THE BULLETIN

Magazine of the Haemophilia Society

AUTUMN 1999 ISSUE 3

Society calls for urgent action in Scotland

The Society has succeeded in its call for a meeting with Scottish ministers after new evidence revealed people with haemophilia in Scotland may have been exposed to hepatitis C through contaminated blood products for up to a year longer than those in the rest of the UK.

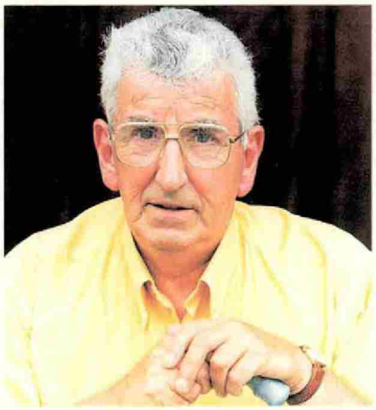
While processes to eliminate the virus, through heat treating blood products, were introduced in England in 1985, it appears this did not happen in Scotland until the end of 1986.

In response to publicity surrounding the issue, Scottish Health Minister Susan Deacon has asked the Society to meet her to discuss our concerns.

Chief Executive Karin Pappenheim said: "We are delighted Susan Deacon has requested a meeting with the Society. It presents us with an opportunity to highlight the plight of those infected with hepatitis.

"We have been campaigning for the last five years for a proper response from the Government to the infection of people with haemophilia with hepatitis and other viruses passed on through contaminated blood products used in their NHS treatment.

"This new evidence that Scotland was behind the rest of the UK in adequately treating blood products is extremely worrying and we believe it highlights the need for an urgent inquiry."



John McAughey

Philip Dolan

A number of members of the Scottish Parliament from all parties are backing the campaign, including SNP deputy leader, John Swinney. Mike Watson, Labour member for Glasgow Cathcart has called on the Scottish Parliament and Scottish Executive to look at the case for a financial settlement for people with haemophilia in the light of the news.

The news generated widespread media coverage and prompted the Society's President, Lord Alf Morris, to write immediately to Health Secretary Frank Dobson asking for a review of the Government's stance.

He said: "What's been demonstrated in Scotland is that so-called facts paraded by successive ministers were not facts at all and it is time now for an urgent review.

"People infected with HIV receive financial help. All we're asking for is equal treatment for people who are infected with HCV. The consequences in all too many cases are the same - a terminal illness."

Reaction in Scotland was led by Philip Dolan, the Society's Vice-Chairman, and John McAughey, Chairman of the Perth Group.

Philip commented: "There is great disappointment within the haemophilia community that the UK Government has yet to respond to our appeal. But there is hope now for those living in Scotland - the issue could be resolved by the Scottish Parliament who could decide to act for Scottish people with haemophilia and HCV."

NOT RELEVANT

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Thanks go to the following pharmaceutical companies who have provided valuable support in 1999.

Baxter • Bayer • BPL • Centeon

CONTACT LIST FOR GROUPS

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

ENGLAND

BRISTOL & SOUTHWEST • CAMBRIDGESHIRE & DISTRICT
CORNWALL • HAMPSHIRE • KENT
LEICESTERSHIRE & RUTLAND • LINCOLN & DISTRICT
NORFOLK & NORWICH • NORTHAMPTON • NORTHERN
NORTH WEST • NOTTINGHAM • OXFORD
SOUTHERN • SOUTH ESSEX • YORKSHIRE

WALES

NORTH WALES • SOUTH WALES

SCOTLAND

PERTH • GRAMPIAN • TAYSIDE
WEST OF SCOTLAND • SOUTH EAST SCOTLAND

NORTHERN IRELAND

Northern Ireland Group

SPECIAL INTEREST

Birchgrove Group

SERVICES AVAILABLE FROM THE SOCIETY

- General information about haemophilia and related bleeding disorders
- Information about Social Security benefits
- Information, advice and support on hepatitis and HIV
- Information for parents of newly-diagnosed children
- Parent support network
- Hardship grants
- Centeon Call pager service
- Caravan holidays in the UK
- Adventure holidays and weekends for children
- Fundraising support
- Assistance with media enquiries
- Information on treatments
- Travel advice and travel insurance advice
- Haemophilia Days and Family Days
- One-off meetings on specific issues, such as hepatitis
- Hepatitis C Support Network
- C. Issues
- Von Willebrands Support Network
- Mild and moderate haemophilia support contacts

For more information about any of the above services, please contact the national office.

Full details of our services are also available on our web site: www.haemophilia.org.uk

Editorial

by Dr David Evans

Various authorities have been introducing regulations for no good reason that I can understand. The American Federal Drugs Administration decided in 1995 that the regulations covering the production of plasma products should meet similar criteria to those governing the production of pharmaceutical drugs. Drugs are made from chemicals, and one batch of chemicals is very similar to another, so the production process can be standard.

Unfortunately, plasma comes from human beings, all of whom are different, so batches of plasma each show slight differences, with the result that for each batch of a plasma-derived blood product, be it factor VIII concentrate, albumin, or immunoglobulin, the production process may need to be modified slightly. Or at least it was. The manufacturers now have to try to produce plasma products in a standard manner, as if they were ordinary drugs. The change is taking time, and meanwhile the products we need and which are derived from plasma, are in short supply.

The methods used for the production of recombinant concentrates mean that a small amount of the proteins used in the earlier stages of manufacture are carried over into the final product.

The American authorities allow slightly more of these so-called residual proteins to remain in the concentrates than the Europeans, so products deemed suitable for Americans with haemophilia are not considered suitable for Europeans with the same condition. Who is right? Let's hope that some common standard can soon be agreed. In the meantime, American products cannot be issued routinely for English patients, and they have to be prescribed for them on a named-patient basis.

As a result of these various regulations, some people with haemophilia are having difficulty getting the product they are used to, or are meeting delays in changing from plasma-derived to recombinant factor. Haemophilia is a world-wide disease. It is a pity that the various authorities cannot agree a world-wide system of inspecting and approving blood and similar products.

For further details see " Treatment Update" on page 4

HCV Action

by Karin Pappenheim, Chief Executive

As this issue of the Bulletin went to press the Society's campaign for people infected with hepatitis C through their NHS treatment had taken a new direction in Scotland, as reported on the front page, prompted by a special investigation by the BBC.

This investigation uncovered evidence that clotting factor product manufactured in Scotland was not safe from HCV contamination until as long as a year after product manufactured in England and used elsewhere in the UK. In Scotland it seems contaminated product was still in use as late as 1987.

Many of our Scottish members are now asking how it could have taken so long for this information to come to light; why did it take a BBC investigation to bring these facts into the open? In the Society's view this only reinforces the demand we have made for a full and open inquiry. Put under the spotlight by press and media coverage of these issues the Scottish Health Minister has requested an urgent meeting with the Society. We hope this will lead to swift action: the Scottish Executive could order an inquiry now into the HCV infection amongst patients treated in Scotland. The Scottish Parliament could make the decision to set up a separate financial assistance scheme for the 200-300 Scots people with haemophilia estimated to have been infected with HCV.

Meanwhile our campaign also continues to make sure that everyone infected with HCV receives the best treatment for the virus. The Society has learned of cases of Health Authorities refusing to fund interferon treatments on grounds of cost. Although the Government has assured us that people with haemophilia and HCV will receive the treatment they need. The former Minister at the Department of Health, Baroness Hayman, wrote in July: "*With regard to the funding of treatment for people with haemophilia infected with hepatitis C, we have made it clear to Health Authorities that care is to be provided for all clinical conditions on the basis of clinical need and effectiveness.*" The Society will remain vigilant to make sure that this assurance is applied and that no one is denied interferon and/or ribavirin because of cost. We will take up any cases reported to us.

NOT RELEVANT

Treatment Update

Compiled by Dr David Evans

New Centre

The new North Hampshire Haemophilia Centre was opened at Uplands House in the North Hampshire Hospital, Basingstoke, on July 6th. The centre developed from the old Treloar Centre which joined forces with the Southampton Haemophilia Centre in 1996.

Lord Mayor Treloar was Lord Mayor of the City of London in 1906-7 and, following a national appeal, set up the Orthopaedic Hospital and College which bears his name in Alton, Hampshire. The aim of the College was "to train and educate boys and girls to face the battle of life with confidence and courage". In 1948 the Hospital was absorbed into the National Health Service. Haemophiliacs first entered the College in 1956. Their numbers grew over the next ten years and Treloar became the main residential school with expertise in managing haemophilia.

The Treloar Haemophilia Centre was set up in 1972 under Dr A Aronstam. The number of haemophiliacs continued to increase, and a full programme of treatment was instigated, including a training programme. Much useful research was conducted by Dr Aronstam, who retired in 1996 having been given the Society's Award. The centre was recognised as a Comprehensive Care Centre in 1994 and soon afterwards became known as the North Hampshire Comprehensive Care Centre. It joined forces with the Southampton Centre in 1996 and moved to Basingstoke in 1998.

Opening the new North Hampshire Haemophilia Centre at Uplands House, North Hampshire Hospital, Basingstoke. From left to right: Mary Clark, Chair of the Hampshire Group, Chris Hodgson, Society chairman, Sir William Wells, Chairman of the NHS Executive, SE Region, and Dr Tim Nokes, the new Centre Director.

The Centre Director is Dr Tim Nokes, aged 44. He came from Great Ormond Street to Basingstoke as Consultant Haematologist in November 1998.

Recombinant problems

For a variety of reasons there have been shortages of recombinant factor VIII in different parts of the country. Bayer has had problems getting in enough supplies of Kogenate because of difficulties with the licensing system in the USA.

Baxter has plenty of Recombinate but there is a European licensing problem because the concentrate contains a slightly higher level of residual protein than the European standards permit. Therefore doctors can only prescribe it on a named-patient basis. This means that they have to prescribe supplies for each individual patient from the company, rather than ordering supplies for all patients at the centre together. They also have to discuss the problem and get consent for its use with each individual patient. The product meets the American standards, which tolerate a slightly higher level. Baxter has applied for harmonisation of the standard, so that Recombinate will be acceptable to the authorities on both sides of the Atlantic, and expect that this will soon be agreed.

Centeon uses the same technique for Bioclate, and therefore has the same problem. They also distribute Helixate which comes from Bayer. They tell me that the problem lies with the American FDA (the organisation which inspects and licences medicines and similar products in the USA) which has changed the way that it approves the techniques used by the American Red Cross, which supplies some of the materials used. They stress that it is not a matter of product safety. The materials are safe; but the FDA has now applied the same standards for producing blood derivatives that they apply for pharmaceutical medicines, so the production techniques have had to be changed to fit the new regulations.

So there are problems with supplies of plasma-derived concentrates from the USA too. BPL uses American plasma, because of the theoretical risk of CJD from British plasma; but they get their plasma from another source in the USA and are now coming back with Replenate and Replenine. There are also products made from non-British but European plasma which will help fill the gap.

All this may mean that there will be delays in transferring some patients from plasma-derived product to recombinant, and some people on recombinant may have to change products. However, it seems unlikely that those on recombinant will have to go back to using plasma-derived products. I must stress that the shortages are not due to any problems with product safety, but with regulations and red tape.

BLOOD DONORS IN CANADA AND THE USA

The Canadian authorities have issued instructions that individuals who have been to the UK should not be blood donors. This is because of the theoretical risk that they might have picked up the agent causing nvCJD by eating British beef. A similar ban is being prepared in the USA. BSE and nvCJD have not been found in these two countries, and the authorities hope that this ban will prevent their appearance. A surprising number of donors in the USA and Canada have visited Britain, and this move will reduce the amount of blood available there by 10 to 15%.

In the UK, it is now policy to reduce the theoretical risk by removing the white cells from blood transfusions.

In Canada, a new national blood agency, the Canadian Blood Services, has been set up to replace the Canadian Red Cross which was discredited after an investigation found that tens of thousands of Canadians were infected with hepatitis B and HIV between 1986 and 1990.

No such investigation has been held in the UK, despite our repeated requests. Karin Pappenheim has recently had a letter published in the *British Medical Journal* to draw doctors' attention to the absence of any Government investigation into why HBV, HCV and HIV were allowed to get into the British blood donor pool, with such devastating results for people with haemophilia.

ReFacto - a new recombinant factor VIII

ReFacto is a new recombinant factor VIII concentrate which is produced by licence from the Genetics Institute of Europe and marketed in the UK by Wyeth. It is the first recombinant which does not contain human albumin as a stabiliser. Research originally started in Sweden in 1983 to modify the factor VIII gene by removing a part called the B-domain, so that the resulting factor VIII has better stability but still retains the full clotting effect. Like other recombinant clotting factors, it is produced in a cell culture technique which in this case uses Chinese hamster ovary cells, which are also used for Recombinate and Bioclate. A small amount of human albumin is used in the cell-culture stage, but it is removed in the purification stage so that the final product contains over 99% factor VIII with less than 1% of other proteins.

ReFacto was launched in June. It comes as a dried powder in a small bottle, and is dissolved for use, like other concentrates. It costs 60p a unit, so the cost of one 500 unit bottle is £300. It has been thoroughly tested in trials. Tests show that it works and is safe.

Bayer and Centeon also plan to have an albumin-free recombinant factor VIII on the market later this year.

Gene Therapy

With all the arguments at present about GM (genetically modified) foods, it is nice to know that some GM experiments appear to be helping to cure haemophilia. The latest American results in mice from the University of North Carolina at Chapel Hill give reason to hope that a cure may one day be developed. There, a gene for factor VIII has been attached to a virus called AAV (adeno-associated virus) and injected into factor VIII deficient mice. Their factor VIII levels rose from 0 to up to 20% and remained stable for up to 11 months.

To put the gene for factor VIII into someone who lacks it, or has an abnormal factor VIII gene like most people with haemophilia, presents enormous difficulties. A way to get the gene into the right cells has to be found. This entails attaching the gene to a virus which can get into (i.e. infect) the cells which are capable of producing the factor. The virus has to have no harmful side-effects. When the gene is in the cells, it has to switch on the production of the factor, and then it has to stay there so that production continues. Our bodies are programmed to react against viruses so the body tends to kill off such a virus. There is also the risk that the body will destroy the new factor VIII. As a result, previous experiments have produced a factor increase for only a short time. Similar problems have bedevilled gene transfer experiments used in an attempt to treat other diseases; but I expect that experts will get there in the end.

The World Federation of Hemophilia published a couple of papers on gene therapy in April 1999. If you would like to read them, please contact the national office.

NOT RELEVANT

How well do you live with Haemophilia, von Willebrand's, Hepatitis C, HIV...??

by GRO-A

GRO-A

All of us with haemophilia, or a related bleeding disorder, have to manage our lives and our condition and we have all learned many ways of doing so. After all we were born with it. In the word of Dr Peter Jones "Life first, haemophilia second". But have you ever wondered if there might be more ways and techniques you could use to live with your haemophilia and any viruses? No? Well neither had I until I was fortunate enough to attend a recent "Self-management for long term conditions" workshop which lasted for several days.

In company with two other people with haemophilia GRO-A and GRO-A I was introduced to a whole range of tools, techniques and philosophies which enable those of us with "a condition" to manage it more effectively and get more out of life. We were also taught how to deliver a well-researched course to introduce other people with haemophilia, or a related bleeding disorder, to these techniques.

At the event there were people with many differing conditions: polio, arthritis, diabetes, hepatitis C, ME, osteoporosis, endometriosis and, of course, haemophilia. We were shown ways in which we could influence our situation positively. It was an education to see how much in common we all had and how the techniques we were being introduced to applied equally to all of us!

We discussed how having an ongoing condition affected all of us, and learned ways of challenging the condition. The key issue for me was the distinction between treating the condition (for which there is the whole medical fraternity on hand to help) and living with the condition which, if your experience is anything like mine, I had to get the hang of on my own. The relationship between these two themes showed quite how much we could do to influence our condition. The group explored topics such as exercise, relaxation, visioning, breathing techniques, nutrition, fatigue, pain management and how to deal with the medical profession. We learned how all these topics, and others besides, interconnect and found ways of managing the whole person not just the condition.

As I said in my introduction, many of us will have discovered our own ways, over years of trial and error, of living with our condition(s). This programme tied all these together into a coherent whole and validated them with some extensively researched materials, which proved their effectiveness. No matter how good you are as a "self manager" it is always useful to add to your repertoire.

By the time you read this article GRO-A and I will have begun running a seven week course for other people with haemophilia or a related bleeding disorder, plus whatever viruses, starting towards the end of September in Bristol. The locations of the spring courses have not yet been finalised, however- ring GRO-D at the national office if you are interested at all, and then come and try one out!

GRO-A - GRO-C
GRO-A GRO-C

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NOT RELEVANT

RED RIBBON PAGES

Combination Therapy without Protease Inhibitors

Some of the greatest excitement at this year's British HIV Association Conference was over the emerging evidence that anti-HIV drug regimes that did not include the class of drugs known as protease inhibitors could be as effective as those that did.

This is important news for two reasons. Firstly, protease inhibitors (such as Indinavir, Ritonavir, Saquinavir and Nelfinavir) have until recently been regarded as the most potent drugs in most triple therapy drug cocktails treating HIV infection. They are extremely potent in suppressing the virus, and stopping people progressing on to AIDS. However, they are often very hard to take, requiring special dietary restrictions, precise timing of doses and a large number of pills. Secondly, for people with haemophilia they have the added problem of causing abnormal bleeding (as reported in Issue 3 of ***The Bulletin*** in 1998 and a forthcoming factsheet available from the Society). Although this is a manageable side effect for most people, and seems to go away within a few months of treatment, for a small minority it is a major reason for stopping treatment. Added to this are the many long-term side effects of protease inhibitors, many of which are only just coming to light. The most common is a change in body fat known as lipodystrophy, where fat disappears from the arms, legs and face, and accumulates in the stomach, or between the shoulder blades (and for women, in the breasts). Although not a life threatening condition, many people find lipodystrophy a very distressing symptom.

What are "Protease Inhibitor Sparing Regimes?"

The new treatment regimes are based on substituting protease inhibitors with any one of three drugs known as Non-Nucleoside Reverse Transcriptase Inhibitors or NNRTIs. These drugs are Nevirapine (brand name Viramune), Delavirdine (Rescriptor), and Efavirenz (Sustiva). Studies have shown that combinations using Nevirapine are at least as effective as regimes using a protease inhibitor, whilst Efavirenz seems to be slightly more effective. In fact, for people with very high viral loads (i.e. high levels of HIV in the blood) at the start of therapy, research suggests that Efavirenz is the most potent drug in clinical use. Delavirdine is not currently licensed in the UK, but is available on a named patient basis, whilst the other two are fully licensed.

Doctors now regard regimes using these drugs, (especially Efavirenz) as viable alternatives to regimes with protease inhibitors. They do not seem to have the long-term side effects of protease inhibitors, and there are no reports of people with haemophilia experiencing increased bleeding whilst on them.

Furthermore, they are easier to take than protease inhibitors. Delavirdine requires three pills three times a day, Nevirapine two pills twice a day and Efavirenz three pills only once a day (compared to as many as six pills three times a day for some protease inhibitors). Timings do not have to be quite as strict as they do with protease inhibitors and there are no dietary restrictions on using them.

The Problems

However, there are drawbacks. Firstly, they do cause some unpleasant, short term side effects. Nevirapine and Delavirdine can cause a rash in about one in five people, which can be severe enough to require a small minority (about 5%) to stop treatment. It can be controlled using steroids such as prednisone.

Efavirenz causes some more bizarre side effects. Dizziness affects about half of those on Efavirenz, and can be severe enough to lay people up in bed for days or weeks at a time. It usually passes within a few weeks of starting treatment, and most people tolerate the drug well afterwards. However, it can also cause particularly vivid dreams, and it is suggested that people with mental health problems (especially anxiety or depression) avoid the drug.

All three drugs may also cause some damage to the liver. Like protease inhibitors, anyone with hepatitis C co-infection taking them will need to have their liver function very closely monitored. The other major problem is that it is very easy for the virus to become resistant to these drugs. If it becomes resistant to one NNRTI, HIV will be resistant to all three, thus cutting down the choices for any future combinations of drugs. Furthermore little is yet known about the long-term effectiveness of these drugs, and what long term side effects (if any) they may cause.

However, NNRTIs are a useful alternative to protease inhibitors, either as part of your first drug regime, or as part of so-called "salvage regimens" when other combinations of drugs fail. Despite the drawbacks, they have many advantages, and are worth discussing with your doctor, especially if you are considering starting therapy for the first time or switching drug regimes.

For more information contact GRO-D at the Society, The AIDS Treatment Project Helpline on 0845 9470047, The Terrence Higgins Trust Helpline on 0207 242 1010/846 4629, or Body Positive Treatments Advisory Service on 0207 287 8010.

RED RIBBON PAGES

Young People's Weekend

June 11th to 13th 1999, Brighton

In June, 22 young people attended a weekend event in Brighton for young men living with haemophilia and HIV, and their partners. The aim of the weekend was to get people together for mutual support, information sharing, and to identify ways in which the Haemophilia Society, the National Birchgrove Group and the Macfarlane Trust could all offer more effective support.

Friday was spent on social events to give everyone a chance to get to know one another. On Saturday morning GRO-D of the Elton John Centre in Brighton talked about HIV treatments. It was an excellent session, with time afterwards for people to talk to GRO-D and each other about their experiences and concerns about combination therapy for HIV.

In the afternoon there was a session on the issues of handling the secrecy of an HIV diagnosis, especially when it came to intimate relationships. A couple came along to the weekend to share their experiences, and there was a chance for people to talk in a larger group and later on in smaller groups about their own experiences. GRO-D and GRO-D GRO-D of the Transformations Agency came along to help run this session.

This was a very moving meeting for a lot of people, and it brought out a lot of the strains HIV positive young men with haemophilia have had to live with for many years. It also gave their wives and girlfriends a chance to talk to each other about the pressures they faced. This was identified by almost everyone as the most useful session of the weekend.

On Sunday we had a discussion about the benefits of self-help. GRO-D from the Birchgrove Group in Wales shared his experiences of setting up the group nearly 13 years ago, and about the things they had achieved over the years. We also had a chance to hear about the group meeting in South West London that GRO-D wrote about in the last edition of ***The Bulletin***.

The feedback from the weekend was mostly very positive. The main comment we got back was, "When are you going to organise another one?" Watch this space!

Many thanks to The Pilgrim Trust for funding the weekend, and to the members of Birchgrove London and South East, The Macfarlane Trust and the staff at St Thomas' Haemophilia Centre, London for helping organise and run everything. Above all though, I would like to say a big thank you to all the young people who attended the weekend, many of whom had never been to anything like this before.

GRO-D

Successful liver transplantation of HIV positive person with haemophilia

Details of a successful liver transplantation on someone with haemophilia, HIV and hepatitis C have recently been published. The patient was transplanted in September 1997. He was a 38-year-old man with moderate haemophilia suffering from end-stage liver disease. Prior to transplantation his HIV RNA had been significantly reduced with protease inhibitor combination anti-retroviral therapy. His doctors concluded that although AIDS had traditionally been an absolute contra-indication to transplantation, perhaps the time had come to re-examine the situation in HIV infected patients receiving highly active anti-retroviral therapy and prospective trials should be undertaken to determine safety and efficacy.

Ragni M V; Dodson S F; Hunt S C; Bontempo F A; et al Liver Transplantation in a Haemophilia Patient with Acquired Immunodeficiency Syndrome Blood; 1999; 93: 1113 - 1114

N.B. Those readers who are co-infected with HIV may wish to receive a copy of the new Haemophilia Society publication 'HIV treatments update' recently produced by GRO-D. For a copy ring GRO-C

GRO-D

Sperm Washing Service Launched in London

The Chelsea & Westminster Hospital in London has launched a sperm washing service for HIV+ men in stable relationships with HIV negative women who want to have children together. This follows recent newspaper articles and press releases reporting the first successful conception using this technique in the UK.

Sperm washing is a technique for virtually eliminating HIV from semen, reducing the infection risk for HIV negative female partners. It is not 100% safe - although no-one knows what the risks are exactly. However there have been no reported cases of a partner being infected in the UK, or in Italy (where the technique was pioneered ten years ago). It is also far from 100% effective (only one conception so far in the UK). However it can offer the hope of having children with minimal risks of HIV infection.

The service is not available on the NHS however, and at a cost of £1,441 for the first course of treatment and £971 for each subsequent course, it does not come cheap. However, the hospital is looking to reduce the costs and develop cheaper techniques in the future that will be just as safe.

If you want more information, please contact Helen Rivas-Torro at the Chelsea and Westminster Hospital, 369 Fulham Road, London SW10 9NH. Telephone 0208 746 8585.

Hepatitis Update

Campaign update

Number 10 involved

It has been a busy time for the HCV campaign not only with the recent blaze of publicity in Scotland, but with much 'behind the scenes' activity at Westminster as well, including an approach to the Prime Minister by a number of senior Labour parliamentarians led by Lord Alf Morris and Roger Godsiff MP. Amongst the signatories to the letter sent to Tony Blair in May, which called for a public inquiry into the contaminated blood disaster, were Lord Robert Winston, Baroness Serota, Frank Field and Norman Goodman. With an appeal coming from such senior and respected members of the Labour Party, it was a shock and disappointment when the Prime Minister refused the request for a meeting, and rejected the call for a public inquiry. He stated: "Though I recognise that people with haemophilia and their families feel a sense of injustice, I am not convinced that a public inquiry would provide greater insight into the problem or pave the way for any further improvements in the safety controls which are now in place".

Not content to leave the matter there, Lord Morris wrote again in July to ask the Prime Minister to reconsider. Although the response was again negative, we can be assured at least that the appeal on behalf of people with haemophilia infected with hepatitis C is being considered at the very highest level.

For further detail, see the full campaign update enclosed with this issue of *The Bulletin*. If you are interested in the campaign, you can sign up to our supporters' database and/or volunteer to become a local campaign coordinator.

Contact GRO-D at the Society for details.

Tests for Hepatitis C

In the past few months I have been contacted by several people with haemophilia who all thought they had hepatitis C, but then learned that this might not be the case. In each case the person was 'antibody positive' for hepatitis C, but 'PCR negative'. Antibody tests only demonstrate that someone has been exposed to the virus in the past, whereas PCR tests demonstrate current infection by detecting the presence of the virus in the blood

It appears that some haemophilia centres have not yet PCR-tested some of their patients. If you are unsure whether you have had this test or not, ask your doctor!

For more information about tests for hepatitis C, including PCR tests, antibody tests and liver function tests, ring us and ask for the new 'Tests for hepatitis C' fact sheet.

GRO-D Hepatitis Worker

Treatment concerns

Our Chief Executive and Hepatitis Worker met Department of Health civil servants in July to raise a number of concerns about hepatitis C and other haemophilia treatment issues. Amongst these was the fact that there is no official national figure for the number of people with haemophilia who are infected with HCV, a matter which the Society has also raised with the UK Haemophilia Centre Directors Organisation (UKHCDO).

Linked to this is the issue of testing, advising and treating people who may have contracted HCV: the Society is still contacted regularly by individuals who have only just learned they have HCV although they will have been infected many years ago.

The previous Government ordered a 'look back' exercise to trace all patients who could have been infected with HCV through blood transfusions, but did not do the same for people with haemophilia who might have been exposed to contaminated blood products. It was apparently assumed that all haemophilia patients would be in regular contact with their haemophilia centre, and that the centre would therefore identify all those who had contracted HCV. Unfortunately the Society's evidence suggests this has not happened consistently. In the last six months we have been in contact with two centres where patients still had not been PCR tested.

Now that we have brought this to the attention of the Department of Health, it looks likely that they will be issuing guidance notes on testing and treatment to all haemophilia centres and requesting the UKHCDO to produce statistics indicating the number of people with haemophilia infected with HCV.

This will mean progress with one of the main objectives of the HCV campaign, which is to ensure that all those infected receive the best possible treatment.

Lord Winston becomes Vice President

Professor Lord Winston has agreed to become a Vice President of the Haemophilia Society. The Director of one of the UK's biggest reproductive medicine departments, based at Hammersmith Hospital, and researcher into various aspects of human reproduction agreed to become Vice President because, he said, he felt that the haemophilia community was being poorly treated by the Government.

He said: "I agreed to become a Vice President because it seemed to me the Government had not fully accepted the way people with haemophilia, infected by viruses, had suffered. There was a lack of justice in the lack of compensation for those with hepatitis C.

"There are questions that need to be asked about the safety of blood products that were used in the treatment of those with haemophilia that caused the infections. But my main point is that if it was reasonable for the Government to provide recompense in other circumstances, why should those infected with hepatitis C not be eligible also."

He added that another reason for his support of the Society was because of his interest in helping people with genetically transmitted conditions.

He said: "Over the last 10 years we have been developing ways of helping people who carry the haemophilia gene who have made the choice to have children without the condition.

"At Hammersmith we have screening processes to help people in this way and we are quite willing to do this for people with haemophilia wanting to have children. It should be possible for it to be paid for out of our charitable funds.

"It is a protracted procedure, as any involving in-vitro fertilisation can be, but the rewards are that with pre-implantation diagnosis we can establish a pregnancy knowing that the child will not be affected by haemophilia."

Lord Winston has been a Consultant Obstetrician and Gynaecologist at Hammersmith Hospital since 1997 and is at the forefront of human reproductive medicine. He established the first NHS unit for in-vitro fertilisation treatment, which was founded in 1981. His team at Hammersmith include among its achievements the birth of the first baby after DNA tests to avoid sex-linked diseases, such as haemophilia. His interests include directing theatre publications, music, broadcasting and politics, among many others. He is married with three children.

Welcoming Lord Winston's appointment as Vice President, Haemophilia Society Chief Executive Karin Pappenheim said: "We are truly delighted that Professor Lord Winston has agreed to support the Society in this way. Having such a well-respected and high profile personality as a Vice President is of enormous value for the Society".

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NOT RELEVANT

STOP PRESS

Alpha Therapeutic will not be producing coagulation products until further notice. Their plant in the USA has been shut down by the authorities due to problems with the water supply. Products already available in the UK are unaffected.

NOT RELEVANT

NOT RELEVANT

NOT RELEVANT

Women with bleeding disorders

There are many women and children out there who are receiving treatment and managing vonW and other more unusual clotting disorders. If you have any information or good advice on issues surrounding these conditions, in particular, treatment, or ways of managing a condition that seem to work for you, please give GRO-D a call at the Society. She is looking to collect together more information on these conditions in order that individuals can receive the best and most up to date treatment. She can be contacted by 'phone on GRO-C GRO-C or by Email GRO-C

Devolution Working Party

The Devolution Working Party set up by the Trustee Board in May this year has now completed its review and has made a number of recommendations for action which are being discussed by the Board in September, and will be reported on fully in the next issue. It was chaired by Simon Taylor. Other members of the group were Philip Dolan from Scotland, Gareth Lewis from Wales, Gordon Clarke from Northern Ireland together with the Society's Chief Executive Karin Pappenheim and Chairman Chris Hodgson. As part of its review the working group carried out surveys of members' views in Scotland, Wales and Northern Ireland. The results in all these countries were a majority in favour of some form of special identity (e.g. Haemophilia Society in Scotland) but, generally, against splitting up the UK Society into four separate charities.

South Wales Group

We welcome back the South Wales Group which has been out of action for a number of years. It is now up and running again with Gareth Lewis as Chairman, David Morgan as Secretary and Ian Tumelty as Treasurer.

NOT RELEVANT