young children to become concerned that they may be drawn into situations that they would prefer not to be as a result of the publicity surrounding our cause. This article may also be upsetting to those of you who have already endured the same pressures as a result of the HIV campaign. We hope however, that if you fit into either of these groups you will understand that MHG's objectives are to give support and to seek recompense for those of us who have hepatitis - particularly hepatitis C (HCV) - and that, of course, is most of us.

MHG hopes to achieve its objectives by working in harmony with the Haemophilia Society and we have been grateful for the support we have obtained. The group fully supports the efforts of the Society in raising awareness and the seeking of compensation in the same way that these were achieved for those with HIV. However, we feel that there are a number of aspects of the hepatitis issue that differ fundamentally from the HIV campaign.

The case for HIV was successful because there was - quite rightly - tremendous public sympathy and support as well as a moral obligation. The Society, in their present campaign, are using the same moral argument, but because HCV is not perceived to be as sensational as HIV, MHG feel that additional arguments need to be developed.

It is our belief that the problem was preventable.

At the time when the contamination of blood supplies took place it is quite true to say that the hepatitis C virus was undetectable and unknown; but the medical profession were aware of the risk of transmitting hepatitis B but nothing was done to prevent it. It is our contention that blood products should have been virally inactivated in order to remove the risk of transmitting hepatitis B at an earlier date. This would have prevented the transmission of hepatitis C as well as hepatitis B.

It is shocking to think that action taken at the right time to prevent an infection risk associated with blood and blood products (hepatitis B), a risk that has been recognised for a very long time, could conceivably have prevented both of the infections (HCV and HIV) that have had such tragic consequences for so many.

Of course, HIV and HCV do have different implications for the patient and HCV is generally not as devastating in the majority of cases as HIV but it does lead in many cases to

chronic liver malfunction and it can have noticeable effects from very soon after the initial infection. In the early stages, psychological effects apart, HCV is likely to disrupt the patient's lifestyle. Patients often suffer regular episodes of extreme fatigue which can seriously affect their ability to stay in regular employment and to enjoy happy family and social lives.

For those who are not infected the implications can be hard to grasp - have you ever been told that it is all in your mind? This is the reason, we believe, that the medical profession have, for the large part and for a long time, overlooked the seriousness of liver disease in people with haemophilia and von Willebrand's disease. We are well aware that hepatitis C has caused some people more problems than the haemophilia they have been treated for.

Manor House Group believes that the Government has an obligation to help everyone who has contracted hepatitis C through the use of blood products. It is, once again, a case of not exercising due care in the use of a medical treatment; it is a case of using one without due consideration for its side-effects.

It may be argued, by those who would wish to put up some kind of defence for what has happened, that hepatitis C was an acceptable risk. To us, this must be a totally unacceptable stance for anyone to take. It is surely one that must be rejected out of hand by those who have suffered the consequences of yet another unwanted insult to their bodies. How many of us were consulted before we were prescribed this acceptable risk?

We believe that a risk can only be considered acceptable when there is no alternative course of action available. For people with mild haemophilia, DDAVP - an alternative completely avoiding the use of blood products - was available. In addition had blood products been virally inactivated at an earlier date, and we find it inconceivable that they could not have been, the risk could have been virtually eliminated for many others.

MHG would like to hear your views. Do you agree with those expressed in this article? Please let us know. If you support us it is vital that you tell us because the proof of your support amplifies what we are able to achieve. We would especially like to hear from you if you have begun a legal action.

We can be contacted via the MHG, 5 Redfern Way, Norden, Rochdale, Lancs, OL11 5NZ, or if you leave a message with the Society's London office we will call you back.

HEPATITIS C AND LIFE INSURANCE

The Society was recently invited to give a talk to 70 Chief Medical Officers at a meeting of the Association of British Insurers. Dr David Evans, Executive Committee member and

GRO-D attended the meeting. Following further discussions at the meeting, it was agreed that the Society would have the opportunity to view and update the main source of information about haemophilia that the Chief Medical Officers use.

The Society will be drawing up guidelines in conjunction with the ABI that will show what people with haemophilia who are HCV positive should expect from life insurance companies. However, several points have already been established thanks to contact with the ABI. They are as follows:

If an individual who has already taken out a life insurance contract later discovers that they are hepatitis C positive, provided the individual completed the proposal form honestly at the time, that policy is valid no matter what diseases or health impairments the individual has since then contracted.

In the same way, an individual who is suffering from a serious medical condition but whose doctor has not told them about the position, is deemed to have taken out the contract honestly and properly, and will also be covered.

It is only on very rare occasions that a life insurance contract is voided and this can occur if an individual deliberately withholds a particularly serious material fact.

It follows therefore that there is no need for an individual to notify a life insurer of a change of risk, be this a risk of health, occupation or other factors. (NB, different considerations apply with annual contracts such as motoring and household, in these cases there is an obligation by policy holders to notify their insurer if the risk changes).

Appealing against an unsatisfactory decision from an insurance company is possible. The person concerned should ask his doctor to write to the company to ask for the decision to be reviewed.

Specific guidelines for people with haemophilia will be published in the Bulletin. If anyone has any problems with their life insurance policy let **GRO-D** at the national office know.

SCOTTISH NATIONAL BLOOD TRANSFUSION SERVICE DEVELOPMENTS FOR HAEMOPHILIA CARE

by Dr Perry, Director, SNBTS National Protein Fractionation Centre

Patients with haemophilia in Scotland and Northern Ireland will be pleased to hear that after much debate, consultation, argument and passion we have christened our high purity Factor VIII product. Henceforth it will be known as "Liberate". This is derived from the place of manufacture (Liberton, Edinburgh) and the hope that the product helps to liberate patients and facilitate a relatively free, normal healthy life. Other contenders for the title were H8 and Tartanate! - the latter did enjoy a brief informal existence after its adoption by haemophilia doctors to distinguish SNBTS products from others.

Clinical trials are now well underway with our new high purity Factor IX concentrate. This product has been designed to satisfy all current and anticipated future safety standards and we hope the product will also "liberate" haemophilia B patients. Unhappily "Libernine" does not tend to convey the same message of freedom in health so the search is on for a suitable name for this product too.

Hemofix (i.e. Hemo FIX) is the front runner at the moment but other suggestions will be warmly welcomed.

Other products under development by the SNBTS include Fibrin Sealant which may find useful applications in

Haemophilia care such as dental extractions - "Glenseal" has been suggested as a possible brand name but the association with double glazing or draught excluders is probably too close for comfort!

INDUSTRY INJECTS CASH

The pharmaceutical industry has generously contributed towards the cost of this year's Adventure & Sport holidays for young people with haemophilia. Alpha Therapeutic, Bayer, BPL, Immuno and Pharmacia have all pledged sponsorship. Graham Barker, the Society's Director of Services said: "The holidays have enabled hundreds of children to enjoy a wide range of challenging activities over the years." Sponsorship of over £1,600 from the London Marathon will also be used towards the holidays.

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BIRMINGHAM HEPATITIS DAY

Following the success of last year's Hepatitis Days, the Society began this year's Hepatitis Roadshow in Birmingham on Saturday 6th May. The meeting was chaired by Andy Cowe of the Haemophilia Society Executive Committee.

Following helpful suggestions from members who attended last year's meetings, the Society made some improvements on the format of the day.

With the new format we were fortunate enough to have the expertise of both a haemophilia consultant, Dr Mike Makris (Sheffield), and one of the country's leading liver specialists, Dr Geoffrey Dusheiko (Royal Free, London). Both talks were very informative, and the addition of a liver specialist proved successful in ensuring that participants were given a well-rounded and detailed picture.

As well as the addition of a liver specialist, the meeting was extended to span a full day. This gave people time to chat over lunch and think of questions they wanted to ask the doctors in the afternoon. The Society

also provided a creche for 8 children so that as many parents as possible had the chance to attend the meeting.

The last item of the day was a Hepatitis Campaign update by Graham Barker. This proved to be a vital addition as Graham was inundated with questions! All round it was an extremely successful day, and the best attended Hepatitis Meeting so far, with a turn out of nearly 70!

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