

## News Update

# *CJD-Blood to Blood Risk-No Longer Theoretical?*

On 17th December 2003 it was announced that a UK Patient who received donor blood during an operation in 1997 developed variant CJD and died six years later. It was reported that this patient died "sometime in the Autumn", but the news was not broken publicly until the same day Saddam was captured. Cynical Haemophiliacs may ponder whether this was "a good day for burying bad news". The Sunday Times on 21st December ran a small article stating that this was the first time that blood has been shown to be capable of transmitting the disease between humans. In the article Haydn who has haemophilia said "When HIV first appeared the doctors dismissed the risk to haemophiliacs. Then they said the same about Hepatitis C, and they were wrong again. When I heard about vCJD I made a point of asking about

it. Again it was dismissed, and once again they have misled us."

John Reid The Health Secretary pointed out that the person that recently died may have contracted vCJD from a dodgy burger and said "It was impossible to be sure which was the route of infection" but added "the possibility of this being transfusion based-related cannot be discounted". For people with haemophilia who knowingly received factor products made from the donor blood of vCJD victims, and who were told not to panic as the risk was only theoretical, John Reid was quoted as saying "the CJD incidents panel considers the risk to this group to be even lower than for those who received whole blood". So hopefully that puts your mind at rest.

### **Recombinant Roll-Out**

Although recombinant for all people with haemophilia was announced in February 2003 the roll-out did not start until December. The access to recombinant in England is however only available to people under the age of 40 years at present. Those over this age have been told this will not be available to them until 2005. The government have chosen this route because they have not found the funds to treat all patients equally and fairly. For many years English patients over the age of 20 have been denied recombinant products although patients in Scotland and Wales of all ages have had a choice in their treatment. Birchgrove feel that this course of action is not only unfair, unjust and discriminatory, but also has once again caused unnecessary divisions between our patient group.

For those that have been given a choice and are under the requisite age band there have been conditions set into their accepting the treatment. Not only has more emphasis been put on treatment diaries and recording but also more importantly on actual factor use. The recombinant

usage has mainly been calculated on patient's consumption in the previous year. This may mean that patients on blood derived factor "strikes", those that did not need much factor last year or those that used blood derived products with extreme caution may be restricted to their usage of recombinant in 2004. This also may have implications with elective surgery.

To ensure that all hospitals do not become dependant on a major supplier of recombinant factor, different products, and generations of recombinant, are being offered to different patients in different PCTs. Again this means that your postcode will determine your product choice. Birchgrove hope that those under 40 years who have campaigned for access to recombinant do not become complacent and that those over 40 years continue to have your support until everyone in the UK with haemophilia are offered the same equitable treatment choices.

See DoH Website

### **Hepatitis C- Financial Assistance scheme**

The Department of Health has still not announced its proposals for the Financial assistance scheme for people who have contracted HCV via factor products. Although this was announced in August 2003, people who are affected are still completely in the dark, (at the time of going to press), as to what the proposals actually mean to them. There has been much speculation about who will be included in this scheme and what the payments will actually mean to people, and how it will reflect on the impact that hepatitis C has had on our lives. Any news on this subject that should be announced before the end of the financial year and will be posted on the Haemophilia Societies web site.

For those living in England and Northern Ireland it is also possible to join a DH mailing list for this information (details of how to do this are available on the Society's website:

[www.haemophilia.org.uk/newshcvinfo0903.htm](http://www.haemophilia.org.uk/newshcvinfo0903.htm))

Additionally, the Scottish Executive Health Department has made an equivalent facility available to those living in Scotland. Those wishing their name to be added to the mailing list should contact:

Fiona Richmond, Scottish Executive Health Department, Health Planning and Quality Division, GER, St Andrews House, Regent Road, Edinburgh

EH1 3DG or by phone 0131 244 2433 or e-mail [fiona.richmond@scotland.gsi.gov.uk](mailto:fiona.richmond@scotland.gsi.gov.uk) with a name and postal address only.

On the 6th January 2004 the All Party Parliamentary Group on Haemophilia, chaired by Michael Connarty MP, wrote to John Reid asking for a meeting at the earliest opportunity to discuss the issues surrounding the undisclosed proposals.

### **House of Lords debate on the ex gratia scheme**

Lord Morris, president of the Haemophilia Society, initiated an hour-long debate on the evening of 11 December. He highlighted the four current campaigning points, namely the possible exclusion of families of the deceased, those who have cleared the virus on treatment and the HIV co-infected, and the disappointment with the level of payments suggested by the Scottish Health Minister, Malcolm Chisholm.

Lord Warner responded on behalf of the government to say the DH was actively working on the scheme and that the Chisholm proposal was not set in stone. The full 8,000-word transcript of the debate is available from Hansard.

[www.parliament.the-stationery-office.co.uk/pa/ld199697/ldhansrd/pdvn/lds03/text/31211-13.htm#31211-13\\_unstar0](http://www.parliament.the-stationery-office.co.uk/pa/ld199697/ldhansrd/pdvn/lds03/text/31211-13.htm#31211-13_unstar0)

## *Another legal case about HCV infection*

In the Autumn of last year Peter Doyle from Ulverston in Cumbria agreed £75,000 in compensation for being infected with HCV from a drug called 'Gammagard' manufactured by Baxter Healthcare Ltd. Mr Doyle was given the drug after being diagnosed with immunoglobulin deficiency in 1991. It was also agreed that he could return to court for a further compensation payment if his condition worsens. Birchgrove wrote to John Reid, the Secretary of State for Health, just in case he had missed the result of this case as it might be useful in working out the financial scheme for haemophiliacs infected with HCV. (£75,000 and a chance for more if you get worse is certainly a bigger sum than the £20,000 Malcolm Chisholm in Scotland suggested!) Also it seemed a good precedent as Mr Doyle already had a medical problem that HCV added to and the treatment was made by a company that makes haemophilia treatments. Not having the time to drop us a hand written note one of John Reid's minions replied with the following:

*At this time, the size of the awards and many other details are still under discussion but we expect to make a further announcement about the scheme shortly.*

*The Department of Health is aware of the settlement between Baxter Healthcare and Mr Peter Doyle and also other litigation that is being pursued between individuals and private companies. As these cases do not directly involve the Department, I would not wish to comment on them. But with regards to your request that they be considered during the deliberations on the hepatitis C scheme, I would like to point out that financial assistance will be provided on compassionate grounds, and is not compensation. With this in mind, the payments cannot be expected to take account of loss of earnings or compare with punitive damages awarded by the courts.*

*Having said that, you will be interested to know that we are considering a number of compensation based schemes during our deliberations, including the Canadian Government's hepatitis C scheme and the recommendations made by the Hepatitis C Working Party to the Haemophilia Society.*

The usual non-response but at least they had to read the letter and think of something to say. We await the announcement and wonder if any money will come through to any of us in time to buy next years Christmas presents.

## Information and support

### British Liver Trust

Information, advice, support and campaigning on all aspects of liver disease including viral hepatitis (A,B,C,etc). A variety of publications and web based details.

**Tel: 01473 276326**

Email: [info@britishlivertrust.org.uk](mailto:info@britishlivertrust.org.uk)

**Website: [www.britishlivertrust.org.uk](http://www.britishlivertrust.org.uk)**

### Haemophilia Society

Information, advice and support.

HIV/HCV worker Babs Evans

[babs@haemophilia.org.uk](mailto:babs@haemophilia.org.uk)

Hepatitis worker John Morris

[john@haemophilia.org.uk](mailto:john@haemophilia.org.uk)

**Tel: 0800 018 6068**

Email: [info@haemophilia.org.uk](mailto:info@haemophilia.org.uk)

**Website: [www.haemophilia.org.uk](http://www.haemophilia.org.uk)**

### HIV and Hepatitis.com

Online publication about treatment.

**Website: [www.hivandhepatitis.com](http://www.hivandhepatitis.com)**

### Mainliners

Support, advice and information for people affected by drugs, HIV and hepatitis.

**Tel: 020 7582 5434**

Email: [linersmain@aol.com](mailto:linersmain@aol.com)

**Website: <http://members.aol.com/linersmain>**

### National AIDS Manual

Provides up to date factual treatment information via free publications and website.

**Tel: 020 7627 3200**

Email: [info@nam.org.uk](mailto:info@nam.org.uk)

**Website: [www.aidsmap.com](http://www.aidsmap.com)**

### The National Hepatitis C Resource Centre

Information and advice for HCV+ people, professionals and the general public.

**Tel: 020 7735 7705**

Email: [advice&info@hep-ccentre.com](mailto:advice&info@hep-ccentre.com)

**Web site: [www.hep-ccentre.com](http://www.hep-ccentre.com)**

### Positively Women

Peer-support services to HIV positive women and their children. Drugs and alcohol support group and bi-monthly newsletter.

**Tel: 020 7713 0222**

Email: [info@positivelywomen.org.uk](mailto:info@positivelywomen.org.uk)

**[www.positivelywomen.org.uk](http://www.positivelywomen.org.uk)**

### Positive Nation

Monthly publication providing a platform for all people affected by HIV and AIDS in the UK.

**Tel: 020 7564 2121**

Email: [subscriptions@positivenation.co.uk](mailto:subscriptions@positivenation.co.uk)

**Website: [www.positivenation.co.uk](http://www.positivenation.co.uk)**

Monthly publication about HIV and quarterly issues about hepatitis

**Tel: 01895 637878**

Email: [andrewb@akitanet.co.uk](mailto:andrewb@akitanet.co.uk)

**Website: [www.howsthat.co.uk](http://www.howsthat.co.uk)**

## Booklets on hepatitis

### A rough guide to hepatitis

Pocket-sized booklet with information about all aspects of hepatitis (from A to G).

Produced by How's That Publishing Limited

**Tel: 01895 637878**

### Hepatitis C...meeting the challenge

Aimed at adults living with a bleeding disorder and HCV or HIV and HCV co-infection. Produced by the Haemophilia Society.

**Tel: 0800 018 6068**

## National Helpline Numbers

### National AIDS Helpline

**Tel: 0800 567 123**

24 hour helpline offering advice on HIV/AIDS

### Terrence Higgins Trust

**Tel: 020 7242 1010**

days per week 12-10pm Advice on HIV/AIDS

### Positive Line

**Tel: 0800 1696806**

staffed by positive people mon-fri 11am-10pm sat/sun 4-10pm

### AIDS Treatment Phone line

**Tel: 0845 947 0047**

Treatment advice from positive people Mon + Wed 3pm-9pm Tues 3pm-6pm

### HIV i-Base

HIV treatment information and support.

**Tel: 0808 800 6013** (treatment info helpline)  
**020 7407 8488**

Email: [admin@i-Base.org.uk](mailto:admin@i-Base.org.uk)

**Website: [www.i-Base.org.uk](http://www.i-Base.org.uk)**

### Immune Development Trust

Offers a broad range of holistic therapies and advice to HIV+ people

**Tel: 020 7704 1555**

**Website: [www.idt.org.uk](http://www.idt.org.uk)**

### Haemophilia Wales

1st Floor,  
100 Whitchurch Road,  
Whitchurch,  
Cardiff CF14 3LY

**Tel: 029 2037 7187**

### Birchgrove North

c/o Body Positive North West,  
Lawrence House,  
City Road,  
Hulme,

Greater Manchester M15 4DE

Email: [birchgrovenorth@hotmail.com](mailto:birchgrovenorth@hotmail.com)



## Diary Dates

### **MEN ONLY WEEKEND**

Friday 12th Sunday 14th March 2004

A weekend at the Renaissance Solihull Hotel for men living with a bleeding disorder and HIV. The Weekend will focus on looking after yourself, body building, fun and friendship, an opportunity to talk to others in similar situations and healthy living. On offer will be a pool and health suite and complementary therapies will also be available. All for £20 or £10 if on means tested benefits. For those not interested in the healthy bits there will of course be comfy armchairs and a well stocked bar. If interested contact Claudette Allen at The MFT. TEL 020 7233 0342 email: socialworker@macfarlane.org.uk

### **Update from the Haemophilia Society**

Babs Evans has left The Society where she supported people living with and affected by haemophilia and HIV for over three years, I am sure those of you that know Babs wish her well in her new role at The National Telephone Helplines Association. The Society have restructured their services recently and Babs' post as HIV/HCV co-infection worker has been changed to a more general role, all HIV enquiries should now be directed to: John Morris, Information and Advice Worker on 0800 018 6068 or email: john@haemophilia.org.uk

If you would like to speak with someone personally affected by haemophilia and HIV at The Society please feel free to call Richard who is in the office and on the same telephone number most Tuesdays or email richard@haemophilia.org.uk

The Society also operates a confidential volunteer telephone support network, simply call 0800 018 6068 between 9am and 5pm or email john@haemophilia.org.uk and ask for a trained volunteer to call you back, you will be asked a few questions in order to match you with a volunteer who has the most relevant experience and a volunteer will ring you, usually within three days.

### **MFT WEB SITE**

The MFT web site is now up and running which is designed to offer information and facilitate accessing the MFT's services. It also has a Bulletin Board where registrants can confidentially leave messages and comments. Check it out on [www.macfarlane.org.uk](http://www.macfarlane.org.uk)

### **Want to have your say?**

Do you have questions you need answering regarding the Hepatitis C financial recompense scheme and the lack of communication with people with haemophilia, or are concerned about the recent news relating to vCJD, or you want to register your thoughts regarding the recombinant roll out and the discriminatory age basis on which it has been adopted? Maybe you may feel that all the above issues are equally important and would be addressed by a public inquiry into the issues of contaminated blood products in the UK. A public inquiry that has so far been ignored by governments.

Write to the **Rt. Hon Dr. John Reid MP, Health Secretary, Richmond House, 79 Whitehall, London, SW1A 2NS**

Send a copy of your letter to your local MP and ask him or her to answer your questions and concerns. Birchgrove would be interested to see your satisfactory (or not) replies.

## Birchgrove is a Forum for:

The treatment of haemophilia and HIV

Taking best care of ourselves, through informed debate.

Staying healthy with both haemophilia and HIV/AIDS

Ways in which HIV affects love and sexuality

The social and psychological aspects of haemophilia and HIV.

## We believe that people with Haemophilia and HIV...

Can be empowered and enabled to deal with HIV/AIDS through relevant information and mutual support.

Can improve their health and extend their lives by expressing feeling and confronting the issues directly

Should be heard and have their needs recognised and not suffer in fear and isolation.

Have a role in the work of the HIV/AIDS community to inform and challenge the ignorance that exists about HIV.

### EDITORIAL TEAM

Mick Mason and Paul Bateman  
& Rob James

## DISCLAIMER

The views expressed in each of the articles are those of the individual authors, and not necessarily those of Birchgrove.

"BIRCHGROVE" is published by Birchgrove Group.

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The Birchgrove newsletter is funded by the haemophilia society