Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

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HEPATITIS C CAMPAIGN NOW LAUNCHED

The Haemophilia Society has launched a campaign for Government help for people infected with the hepatitis C virus.

Speaking at the launch Society Chairman The Rev Preb Alan Tanner said: "Over 3,000 people with haemophilia have been infected with this potentially life-threatening virus through treatment with clotting factor concentrates before 1986 and over 40 have died. They were infected in exactly the same way as over 1,200 people with haemophilia contracted the HIV virus - through treatment with contaminated blood products. Yet while those infected with HIV receive financial help from the Government those with hepatitis C receive nothing."

The campaign objectives are:

- More equitable treatment in financial terms between those people with haemophilia infected with hepatitis C (HCV) through contaminated blood products and those infected with HIV through contaminated blood products, specifically:

  An across the board ex-gratia payment to all those infected with HCV through contaminated blood products.

  Access to a hardship fund for those who become ill and the dependants of those who die.

  As a matter of urgency, payments to those who are already ill and the dependants of those who have died.

- Adequate resources for haemophilia centres to enable them to provide the best possible treatment and care for people with haemophilia and hepatitis.

- Adequate resources for research into the prognosis and treatment of HCV.

- A public education programme that provides reassurance about the methods of transmission of hepatitis C and explains that ordinary social contact is not a means of transmission.

In addition to the campaign the Society has been active on other hepatitis matters. It has been successful in persuading the Government to give some funding to support research into the effects of living with hepatitis C. There are plans to employ a researcher for six months to investigate the effects of hepatitis C on people with haemophilia.

The Society has also received the new guidelines on the diagnosis and management of chronic liver disease in haemophilia from the Haemophilia Centre Directors' Organisation.

Commenting on the guidelines, Graham Barker Director of Services for the Society said: "The Society welcomes the publication of the guidelines, particularly the recommendation that consultant liver specialists are involved in treatment. "A factor to consider is that to follow the guidelines will probably cost the health service more. The Society will be writing to Health Authority purchasers to highlight the need for them to assign sufficient budgets."

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EDITORIAL by Bulletin editor Andy Cowe

The launch of the hepatitis C campaign is only the beginning of the Society's efforts to get fair treatment for people with haemophilia infected with the hepatitis C virus. There is a long way yet to go before we can convince the Government that they have a moral duty to help.

A good start has been made, with questions and debates held in the House of Lords, but we also need to apply pressure through Members of Parliament. To do this needs the support of the members of the Society as a whole. A letter to a local MP from one person may not appear to carry much weight, but if thousands of Society members write to their MPs supporting the campaign the weight of opinion can only help our cause.

The aims of the campaign are detailed on the front page of the Bulletin, but the reasoning behind those aims is equally important. People with haemophilia were infected with hepatitis C (HCV) in exactly the same way as those who were infected with the HIV virus. Hepatitis C is a life threatening condition that also seriously affects the quality of life for those infected. People may not go on to develop serious liver damage, but equally they do not know if they they will. This uncertainty can have a bad effect on the lives of people infected with the virus, who cannot confidently plan for the future.

The Society accepts that while there are some differences between the HIV and HCV infections, the similarities are strong enough to warrant the Government accepting its moral duty to help those people with haemophilia infected with HCV.

The attempt to persuade the Government may be a long and difficult one, but your support is needed if we are to be successful.

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
- ★ 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.

BPL
BIO PRODUCTS LABORATORY

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.

In this issue

GUIDELINES ON THE DIAGNOSIS AND MANAGEMENT OF HEPATITIS C

The Guidelines on the Diagnosis and Management of Chronic Liver Disease in Haemophilia have just been produced by the working party on chronic liver disease in haemophilia of the UK Haemophilia Centre Directors' Organisation. The working party is made up of: Professor F E Preston, Dr G Dusheiko, Dr C A Lee, Dr C A Ludlam and Dr P L F Giangrande.

The main points of the Guidelines are:

- **People should be kept fully informed about the results of all their laboratory tests, including their HCV antibody status. Clinical implications and findings should also be discussed.**
- **Consultant liver specialists should be involved in treatment decisions.**
- **All people who have been treated with blood products should be tested with an HCV antibody test (this tests if you have been exposed to the hepatitis C virus).**
- **People who have been treated with blood products and are HIV positive, but test HCV antibody negative should have a PCR test (this tests for the actual presence of the virus).**
- **HCV antibody tests should be offered to all sexual partners of people who test positive for the HCV antibody. (This is because there is thought to be a slight risk of sexual transmission).**
- **People infected with HCV who have abnormal ALT/AST levels (this is the presence of an enzyme in the blood which may indicate abnormal liver function) should attend for review at approximately 4 month intervals.**
- **People with evidence of chronic HCV-related liver disease should be considered for treatment with interferon, but for people with severe liver disease interferon is of little value and may be hazardous.**
- **The genotype of the hepatitis C virus and the amount of the virus circulating in the blood should be determined before treatment decisions are taken. If the virus present is of genotype 1 and/or there are high levels of circulating virus, then sustained responses to interferon are less likely.**
- **Hepatitis C can be managed in most people without the necessity for a liver biopsy. If a biopsy is undertaken (usually where a focal lesion has been detected by ultrasound scan) then the biopsy should be performed by an experienced operator.**
- **Endoscopy is recommended every five years for people over the age of 45 and/or those infected with the virus for 30 years - and this interval could be reduced for people co-infected with HIV.**
- **For people with cirrhosis abdominal ultrasound scans and alpha fetoprotein determination are recommended at approximately four monthly intervals.**

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Directory includes new information on HIV and AIDS

A new easier to use HIV and AIDS Treatments Directory is now available as part of the National AIDS Manual.

The new directory has been designed for both quick reference and for more detailed reading and research. A wide range of treatment issues are looked at in the opening chapters. These are followed by a simplified series of A to Z sections which include treatments, opportunistic infections, complementary and alternative therapies and treatment centres.

All the information has been completely updated and revised. New references include:

- all treatments for HIV and AIDS, including drugs for opportunistic infections as well as antiviral drugs and immune modulators.
- detailed information on complementary and alternative therapies.
- comprehensive listings of clinics and treatment centres.
- an in-depth overview of treatment and lifestyle choices.
- updated information on getting treatment, the practical issues and the problems of obtaining and taking drugs.

For further information, contact: the NAM Charitable Trust, 52 The Eurolink Centre, 49 Effra Road, London SW2 1BZ. Tel: 071 737 1846.

A PROFILE OF SOCIETY CHAIRMAN – REVEREND PREBENDARY ALAN TANNER

The Reverend Prebendary Alan Tanner holds numerous offices in diverse areas. As well as being chairman of the Haemophilia Society and the Macfarlane Trust, he is also chairman of the World Federation of Haemophilia and of the Eileen Trust. He is on the board of governors of two schools and is chaplain to several livery companies. His current professional appointments include that of Rector of the church of St Botolph without, in the City of London, priest-in-charge of four neighbouring churches, Area Dean of the City and Prebendary of St Paul's Cathedral.

When the Bulletin spoke to the Revd Prebendary Alan Tanner in February, he had just celebrated his 70th birthday. Yet there are no plans to take things a little easier from now on.

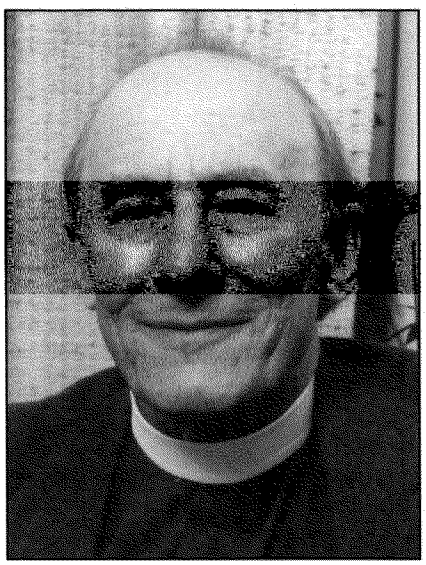
Alan aims to stay at St. Botolph's for another couple of years until the future of the City of London's churches - some of which currently hang in the balance - will be decided. There is still some work to be done on the church of St. Botolph following the Bishopsgate bombing a couple of years ago although restoration will be complete in a few months.

And then, of course, there are his 'hobbies' ... haemophilia and education.

Alan is a Governor of the Central Foundation School and Chairman of his old school - Coopers' Company and Coborn. He says: "At the moment there are all sorts of issues in education, for instance grant maintained status versus local authority control. There are as many issues in education as there are in the health service."

Alan's son, Mark, a sculptor, GRO-C GRO-C He also has three daughters, the eldest of whom is the Administrator at St. Botolph's and the youngest - identical twins - are art teachers.

Alan and his wife, Tess, live in GRO-C North West London. He said:



Reverend Prebendary Alan Tanner

"It's very convenient because it's near to the Royal Free Hospital and I'm head of the Royal Free fan club." One of son Mark's sculptures can be seen at the new building for the Haemophilia Centre there.

As chairman of the Haemophilia Society, Alan's job is to hold all the activities of the Society together. He presides at meetings, represents the Society when there is contact with the Government, medical authorities or other interested parties. Generally, he aims to see that support for people with haemophilia is maintained.

His roles as chairman of the Macfarlane Trust and the Eileen Trust include presiding at meetings, managing the funds and helping to decide on how to administer the money.

Developing countries are of particular concern for Alan and he has visited India on several occasions as chairman of the World Federation of Hemophilia.

"It is worrying to see the plight of people with haemophilia over there. But the WFH is a strong organisation and what they have done recently is very, very encouraging."

As Rector of St. Botolph without, Alan looks after the parish, advising and counselling people. He conducts daily services on week days (since the City practically closes at the weekend), and his Sunday job is that of preacher of the Charterhouse consisting of 40 Brothers of the Foundation, some of whom are retired priests. He is also Area Dean of the City and is priest-in-charge of four other City churches. As a prebendary of St Paul's Cathedral, there is some preaching work to be done but generally the day-to-day work is carried out by the Dean and Chapter. There are around 30 prebendaries in the diocese of London and he maintains that really the title is 'rather like a long-service medal'!

Alan first set out to become a scientist. He won a scholarship to study physics at Cambridge University but the following year 1944 - was called up to the navy. This gave him time to reflect, he thought about carrying on with a regular commission in the navy but, instead, he decided on the Church and went to Oxford to read theology.

"I never saw switching from science to the Church as a big thing," he said. "Scientists and theologians are alike in that they are both thinking people."

His experience as a clergyman is obviously invaluable when it comes to dealing with those affected by haemophilia.

"I see people as they go through various stages of difficulty. There are the newly diagnosed and their families - especially those with no history of haemophilia. There are the problems faced by girls who are potential carriers, they need to be counselled on marriage and children. Then, of course, there is now the hepatitis C issue and the very difficult cases of those with HIV infection."

Alan combines his formal church role with that of chairman of the Haemophilia Society when there is an annual thanksgiving service held at St. Botolph's. The service is open to everyone who wishes to remember anyone they have known who has had haemophilia.

He added: "My overriding concerns are for all people with haemophilia - among whom are those with HIV/AIDS and, now, those with hepatitis C. I am particularly concerned about those who are isolated. People living in the great conurbations are served well by the Haemophilia Centres but for those living in the country, help is not so readily available. I aim to see that the Society looks after everyone who needs support."

FOUR YEARS ACTIVITIES OF THE HUNGARIAN ASSOCIATES OF HAEMOPHILIA

by Tamas Pelyhe, President of the HAH

The story of the HAH began in the flat of a person with haemophilia with a discussion. Ten Hungarians had twenty views about the planned organisation. In spite of this "harmony" we were able to found our society!

In 1990 when the HAH was born haemophilia treatment was based on cryo and prothrombin complex concentrate in Hungary. Outworn conceptions of treatment were common, the doses varied on a large scale between the different treatment centres and followed always the available supply. Briefly, the patients were under treated. There was no patient education. Joint and musculoskeletal problems were widespread. Patients were thought to be disabled people with very limited possibilities. The only benefit of the lack of the commercial factors was the relatively low measure of the HIV infection.

We started without money or instruments, without any experience of how to maintain such a society. (After the changes in 1989-90 hundreds and hundreds of civil organisations worked on this way in Hungary). With a big delay and very little chance to grow, but a lot of enthusiasm to represent the people with bleeding disorders.

The most important goal has been to achieve the comprehensive haemophilia care and to have an adequate and safe factor supply. In spite of the real tension between patients, relatives and haemophilia treaters we tried to create the common activity and cooperation of the interested parties. The mission of the HAH was to show such activity which can prove to everybody that persons with haemophilia are able to live a normal life if adequate treatment is available.

First of all we tried to increase the claims of our haemophilia community. We made known what happens in the world. The contact with the other European haemophilia societies guaranteed the arguments. We invited European visitors to our events. Some of the lectures of these foreign haemophilia experts were a revelation and not only for the patients. The summer camps proved to be the synthesis of the comprehensive haemophilia care. Meetings, haemophilia days, and general assemblies delivered the information. Today our programmes have full

The staff at hungarian Haemophilia Association from left to right: T. Pelyhe, J. Galir, M. Kardos M.D., Eva Magori, L. Kalasz M.D., L. Nemes M.D., L. Toth

houses. Dozens of edited booklets have been successful. Several reports in the media/press made the disease and the HAH known to the public. Education programmes are going on everywhere. We tried to proliferate the long experiences of the west European countries adopting their activities.

Since 1992 the health policy ensures that we have commercial factors and in 1994 haemophilia treatment has dramatically changed in Hungary. Products that are not virally inactivated are no longer used and the safe factor supply has grown from 0.5 IU to approx 1.4 IU/person. Selective prophylaxis and home therapy have appeared and become more and more common. HAH and the responsible haemophilia treaters are introducing regular and controlled home care.

The Hungarian Association of Haemophilia is a voluntary, civil organisation. The unpaid staff has not enough time to manage the affairs above. Sometimes it appears impossible to maintain this activity. We are urged to surmount this obstacle because after all our work is a wonderful adventure.

Hepatitis C Litigation – Time Limits for Making Claims

The Haemophilia Society can neither encourage nor discourage individuals from pursuing litigation (and certainly cannot advise on the merit of any individual case) but the Society feels it important to point out that those who are considering seeking legal advice concerning a possible claim for medical negligence, should not delay in seeking advice in view of the strict time limits which apply to such claims.

The following advice has been received from a leading firm of solicitors experienced in haemophilia litigation, with regard to time limits:

"There may be people with haemophilia infected with the hepatitis C virus who are considering seeking legal advice concerning a possible claim for medical negligence. If you are in this position, you should not delay in seeking advice in view of the strict time limits which apply to such claims.

"By law, if a person has been "injured" as a result of medical negligence, then a claim must be made within 3 years of the date of the "injury" ie the date of infection with hepatitis C. Most people are completely unaware of having been affected at that time. In such cases, the three year time period does not begin until the date that they first become aware that they have been infected. This will usually be when a person is informed of a positive test result."

Individuals concerned may contact a lawyer of their choice and the Society has a list of solicitors currently involved in hepatitis claims.

Individuals in receipt of treatment in Scotland and Northern Ireland should please bear in mind that advice should be sought in their respective countries.

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PROPHYLAXIS AND THE FAMILY

– The Bulletin talks to three families

GRO-A is seven years old and has been receiving prophylactic treatment for his severe haemophilia A since he was four.

His mother, GRO-A tells how GRO-A's **treatment affected him and the family.**

"We first heard about prophylaxis from other parents, and it seemed to be the right thing for GRO-A, as he had already had a number of bleeds and we wanted him to be able to lead as normal a life as possible," she said.

GRO-A was transferred to St Thomas' Hospital in London for the prophylactic treatment.

"They were extremely helpful," she said. "At first we had to go in to the hospital three times a week for his treatment, and to learn how to administer it ourselves. But after a couple of months they suggested that we try treating GRO-A at home."

GRO-A and her husband GRO-A took turns in giving GRO-A his treatment, which he has three times a week into his arm.

"Now GRO-A very rarely misses school because of his haemophilia and is a healthy, happy little boy."

"At first it was very difficult," she said. "We had a lot of difficulty in finding a vein. St Thomas' had warned us not to try to give the injection for too long - if we couldn't find the vein after three tries then we should stop, as it was then unlikely that we would succeed.

"But we got a lot of support from St Thomas', and the nurse would also come around to help. It was very reassuring to know that they were there to give us support, even if it was simply advice over the phone."

Things got a lot better for a while, but then the problems in finding a vein started up again, and St Thomas' suggested that they stop the treatment for a while.

"Frankly it was a relief when we stopped, we'd lost confidence and weren't succeeding," said GRO-A. The relief soon faded when GRO-A had a bad bleed.

"It was then that we realised that the treatment *really was worth all of the trouble," said* GRO-A. "GRO-A is back on prophylaxis now and is getting on very well.

"We do still have bad times and good times, but it is better for everyone that GRO-A is on the treatment. He has had a bleed in spite of receiving regular doses of factor VIII, but that was because he had outgrown his treatment and needed larger doses."

GRO-A is quite clear about the benefits of prophylaxis. "Haemophilia affects the whole family. Before GRO-A was on the treatment he would have bleeds in the middle of the night and we would have to take him to hospital. Our two daughters, GRO-A and GRO-A would go to bed not knowing if their brother and parents would be there in the morning or if someone else would be looking after them. Also it is a great worry to children if their brother is ill - it even affected their school work.

"Now GRO-A very rarely misses school because of his haemophilia and is a healthy, happy little boy. He doesn't do many sports that involve running because his hips were affected by earlier bleeds, but he does a lot of swimming and cycling. Before he was on prophylaxis he always had a lot of bruises, but now he very rarely has one at all. It is very reassuring to know that the regular injections three times a week keep the factor VIII level in his blood topped up."

Her advice to anyone thinking about prophylaxis for their child is: "I'd heartily recommend it, but don't be discouraged if it isn't easy at first. You will have a lot *of ups and downs,* **but if you work as a** team with your treatment centre you will eventually see the benefits. It is also very important not to feel isolated, there are lots of other parents in your situation, try to get in touch with them and you can support each other and talk over problems that you have faced - it really *helps."*

The last edition of the Bulletin featured the clinical aspect of prophylaxis. For this edition, the Bulletin spoke to three families to find out what prophylaxis means for them. Here are their stories.

What a transformation

by Mrs GRO-A

Prophylaxis is wonderful. GRO-A and GRO-A ages 15 and 13, have only had prophylaxis for 15 months after transferring their care from Birmingham Children's Hospital to St Thomas' in London.

Before prophylaxis bleeds were fairly frequent, sometimes serious enough to need hospital admission, and joints became progressively more damaged. There were frequent trips to hospital for advice, even though we were on home treatment, quite a bit of pain, lots of inconvenience and interruption to schooling and social events. GRO-A said he used to feel guilty when bleeds interfered with family plans, annoyed because he had a bleed and didn't want it, and felt let down and burdened by his haemophilia.

Now, the difference is almost unbelievable. Prophylaxis has helped the boys to feel as free as their mates, lets them forget that they have haemophilia, lets them join in team activities because they can have **confidence that they will not be letting the team down at the last minute, frees them from always worrying** *about their health,* from checking when waking every morning to see where the bleed is today. It allows them to feel more independent of their mum - quite important to *teenagers!*

The tangible disadvantage is having to inject Factor 8 three times per week; a price well worth paying. Another possible disadvantage is the effect of a greater volume of Factor 8 on their health, although all the tests so far have indicated improvement rather than any deterioration.

As parents we no longer have to watch them suffer, we don't have to worry when they do things which may have caused bleeds before, we can enjoy watching them flourish, we can work freely without always being prepared for the bleep to go off. And the almost certain prospect of one son being wheelchair-bound has gone. Our only regret is that we didn't ensure that they had prophylaxis years ago.

GRO-A

GRO-A

GRO-A *left*

Prophylaxis Wins

by Mrs GRO-A

I find the debate on prophylaxis very interesting. My son, GRO-A, is just 7 years old; he has severe haemophilia A and is under St Thomas' Hospital, London.

Until about April last year, GRO-A was unable to go on prophylaxis as his veins were very difficult to access and I was unable to administer treatment myself, *so GRO-A was treated on demand at St* Thomas'.

Given GRO-A's relatively late start on prophylaxis, I feel I have had considerable experience of treatment both on demand, and as a preventive measure.

GRO-A's veins are far from brilliant and giving him treatment first thing in the morning before school, three times a week, is like taking an exam! But when we were "treating him on demand", GRO-A was having many bleeds, especially in his ankles and knees (in fact he was practically on prophylaxis he was needing so much treatment).

Now I rarely have to treat him because of a bleed. He no longer has to crawl around the floor because a bleed has occurred during the night and he cannot walk in the morning: some of these bleeds took a couple of days treatment to "cure". Prevention is better than cure: I firmly believe prophylaxis will have benefited him greatly in later life.

Physical benefits apart, the other advantages are worth the three times a week trauma. GRO-A can jump around, climb castle walls, and generally zip around without the constant background chant of "GRO-A, be careful! Mind, be careful!" He has definitely been bouncier since starting on prophylaxis. (I think this is an advantage!) In addition, people feel happier looking after GRO-A, knowing he has been treated - and so do I! I spend less time being on edge, wondering if I am going to be bleeped.

One argument against is that by giving prophylaxis, attention is being drawn from the condition - but the fact is the condition does exist, and far better to prevent bleeds in the first place, and lead a normal life, than constantly be aware that an action may cause a bleed. After *treatment, we can all relax. Going on holi*day to France last year (our very first trip abroad with GRO-A) happened because we were on prophylaxis and we knew we wouldn't be carrying GRO-A around. He would definitely have had at least one bleed on that holiday that would have made life uncomfortable for him.

I know that cost is another consideration - here again I believe prevention can be cheaper than the constant extra medical attention GRO-A would probably need when he was older due to damage to his joints.

Prophylaxis had drastically reduced GRO-A's bleeds and made us all more relaxed.

Dear Doctor....

Dear Doctor

I have severe von Willebrand disease and have in the past been treated with cryoprecipitate. Is there any alternative, and are there any dangers associated with cryo ?

Cryoprecipitate is an extract of blood plasma containing both factor VIIIc and von Willebrand factor. Because of the high concentration of von Willebrand factor it is a highly effective treatment. One disadvantage is that some individuals have developed allergic reactions to it after repeated uses. However, it is no longer used as first line treatment for von Willebrand's disease for three main reasons:

1. DDAVP can be used in some individuals with mild vWd. In some patients the drug DDAVP can be given by intravenous infusion. This is suitable for some types of vWd, but not all, and is generally most effective in mildly affected individuals. It is not suitable for patients with severe disease ie very low levels of von Willebrand factor) because it works by releasing your own von Willebrand factor from storage sites.

2. Non heat-treated blood products carry a small risk of viral transmission. Unsterilised blood products may still transmit viral infections. While this risk is reduced by screening all blood donors for evidence of infection by hepatitis viruses (hepatitis B for many years, hepatitis C from October 1991) and HIV (since 1985) a very small risk of viral transmission remains. Because of this it is preferable to use heat treated (sterilised) blood products wherever possible.

3. Newer sterile concentrates are available which are effective and safe. What products are available? There are two products widely used at present. These are both 'intermediate purity' factor VIII concentrates previously used for haemophilia which are known to contain adequate quantities of von Willebrand factor. They are BPL concentrate 8Y producedin the UK and Haemate P. which is produced in Germany. There is also a newer pure von Willebrand factor concentrate which is manufactured by CRTS Lille in France. None of these products has been known to transmit any of the viruses mentioned above. Individuals with severe von Willebrand disease should be given vaccine against hepatitis A as soon as the condition is diagnosed as this will further reduce the risk of infection with these viruses from any blood products. Where blood products are needed, one of these concentrates is now preferable as first treatment rather than cryoprecipitate.

The answers for this edition's dear doctor section come from Dr Paula Bolton-Maggs of the royal Liverpool Children's Hospital and Dr Charles Hay of Manchester Royal Infirmary.

Very occasionally, despite the use of these products a person with von Willebrand disease may still bleed excessively for reasons which are not fully understood - perhaps because the von Willebrand factor in the concentrates has been altered in some way by the processing and is not exactly the same as normal. In these instances one might use cryoprecipitate but only when the other approaches have been unsuccessful.

Dr Paula Bolton-Maggs

Dear Doctor

Are there any drugs/anaesthetics that are commonly used by people with haemophilia that should not be used if they also have the hepatitis C virus, if so what are they and what alternatives should be considered?

Most patients infected with hepatitis C will have very mild hepatitis and need not take special precautions with drugs since their liver will be functioning more or less normally. The small minority of patients with more severe liver disease such as cirrhosis may metabolise and eliminate some drugs more slowly than usual leading to a build up of the drug in the circulation. This leads to increased toxicity with some drugs whose toxicity is dose related, and to an exaggeration of the therapeutic effect with most drugs. Some drugs are prescribed in reduced dosage to such individuals. These include sedatives, pain killers, some diuretics, non-steroidal anti-inflammatory agents, steroids and many others.

Dear Doctor

Can the hepatitis C virus be spread by clearing up blood spillage, such as from a child's nose bleeds. If so, what precautions should be taken.

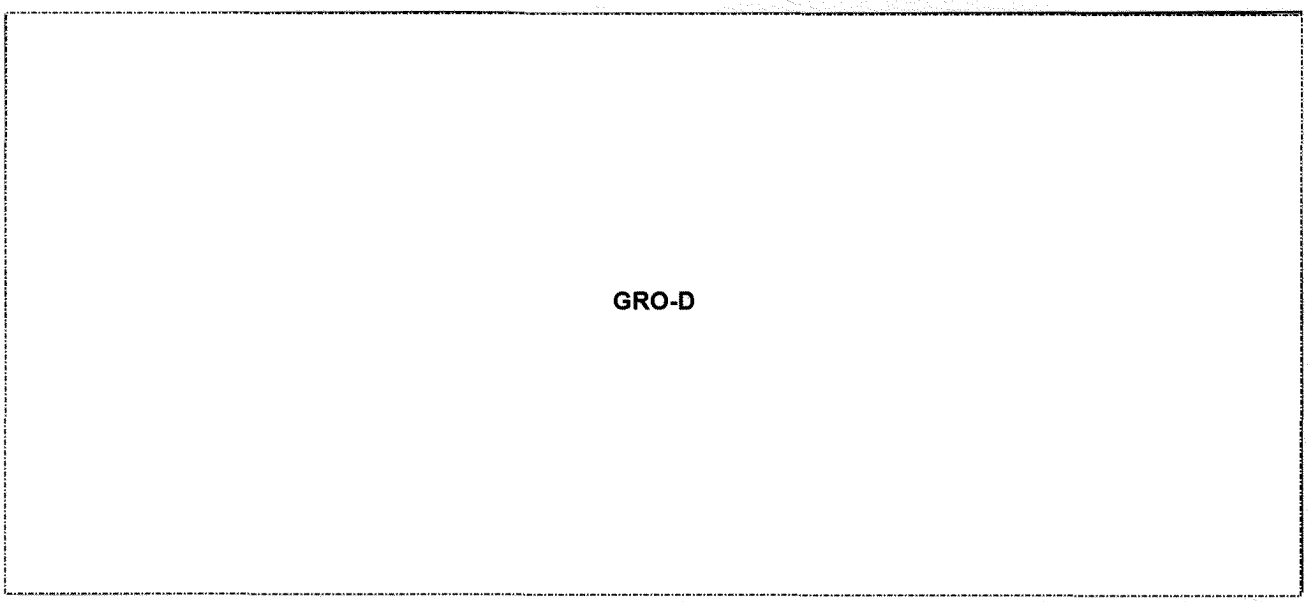
If the patient is hepatitis C positive, then it is theoretically possible to contract hepatitis C from their spilt blood, although the risk is very small since it would have to enter the blood stream. This risk would be greater if the person clearing up the blood had an open wound or skin disease such as eczema or psoriasis leading to broken skin. All that is usually necessary when inadvertently exposed to blood is to clean one's skin afterwards with soap and water. Plastic gloves should be worn when mopping up the blood.

Needlestick injury presents a greater but still small risk of transmission of hepatitis C, and all needles should be disposed of carefully in Burns Bins. Hepatitis C is not particularly infectious and is less readily transmissible than Hepatitis B or HIV from individuals infected with these viruses.

Bear in mind that only patients treated with factor VIII concentrate before 1985-86 will have contracted hepatitis C from concentrate and those below the age of 10 will therefore be very unlikely to be Hepatitis C positive. Bear in mind also that nose bleeds are more a feature of von Willebrand disease than haemophilia. Most people with von Willebrand disease have mild type 1 disease and respond to DDAVP. Few of these people will have been treated with factor VIII concentrate and most will not have been infected with hepatitis C.

Dr Charles Hay

THE CHAIRMAN'S CONFERENCE A GREAT SUCCESS



On the 19-20th November last year the Society held its biggest ever conference for its members at the de Vere hotel in Coventry. Nearly 250 people attended this two day event, including a number of children. Creche facilities were provided for 20 young children enabling many parents to attend a Society meeting for the first time. These parents not only had the opportunity to listen to the lectures and take part in the workshops but also to meet and make contact with other parents. This was one of the successes of the conference.

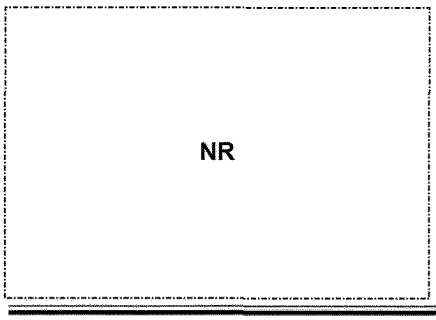
Unfortunately only 20 creche places could be provided and a large number of parents had to be turned down. This shows how important it is for the Society to offer children's facilities at the conferences it organises.

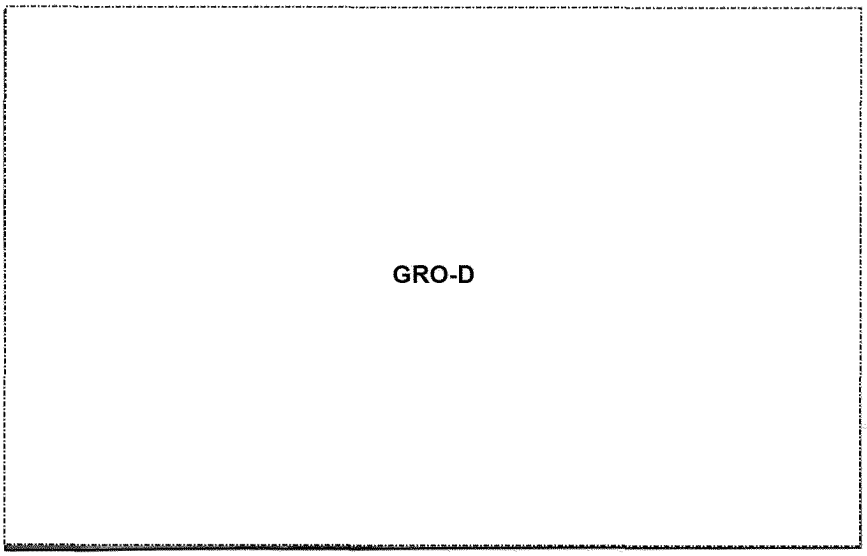
The two days were taken up with lectures and workshops on a range of different aspects of haemophilia treatment and care. The Saturday morning kicked off with two presentations. Dr Paul Giangrande from the Oxford Haemophilia Centre spoke about the potential of recombinant factor VIII in haemophilia treatment and Dr Jonathan Cooke, the Director of Pharmacy at the South Manchester University Hospitals NHS Trust spoke about the role of health economic analysis in haemophilia care.

There were discussion workshops on HIV treatment, von Willebrand disease, prophylaxis, inhibitors, orthopaedics and - the highlight of the conference - a session by Dr David Mutimer from the Queen Elizabeth Hospital Birmingham on hepatitis C. For many of those attending this was their first chance to hear a liver specialist talking in detail about hepatitis C.

There were also more informal drop-in sessions that provided opportunities to meet the staff and members of the Society who were directly involved in some of the Society's activities. These included benefits advice, support to parents of young children and fundraising. The Macfarlane Trust was represented and both the Birchgrove Group and the Manor House Group ran their own sessions to explain who they were and what they planned to do. Both of these latter two sessions attracted large audiences.

The weekend finished with a lecture by Professor Ian Peake from the Royal Hallamshire Hospital, Sheffield, on the subject of gene therapy and haemophilia. For most people the conference was a great success with opportunities not just to receive the latest information but also to chat on an informal basis with others about shared experiences.





Children were catered for at the Conference

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TWO PRODUCTS LICENSED TO TREAT HEPATITIS C

Two products for the treatment of hepatitis C have been licensed recently.

The first, Roferon-A is a genetically engineered product researched and developed by Hoffman-La Roche Ltd. It is in the form of an injection that people can be trained to give themselves. The drug works in the same way as natural interferon, by helping the body to kill the virus particles which are infecting it.

Speaking at the launch of Roferon-A in hepatitis C, Professor Howard Thomas from the Liver Unit at St Mary's Hospital, London said: "Hepatitis C is a difficult disease to treat, but we feel we are making advances all the time and using interferon in different ways to achieve better results in more patients." The second product - Vitaferon R from Schering-Plough is also administered by injection.

Describing the rationale behind the launch Peter Martin, Managing Director of Schering-Plough (UK) pointed out, "people with hepatitis have very different needs from other patients on interferon therapy. It is to meet those needs that Vitaferon and the accompanying patient support package have been developed."

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MANOR HOUSE GROUP TELLS US ABOUT ITSELF

Manor House Group was formed in July of 1994 by the coming together of a few like-minded members of the North West and Birmingham Groups of the Society. Through informal contacts made at various Society events they came to realise that they had in common the belief that the incidence of hepatitis among people with haemophilia and those with von Willebrand's disease was not being dealt with as the serious issue that they felt it to be.

To give its efforts some focus, Manor House Group declared certain aims which are:

- To encourage awareness of the issues arising from hepatitis infection which has been caused by infected therapeutic products and to overcome complacency and inactivity where these restrict the availability of information.
- To promote the concept of national minimum standards of care for the diagnosis, monitoring and treatment of liver conditions acquired by those suffering from haemophilia and other haemorrhagic disorders.
- To ensure that blood products are available to infected patients which are selected using clinical criteria only.
- To encourage,where appropriate, those who are infected and those who are affected to consider litigation as a means of obtaining compensation and to actively pursue more general steps leading to compensation from public funds.
- To maintain close scrutiny of events in public affairs, healthcare provision and commerce which bear on the care and well-being of those whom the Group represents.
- To cooperate constructively with any organisation whose aims are consistent with and complementary to its own.

Hepatitis infection is, in the history of haemophilia, one of the most serious issues with which we have had to deal and is certainly the single most important issue that has ever directly affected such a high proportion of us.

It is not Manor House Group's intention to be alarmist or to generate fears where presently there aren't any but we do intend that the seriousness of the problem is appreciated and that obstacles which lie in the way of obtaining acceptable solutions to it are overcome.

Although Manor House Group does not envisage becoming a membership organisation we do seek the views and opinions of anyone who is infected (or affected in some other way) by hepatitis C. We can be contacted by dropping a line to:

Manor House Group, 5 Redfern Way, Norden, Rochdale, OL11 5NZ.

WHAT YOU REALLY NEED TO KNOW ABOUT HEPATITIS

The Society has a limited number of copies of a video about hepatitis available for loan.

Introduced by John Cleese, and presented by Dr Robert Buckman the video explains simply what hepatitis is, how it is treated and precautions that should be taken.

If you would like to borrow a copy of the video, please contact the Society national office.

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HEPATITIS DAY

The Society is organising a Hepatitis Day in Birmingham on Saturday 6 May 1995. The meeting will be held in the Apollo Hotel, Hagley Road, Birmingham, starting at 11.00am and lunch will be provided at a charge of £5 per head. The Day will include presentations from a liver specialist and a haemophilia consultant.

Details and application forms are available from GRO-D at the national office, and invitations will be sent to all members in the area nearer to the date.

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