Witness Name: Katherine Victoria Burt

Statement No: WITN6392001

Exhibits: WITN6392002 - WITN6392267

INFECTED BLOOD INQUIRY

WITN6392193

1997 ISSUE 1

THE BULLETIN

Magazine of the Haemophilia Society

NOT RELEVANT

NOT RELEVANT

WELCOME TO THE NEW LOOK BULLETIN

We've completely redesigned the Bulletin to make it more user friendly and make sure that everyone is kept informed about what is going on in the world of haemophilia.

In our new-look, brighter pages you'll find articles on campaigning, fundraising, a new families' section, as well as all the information on treatment and Society issues you'd expect.

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Member of the World Federation of Hemophilia

Editor of The Bulletin
Andy Cowe

The Haemophilia Society gratefully acknowledges the financial support of the following companies whose contributions to our Pharmaceutical Industry Fund help us to provide our membership services.

Many thanks to:

Alpha Therapeutic
Bayer
Baxter Healthcare
BPL
Centeon
Genetics Interest Group

Editorial by Bulletin Editor Andy Cowe

Welcome to the first issue of The Bulletin in 1997 in its new format. The Bulletin is our main means of communication with our membership and we are always on the lookout for ways of making it look more attractive. Please let us know what you think of the new style and as always we welcome ideas for future articles and features.

It is always encouraging to report a "good news" item – our last edition included an article looking for a family for 13 year old GRO-D Bulletin readers responded quickly to this request with eighteen offers of help. A small number of these are now being followed up in detail and we hope that GRO-D will soon be settled with a new family. We thank all those who responded, and who have demonstrated how caring and generous our haemophilia community can be.

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
* The Essentials of Haemophilia Care
* Haemophilia and School
* Haemophilia and Hepatitis C
* 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:

* Information and help with benefits, in particular Disability Living Allowance
* Parent Support Network
* Hardship grants
* Centeon Call 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.

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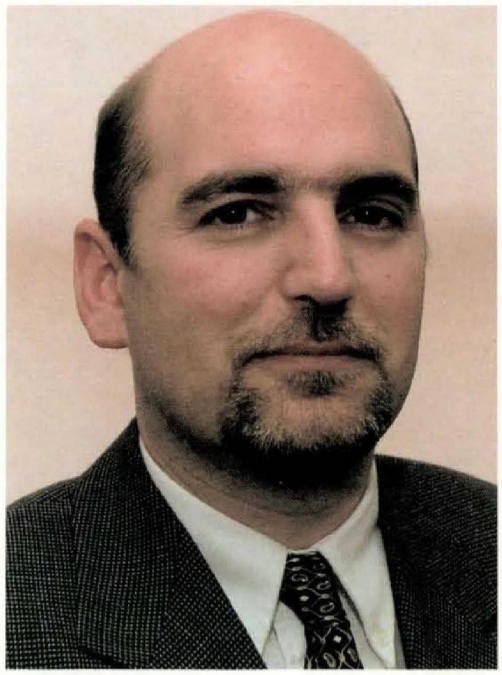
CHIEF EXECUTIVE APPOINTED FOR THE HAEMOPHILIA SOCIETY

Tony Wilson was appointed as the Chief Executive of the Haemophilia Society in February.

Tony joined the Haemophilia Society just over a year ago. He has a broad background in charity work and has held senior management positions both in campaigning and membership-based organisations, including the Women's Royal Voluntary Service.



Tony Wilson

His role is to provide strong leadership for the Society, ensuring that it operates efficiently to provide maximum benefit to its members.

He is also responsible for ensuring that the Society operates on a sound financial footing, leading fund raising activities and managing the implementation of the Trustees' strategic plans.

Tony is married with two young children and lives at GRO-C

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NEW CONSTITUTIONAL ARRANGEMENTS

Like all charities, the Haemophilia Society has to keep up to date with changes in current legislation.

Recently the focus has been on accountability and financial reporting. The effect of these new standards is that charities must keep detailed information about how and when they spend their money.

This is why in January we sent new group rules and monthly accounting returns to all local groups. Please note that they are the third draft dated 15.10.96. and replace all previous documents.

They should be formally adopted at your next AGM, with a signed copy returned to Tony Wilson at the national office by December 1997 at the latest. If your group has any problems with complying with any of the conditions please contact Tony Wilson at the national office as soon as possible.

The rules were designed to be flexible so groups can make regulations to meet local needs which can be agreed with the national office.

The rules fall broadly into four areas

1. Setting up the group, its goals and powers.
2. The group's internal set up, eg Membership, Committee and Officers.
3. Rules for meetings, decision and other proceedings.
4. Receipts, expenditure, banking and bookkeeping.

If any members would like to know more about their nearest group, or would like to consider setting up their own local group, they should contact the national office.

ELECTION OF SOCIETY TRUSTEES

Our new constitution requires Trustees to stand down after having served six years on the board, as a result there will be several vacancies for Trustees this year.

The information below is a brief summary of the duties of a Trustee and we hope that it will help those people who are considering putting themselves forward for this important position.

The role of a Trustee of the Haemophilia Society is both demanding and satisfying. Everyone who sits on the board must be prepared to dedicate time and effort to the task. They must have the ability to face the challenge of shaping the Haemophilia Society's direction for the future as well as a willingness to accept responsibility for the actions and financial probity of the Society.

Trustees sit on committees dealing with particular aspects of haemophilia care and support where they will help to determine what services the Society provides.

Trustees also have links with particular local groups. This allows the group to be informed about national Society developments and for the board of Trustees to obtain information at a local level.

If any Haemophilia Society member feels they would like to stand for the post of Trustee, or would simply like to find out more about what it involves, please call Tony Wilson at the national office on 0171 928 2020.

SOCIETY NATIONAL OFFICE MOVE

The Society has just signed the lease on a new location for the national office.

The new offices are much more suitable for the Society as they are on one floor with lift access, thus making them much more accessible for Society members. In addition there is sufficient space for a meeting room.

The move is expected to take place very soon. The new address will be: Third Floor, Chesterfield House, 385 Euston Road, London NW1 3AU. Tel: 0171 380 0600. Fax: 0171 387 8220.

GRO-A STILL GOING STRONG AT 92

We think we've found the oldest member of the haemophilia Society - but we could be wrong! If you know of anyone with haemophilia who is older than GRO-A *or just has an interesting story to tell, please write to the editor care of the national office.*

GRO-A

GRO-A

GRO-A was born in Clydebank in 1905 of English and Welsh parents and was the third youngest of eight children.

He went to school in Dumbarton, leaving at the age of 14 to work GRO-C GRO-C in Dumbarton. At the age of 16 he moved GRO-C GRO-C where he served a six-year apprenticeship to become a lofter, which involved liaising between the drafting department and the workshop.

Later in his career he moved on from working on ships at the yard to become involved in the aircraft section. One of the projects he worked on was a top secret flying boat, details of which are still unavailable. GRO-A worked until he was 65, latterly at a torpedo factory, where he did office work.

His type of haemophilia is undefined, and he only needs to receive treatment infrequently. For the earlier part of his life he was treated at the Vale of Leven hospital in Alexandria, and it is only in the last 30 years that he has been treated at Glasgow Royal Infirmary's haemophilia centre. His older brother, GRO-A had the same type of haemophilia and died as a result over 30 years ago.

GRO-A now lives alone - his wife died in 1963, and his son, GRO-D lives in England. He does not smoke or drink and is still very fit, often going for long walks in the surrounding countryside. Until recent years he was an active member of a local choir

He says that it has been touch and go on occasions during his long life - he nearly died after a stomach operation when he was younger, and has hepatitis C from treatment with contaminated blood products.

The Society would like to wish GRO-A continued good health and happy walks in the highlands!

CAN YOU HELP?

The Haemophilia Society has received a request for help from author GRO-D She writes:

GRO-D

As a follow-up to my book: GRO-C GRO-C (Ashgrove Press, 1989) I am planning to write another book: GRO-C GRO-C

I need as many first-hand experiences as possible to give a comprehensive view of living with haemophilia in the teenage years, as the book will be based largely on real-life experiences.

I would therefore be grateful for your accounts of living with haemophilia, HIV, AIDS, hepatitis, indeed any aspect of the condition which you consider relevant.

I would particularly welcome views, experiences and feelings from teenagers as well as from parents or anyone concerned with the care and treatment of a teenager with haemophilia.

All information will be treated with the utmost confidentiality and I will reply to everyone who contacts me.

Please address any correspondence to: Mrs GRO-A GRO-C GRO-C

CORRECTION

Alphanate and Parvovirus

Alpha Therapeutic have pointed out that although the manufacturing and viral inactivation processes used with Alphanate destroy significant quantities of parvovirus, they do not claim, as was stated in the footnote to Dr Evans' article on parvovirus in the last edition of the Bulletin, that it will not transmit parvovirus. There will always be a residual risk of transmission, however small.

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PROTEASE INHIBITORS

***Dr Christine Lee** of the Royal Free Hospital, London, explains about a new treatment for HIV.*

There are three protease inhibitors currently licensed in the United Kingdom: saquinavir, ritonavir and indinavir. These drugs are inhibitors of an enzyme called HIV protease. They stop HIV replication by preventing the breakdown of proteins called 'gag' and 'gag-pol' polyproteins. This means that the HIV virus produced is not infectious. Protease inhibitors may reduce the HIV viral load by up to 1,000 fold, that is three logs, and also, may produce a sustained increase in the CD4 count.

The protease inhibitors are, however, poorly tolerated. In particular, there have been reports of patients with severe haemophilia A developing severe haematomas a few days after commencement of ritonavir treatment. The reason for this side-effect at the present time is not clear.

Saquinavir is poorly absorbed and is broken down in the liver by the P450 enzyme. Side effects of saquinavir are usually mild gastrointestinal symptoms. The standard dose of saquinavir is 600 mg three times a day and it has a less strong effect on HIV suppression and CD4 cell increase than indinavir and ritonavir.

Ritonavir in a dose of 600 mg twice a day has a dramatic effect on viral load and may cause a 1.2-2 log reduction (2,000 times) in two weeks of commencement of therapy accompanied by an increase of the CD4 count by 200µl. However, the side-effects are severe and include nausea, vomiting, diarrhoea and parasthesae.

Indinavir in a dose of 800mg three times daily also causes a good reduction in HIV viral load of 1.5 logs (1-2,000 times) after six months' treatment and also a sustained increase of the CD4 count up to 100µl for more than a year. However, indinavir is associated with increases in the bilirubin level and can cause stones in the kidney in a small number of patients.

There are two ways of assessing treatment for HIV, that is with clinical endpoint studies and observing the effect on progression of HIV disease or so called 'surrogate marker' studies which show the response to treatment of HIV viral suppression and CD4 increase. There are now data from a number of clinical endpoint studies that show there is benefit from combination of two antiviral drugs over zidovudine (or AZT) monotherapy.

Although triple combinations, including a protease inhibitor, are being increasingly recommended, there is as yet, no completed endpoint study which shows conclusively that combinations of three drugs are better than two. The enthusiasm for such triple combinations is the profound effect on so-called surrogate markers - the HIV viral load and the CD4 count.

Recent studies have shown that a single measurement of HIV plasma viral load soon after seroconversion is predictive of subsequent progression of HIV disease. Thus in the Multicentre AIDS Cohorts Study (MACS) involving 1604 patients, in those patients who had a high viral load of over 30,000 copies/ml, there was a median survival of only 4.4 years.

Therefore, irrespective of the CD4 count, starting therapy in patients with a high viral load makes sense. Conversely, viral load testing may also help to identify patients with low viral loads, who have a good prognosis without therapy. At present, it is rational to delay treatment in such patients, as progression in the short term is very low and it may be that better initial combinations will become available in the future.

The principles of antiretroviral chemotherapy are summarised below:

- Evaluate risk of progression in each patient
- Assess risk factors for use of each drug
- Monitor response to treatment with CD4 counts and HIV-1 viral load
- Alter treatment if a patient does not respond or relapses.

HAEMOPHILIA TREATMENT IN AN EMERGENCY

We've heard a number of stories where people have had problems in identifying where they should go in an emergency, so we asked ***Dr Peter Jones*** *to tell us how they do things in Newcastle.*

Severe Trauma

When somebody with haemophilia is injured, usual first aid measures apply. It would be crazy to shunt somebody who is bleeding after a road traffic accident to a Haemophilia Centre 50 miles away, when Casualty is a mile down the road. However, it is vital in these circumstances that the staff looking after the patient are aware of the underlying haemophilia. One of the first things that Casualty staff do on receiving a badly injured patient is to look for identification and medical details in the form of special cards, identity bracelets or medicines. That is why it is ESSENTIAL that everybody with haemophilia wears identification in the form of an SOS Medic Alert or Talisman bracelet or necklace, and that the haemophilia card is always carried.

When staff are not aware of haemophilia then consequences may be lethal. If a relative or friend accompanying somebody with haemophilia to Casualty is unsure about the response of staff to the knowledge that the patient has haemophilia, he or she should immediately phone the patient's usual Haemophilia Centre for advice.

Haemophilic bleeding

Casualty is the worst place for somebody with haemophilia seeking routine treatment. This is because

- staff are often busy with other cases, many of which appear more urgent than a haemophilic bleed
- haemophilia is rare and it is unlikely that staff will have seen somebody with the disorder before
- staff, especially if they are junior, may be reluctant to take a patient's advice about the best therapy or referral
- the one thing Casualty staff are particularly good at is the rapid assessment of physical signs but, because the majority of haemophilic bleeds are internal, physical signs do not usually appear for some time
- staff may wish to carry out unnecessary investigations, especially x-rays, when all that is really needed is immediate treatment.

It therefore follows that everyone with haemophilia must know EXACTLY who to phone when they need help. They should know about transport to hospital at any time, and where to go for treatment. In many cases the arrangement is simply to phone the Haemophilia Centre itself or, when closed, the ward responsible for the care of children or adults with haemophilia. Appropriate transport is then organised by the staff.

Inevitably there will be times, perhaps whilst on holiday, when people with haemophilia, or parents of children with haemophilia, will meet staff who do not know them and perhaps know nothing about haemophilia itself. On these occasions waits and questions can be very frustrating, and much time lost in prevarication or unnecessary investigation. In order to overcome these difficulties we give our families an "empowering letter". This idea was suggested to us by the mother of two boys with haemophilia who became fed up having to wait for therapy when the Haemophilia Centre was closed and when the boys had to see a junior doctor on the ward.

TO WHOM IT MAY CONCERN

GRO-A and GRO-A are the parents of GRO-A, who has severe haemophilia A. GRO-A presently needs treatment in hospital because he is still too young to accept home therapy. His parents have been trained to recognise the early symptoms and signs of bleeding, which is usually into a joint or muscle. They also know when rapid treatment is essential in order to protect GRO-A from further damage. We would be very grateful if you could act directly on his parents' wishes and treat him accordingly and as quickly as possible. If you have any questions relating to GRO-A's care please do not hesitate to contact the Doctor on
Call for Haemophilia via the Switchboard.

Haemophilia Centre Director

If you've experienced any difficulties about receiving treatment for accident or emergency, contact Graham Barker at the national office.

RECOMBINANT FACTOR VIII

The media spotlight has focused sharply on recombinant factor VIII recently.

Three aspects of recombinant have been attracting attention - VAT; whether health authorities are willing to fund the use of recombinant; and the call for a judicial review.

VAT

Value Added Tax was imposed on recombinant factor VIII in November 1995 by Customs and Excise. The decision was challenged at the end of 1996 by Baxter, a pharmaceutical company that produces a recombinant factor VIII.

This challenge took place at a VAT Tribunal in London, where the arguments centred around complex definitions of whether or not recombinant factor VIII was derived from human blood and therefore exempt. Unfortunately, the tribunal ruled against Baxter, so the tax on recombinant remains at 17.5%.

The Society has written to the Chancellor of the Exchequer to ask him to lower the rate, as under European Directive he is able to set the VAT at a level as low as 5%.

Funding of Recombinant factor VIII by Health Authorities

The difficulties with obtaining funding for recombinant for children with haemophilia seems to be largely as a result of the way the NHS purchasing system operates.

The NHS operates on the purchaser/provider system. Services and treatments are paid for by the health authorities - the purchasers. The treatments and services are bought from the hospitals - the providers. As a result each health authority makes the funding decisions for the treatment of people living in its area. So the health authority and not the haemophilia consultant makes the decision on whether funding is available to purchase recombinant factor VIII.

Health authorities in different parts of the country have differing views on whether recombinant should be funded.

This has resulted in some haemophilia centres, such as Great Ormond Street, Royal Free, St Thomas', Oxford and Canterbury being able to provide recombinant for their children, while others cannot make it available at all.

Funding for recombinant factor VIII is also available in Scotland, where the Scottish Office has made money available to pay for its use for children.

This situation is highlighted even more strongly in some centres, where different health authorities using the centre have different purchasing policies, which can result in some children in the same centre having recombinant while others do not. This obviously unfair situation has been highlighted in a recent letter from the United Kingdom Haemophilia Centre Directors' Organisation (UKHCDO) to the British Medical Journal, as well as in recent media reports.

The Haemophilia Society has been actively campaigning to have the currently unfair system of allocation of funding for recombinant factor VIII rectified and has written to the Secretary of State for Health Stephen Dorrell asking for the government to intervene.

Judicial Review

A move to seek leave to hold a judicial review by the high court attracted considerable media attention. The circumstances of the case came about because of purchasing policies of health authorities.

The consultant haematologist at the haemophilia centre decided on clinical grounds to put a number of children on to treatment with recombinant factor VIII. Unfortunately, when approached for funding for the treatment by the hospital trust, the health authorities said that they would not fund the product. The trust said it was unable to continue to supply recombinant without a guarantee of funding from the health authorities. This meant that the children using recombinant factor VIII would be forced to return to treatment with plasma derived factor VIII once their supplies of recombinant were used up.

Four families went to the High Court to seek a judicial review of their health authorities' decision

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to impose a blanket policy of refusing to fund recombinant factor VIII without taking into account individual circumstances. The Judge ruled that the call for a review of the process the health authorities had used in imposing the blanket decision was premature as no special cases had yet been put forward. He said that the parents could consider whether their child was a special case, and if so to make representations to the health authorities. There would he said then be an expectation that the health authority would give each case due consideration.

It should be borne in mind that it is the role of the health authorities to decide between conflicting treatment needs on how to spend their limited resources. It is most unlikely that the Courts would overrule the decision on a particular treatment. The review, if granted, would only have been able to instruct health authorities to review how they made their decision, not overturn it.

How do I obtain recombinant factor VIII?

The Haemophilia Society's policy and also the view of the UKHCDO is that recombinant factor VIII should be available for the treatment of children with haemophilia A. However, many parents are experiencing difficulties in obtaining access to this treatment. Parents looking into the availability of recombinant factor VIII for their child should bear in mind the following.

Firstly, you should remember that the only recombinant clotting factor licensed in the UK is recombinant factor VIII. As yet, recombinant factor IX is not licensed for use in the UK.

You should also remember that while plasma derived factor VIII is not quite as safe as the recombinant alternative, it is still a very effective treatment for haemophilia. Technology has moved on since the 1980s when widespread infections of people with haemophilia took place from plasma derived clotting factors. There have been no recorded cases of people with haemophilia in the UK being infected with HIV or hepatitis C from plasma derived factor VIII since viral inactivation procedures were introduced.

For this reason, the Society would not advise parents to withhold treatment with plasma derived product from their children .

If you are trying to obtain treatment with recombinant factor VIII for your child, you should first have a discussion with your centre director, who will be able let you know of its availability at your centre. If the reason that your child is not receiving recombinant is that the health authority is refusing to fund it, then you may wish to approach the health authority directly to explain why your child should be treated as a special case.

The Society can help you in this process. Graham Barker at the national office will work with individuals or groups who are trying to persuade their health authorities that their child should receive recombinant.

BARRISTER'S OPINION

The Barrister's opinion on hepatitis C litigation is now available for solicitors dealing with such cases. The Society has been informed that so far very few solicitors have taken the opportunity to obtain a copy of the opinion. If you are taking legal action about hepatitis C infection, why not check with your solicitor to see if they have obtained a copy.

HEPATITIS C HANDBOOK

A new hepatitis C handbook has just been published.

Written by GRO-D , the handbook is an extremely thorough guide to hepatitis C, covering not only medical issues, but also alternative treatments and lifestyle.

While the book can be quite technical in parts, it is appropriate for the lay person as well as the professional.

The book is available by mail order, if it is not stocked in your local bookshop. If you would like to order a copy send a cheque for £14.99 made out to Catalyst Press (which includes £2 postage and packing) to GRO-D GRO-C London GRO-C

RED RIBBON PAGE

Birchgrove Wales Lottery Success

Birchgrove Wales are pleased to announce that it was us. Yes, we were successful with our bid to the National Lotteries Charity Board.

We received a grant of over £70,000 over three years to enable us to provide additional care and support to families and children affected by HIV/HCV including support meetings, therapeutic breaks, child care and counselling. It will also allow us to provide information and support to children appropriate to their special needs.

We are looking to employ a family and children's worker, who will be able to encourage partners and carers to meet for mutual support, we will also offer specialised counselling and support group facilitation. We will also be able to offer support and activities for children whose parent is affected or has died.

Birchgrove Wales is in the process of finalising the working structure for this project and will be setting up a management committee to over see the running of this project with the local Birchgrove Wales steering Group.

GRO-D - *Chair Birchgrove Wales*

GRO-A
1957-1997

GRO-A, a fellow founder member of Birchgrove died bravely on GRO-C 1997.

It's not often that I can say someone had actually changed my life, but GRO-A had certainly done that. His vision for the future was an inspiration to us all at Birchgrove, his kindness and generosity, his understanding of the wider implication of HIV/AIDS were amazing. He was a determined man who would fight for what he saw as rights for people with Haemophilia HIV/AIDS, and later on HCV. GRO-A had a certain "knack" at communicating with both strangers and friends. He was a man who had not given up hope on life, nor had he shut himself off from the suffering of other bleeders. He put his energy and sometimes anger into creating something for the future, something based on the self–help ethos, something that would help to give people back their dignity that had been torn away by HIV/AIDS. Something that would help, something that people could relate to and understand, something to give them hope for a very uncertain future.

That was and is Birchgrove.

GRO-A was a proud and loving father to GRO-A and GRO-A and a friend and husband to GRO-A who

GRO-A

not only lost her husband, but also her best friend. GRO-A loved life and this showed in the way he lived. GRO-A knowledge and understanding on many diverse subjects was out of this world, we would spend hours just talking and then realise the day was over and we had not done any work. I will miss GRO-A so much. To me he was a guiding light, a best friend, someone who cared and would put other people first.

Knowing GRO-A for nearly 30 years has given me something special, and knowing that this man achieved more in his 39 years than most people achieve in a lifetime will always remain with me.

I send my love to GRO-A GRO-A, GRO-A and all of Paul's family.

Remember who he was and what he had created, it will live on for eternity.

From a loving friend
GRO-D

National Birchgrove Group,
PO Box 9, Abertillery NP3 1YD.
Lo Call 0345 697231

HEPATITIS C RALLY A SUCCESS

A rally in support of people with haemophilia and hepatitis C was held at the Houses of Parliament at the end of last year.

Attendance was excellent with about 120 members present. The lobbying activity began with the presentation of a petition at 10 Downing Street in support of the call for Government assistance. The petition held a staggering 30,000 signatures gathered from all over the country (many thanks to all those who sent them in).

After the petition had been handed over, the focus moved on to the House of Commons itself. Around 120 people with haemophilia gathered outside with banners and placards, and were filmed and photographed by TV and newspapers.

GRO-D

Then the group moved inside to meet up with their MPs and lobby them for their support. The afternoon ended with a meeting in the Grand Committee Room of the House, which was addressed by supportive MPs including Alf Morris, John Marshall and Simon Hughes.

"It was a very productive day," said Rev Prebendary Alan Tanner. "We have managed to show in a concrete way the depth of feeling there is about the issue and it was a great opportunity to make MPs more aware of our concerns."

The Society is now targeting Labour MPs to try to ensure that hepatitis C remains high on the Labour Party agenda and is seen as a valid political issue. This has already been quite successful, with Labour Health Spokesman Chris Smith indicating a willingness to have a meeting with the Society either just before or just after the General election.

Alf Morris MP again raised the issue in a recent debate in Parliament on the NHS he said: "The Government know that we are right and that our campaign is completely free from party animus.

"They know too that given the nod by Ministers, the Commons would settle the matter within an hour.

"The Government's legislative programme is gossamer thin. Parliamentary time could unquestionably be found. If Ministers fail to act and the campaign has to go on, then go on it will, but I most strongly urge the Secretary of State to act now ..."

If you want to help the campaign, why not write to your local MP, or prospective parliamentary candidate asking for their support. The more we can get on board the better are our chances of success.

GRO-D

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