TheBirchgrove

APRIL 2001

Tel : 02920520029Email : birchgrovegroup.org.uk

Private-Eye Blood Money

April 6th 2001

Last months high court award of damages and compensation to 114 patients infected with the potentially fatal liver disease hepatitis C from contaminated blood supplies underlines the government's shameful treatment of the country's 4,000 haemophiliacs who have been living under a similar death sentence.

They do not benefit from last week's landmark ruling, because they were infected by contaminated blood before the 1988 consumer legislation, under which the patients scored their court victory, came into force. The government has consistently refused them or their families any compensation.

With health ministers considering an appeal against the recent high court ruling, there is no indication of any softening of attitude. Last Friday health minister Lord Hunt offered only "sympathy" dead handy for anyone who is sick or dying from this vicious strain of hepatitis virus which can cause cirrhosis, liver failure and liver cancer.

More than 100 victims have already died and many more will do so in the coming years. Not only is the government refusing financial aid, it is also refusing to hold a public inquiry into how bad blood supplies went unchecked for so many years. More than 1,200 haemophiliacs were also infected with HIV, of whom 900 have already died from AIDs.

The government's refusal to hold a public inquiry perhaps has something to do with the fact that an inquiry would reveal a continuing scandal of greater magnitude even than BSE.

It would reveal that the risks of contaminated blood supplies have been well known for well over 20 years certainly during the crucial period that haemophiliacs were being given infected blood products. It would show that the UK ignored warnings not to import from countries like the US, which was harvesting supplies from prisoners, down and outs and drug addicts.

An inquiry would also highlight the continuing dangers of human blood products. In the last few weeks many in the stricken haemophiliac community have learned that as well as being given HIV, and hepatitis B and C from contaminated blood in the 70s and 80s, they were, in the late 90s, also exposed to new-variant CJD.

An inquiry would also highlight the fact that in England, unlike in Ireland, Wales and Scotland the health department is still refusing to provide safe synthetic blood clotting agents to adult haemophiliacs because they are too costly.

The latest nvCJD bombshell has prompted hundreds of haemophiliacs around the country to go on a "treatment strike", believing the pain and risk from their bleeding condition is less than that posed by the diseases to which they have already been exposed or could still be exposed. - through contaminated blood.

One such victim is 34-year-old Mick Mason who has HIV, hepatitis B and C and who learned in January that he had also been exposed to 40 doses of nvCJD. It was the last straw. Although he risks dying from a "bleed", he is declining human blood product treatment in protest. "I may as well go down fighting," he said. "They have already given me four potentially fatal diseases --- What can be worse?"

In 1990 the Tory governments miserly concessions to those known to have subsequently contracted HIV were "sympathy payments" of between £20,000 and £60,000 to settle their claim for damages, with no admission of liability. As many of them believed they had little time to live they accepted. But here lies another scandal which should be investigated. Under threat of having the financial offer withdrawn, they were also obliged to sign a waiver, saying they would not sue for hepatitis C if they eventually contracted it.

At that stage, none of them knew they had hepatitis C and they say they were told that it wasn't that serious, let alone potentially fatal.

Victims who have HIV and hepatitis C and now face the further potential threat of nvCJD are seeking to have the waivers they signed declared illegal by courts. It is their first legal obstacle to compensation and a public airing of their case.

While Ireland, Canada and Germany have set up generous compensation schemes for sufferers and their families and launched public inquiries to discover what went wrong, English victims are increasingly sickened by the Blair government's peddling of the line that "no public interest would be served" by an inquiry.

"BIRCHGROVE" is published by:

The Birchgrove Group,
P.O. Box 9, Abertillery
Gwent NP3 1YD.
Tel: (0345) 697231 (Helpline) (02920) 387960 (Admin.)

Email : Editor@birchgrovegroup.org.uk

Editor: Gareth Lewis

Meeting Lord Hunt

P Bateman

Hi All Hope everyone is OK. I thought people would like an update on the Lord Hunt Meeting yesterday at the dept of Health,

Especially those that are fighting for access to recombinant.

Although the meeting was specifically set up to discuss access to recombinant for all, the recent events with BPL and the CJD letter gave another focus and reason to discuss also safety of blood products, the feelings of the haemophilia population to CJD and the ongoing Campaign for a public inquiry and financial recompense for HCV infection.

The meeting lasted an hour and 20 mins, so there was alot to discuss.

Lord Hunt and Charles Lister both listened to everything we had to say and took plenty of notes. Lord Hunt seemed genuinely concerned and asked a lot of questions, and asked us all for our individual feelings or arguments. he didnt pass comment on anything, as he explained the purpose for the meeting was for him to take on board our questions and concerns and aims and he would get back to us when he had time to consider the many issues we raised.

He didnt give a time for a response but said he would give it his immediate attention and we should hear something soon.

The main issues raised were: Provision of recombinant on safety grounds as it is the treatment of choice. For the govt to make a commitment to provide recombinant, so that the companies can start to produce it.(No orders no production). The safety of blood products for people (with inhibitors, vonWillibrands+ rarer bleeding disorders) that will have no access to recombinant products of any kind.

The concerns over plasma supply. If no one is using British Donors because of CJD, and CJD has already been found in germany, France, Portugal and Spain then it is reasonable to assume that their blood will be banned from donation. this would put an increasing pressure on the whole of Europe to use US plasma. This increase in demand would inevitably increase the price and put pressures on the US to find as much blood as possible. This could have effects on the quality.

More importantly the arguments for recombinant being too expensive for the health authorities will not hold much weight as the cost of blood derived Factor increases.

Recombinant could actually be cheaper in a 12 months for instance.

It was discussed that proceedures need to be implemented now as to how to approach the ethical issues surrounding testing for CJD. when will a test be available, what kind of support will be offered, what proceedures will be put in place to cope with worst case scenario

(every Haemophiliac over the age of 3 being exposed to CJD ???).

We dont want the same mistakes that happened with HIV and HCV with no counselling no support no diagnosis for some etc.

The feelings of the membership of the society were highlighted to Lord Hunt and an overall image of the campiagns, patients on treatment strikes, Media coverage, canada, ireland, the blood brothers video and some of our personal accounts of living with all or some of these viruses were all given plenty of "air time" at the meeting. When we get recombinant who will get it first?? This was an issue that needs to considered as it would be ridiculous to think that we can all get it tomorrow. How much we get and how soon will depend on the level of commitment and spending that the Health

Department allows. If production was set up and stocks were, or are there already, who decides who gets it and who doesn't???

It has already been well documented that Blood derived factor has immunosupressant qualities which is detrimental for anyone with HIV so I would like to think that the Coinfected would be first choice. I did make the point though that this would again run the risks of further divisions between co+ mono infected at a time when we are united on the CJD issue. If supplies are there I dont think we will have that much difficulty in convincing the Govt. There must only be around 350 coinfected in England not on recombinant I would guess so it wouldnt cost them that much to supply.

It was suggested that recombinant should be phased in on an age band consistent with production and supply. If there was enough supply say in six months time to cover 16 -25 year olds for instance, and when production and supply increases this would be raised to -30 year olds etc. These are only ideas and nothing will be done untill the Govt and Dept of health make a firm commitment to supply all PWH and come up with the readies at the same time.

It was stated that the confidence of PWH is at an alltime low. After being exposed to HAV, HBV,HCV, HIV and now the final insult of the theoretical risk of CJD and we still have not had an Inquiry, no recompense for HCV and no lookback study into HCV and Haemophilia and no public acknowledgemnet of our plight, peoples feelings were as strong as they were in the 80;s with HIV.

Before we left ,CH left Lord Hunt a copy of the Blood brothers Video and he asked if he would give it to Tony Blaaaaiiir when he had watched it.

I left a copy of the article from the Northern Echo 22.12.2000 which talks of campaigns, criminal charges, and "huge ramifications for the UK haemophiliacs" with Lord Hunt to give him a flavour of grassroots activity.

Lord Hunt seemed very interested and it was a lot better to meet and put these issues to him face to face than wait 6 months for a reply to my angry letters. I hope he comes up with the goods.

In the meantime i suggest that we all keep as much pressure on as possible. There hasn;t been a National news item yet about 9000 haemophiliacs theoretically exposed to CJD but it will come and the shit will hit the fan.

These are my personal accounts of yesterday and not a reflection of probably what the Government or the Soc would want broadcasting.

I dont know. Please get back to me on any issues I have raised if you want. I would like to think positively that this time they cannot ignore us,

Take care

Paul

Insert

THIS AFFECTS YOU- AS A PROFESSIONAL AND A PATIENT

Please forward NOW to list of which you are a member - eg GP-UK,
The Health and Social Care Bill, due to pass through the House of Lord later this month contains a clause (currently 68) which, if and when passed, will bring a forcible end to patient confidentiality and privacy in the UK.
This grants the Secretary of state legal powers to effectively commandeer all personal medical information, granting the Government untrammelled, unobserved, access to all our medical records without consent, notification or any right to opt out.

Doctors are to be compelled to provide information regardless of previous expectation and agreements that it would be kept confidential on pain of criminal prosecution and a £5000 fine in each instance.
The effect on the future practice of medicine here can only be imagined but it is likely that this will include patients deferring or declining treatment which involves the provision of samples from which DNA may be extracted - including blood donations.

Although the clause applies to paper as well as electronic records it is likely that NHS reaction to such a law would deter may doctor and health professionals from participating in trials and implementation towards EPR (electronic patient records) which forms a key part of the survival strategy for the NHS.
This legislation is being vigorously opposed.

Among those keenly concerned are Fleur Fisher, Char, BMA Foundation for AIDS, Ross Anderson, Cambridge University Computer Laboratory Caspar Bowden, Foundation for Information Policy Research and myself (Barry James, Chair, New NHS Intranet & Internet Conference).
In order to gauge and quantify the depth of opposition we are now launching an online survey, and we need your help.

PLEASE go to
www.nhspeople.net/impact/survey.htm

to express your opinion, right now if possible (time is of the essence).
More information is available at the Medical Privacy Site:
http://www.garjuss.com/medicalprivacy

Blood fear over CJD

By Tom Peterkin
Health Correspondent
Scotland on Sunday

Scientists uncover first evidence that transfusions could have led to deadly infection linked to'mad cow disease'
TENS of thousands of people could have been infected with the human form of mad cow disease after receiving transfusions of infected blood, according to new research.
Scottish and French scientists have uncovered the first hard evidence that new variant CJD can be passed from person to person, most likely by blood transfusions.

In the past, experts have said there is a theoretical risk of vCJD being passed in this manner, and as a result UK blood supplies have been filtered since the late 1990s to reduce the risk of contamination.
But new experiments on monkeys have proved vCJD can be transmitted from primate to primate. The study also shows that prions – the infectious agents that cause the disease – become more virulent when they jump from animal to animal, and lie dormant for less time once they are transferred.

This opens the chilling prospect that thousands of people who received vCJD-contaminated blood before screening began in 1998 will develop a worse form of the disease in less time. Dr Jean-Phillipe Deslys, of the Department de Recherche Medicale, Recherches du Service de Sante des Armees, said they had proved the BSE agent believed to cause vCJD could be passed between primates.
He said: "This study means that the risk from transfusions is high and we also think that it means that infection through surgical instruments is possible. It is impossible to calculate how many people may have been infected through these means."
The scientists found that the behaviour of the BSE agent in monkeys was almost exactly the same as in humans, making the experiments, carried out in France, as close as possible to a human model. Previous studies investigating the transmission of vCJD have concentrated on mice and sheep.

The process of blood transfusion was recreated by injecting a type of monkey known as a macaque with brain tissue from a BSE-infected cow.
Brain tissue from the monkey was then injected into the blood stream of other macaques.
Within just 25 months the monkeys were showing the deadly symptoms of the disease. Brain tissue was used to speed up the experiment although it has the same ultimate effect as blood.

Dr Moira Bruce of the Institute for Animal Health in Edinburgh, who collaborated on the project, said: "Intravenous transmission between primates is really quick. This possibility has been examined from a public health point of view and there have been measures recently introduced to substantially reduce the risk of the spread of the disease."
In July 1998 the government's expert panel on BSE and vCJD, the spongiform Encephalopathy Advisory Committee, predicted that there was a risk the agent could be transmitted in white blood cells.

A screening programme was introduced to filter out white blood cells before transfusion.
New variant CJD has claimed 80 lives since it was first detected in 1996, but its incubation period has kept its incidence shrouded in uncertainty.

Operations to remove tonsils have also been banned in many hospitals throughout the UK because of the risk that the disease can be transmitted by the re-use of scalpels.
It is known that at least 13 of the British victims of variant CJD have been blood donors and authorities have been struggling over the ethical problem of whether people who have received blood transfusions or vaccinations including donations from these should be informed of the potential risk.
General guidance is that recipients should not be informed since there is no test, no cure and no treatment for vCJD.

A REPLY TO A REPLY OF A REPLY

FACTOR VIII AND PERCEIVED RISK.

As a severe haemophiliac in my mid sixties I too have been infected in the past twenty odd years by: hepatitis B, in the mid seventies (when it was known as Australian antigen), and latterly by HIV and hepatitis C. As far as hepatitis D, E et al, are concerned the court is still out!

I too share the concerns and unease of Richard and 'B I O'Hazard', plus mounting anger at the incompetence and reticence of much of the medical profession with regard to their handling of this ever-expanding scenario of virat contamination of blood products. Most of all, anger at the complete lack of real concern expressed by past and present governments, for their role in this fiasco. A tragedy, which resulted from the failure in the 1970's to build a facility to produce blood coagulation factors, plus the failure to institute heat-treatment for coagulation products, when it first became available in the early 1980's. How can anyone feel confidence ever again, in assurances from all those whose previous assurances have resulted in the deaths of so many innocent people, and the devastation of so many other lives – their families, partners and friends?

And yet, and yet, I am also haunted by other, earlier, memories of all those years before the 'new' treatments became available. Much of the first thirty years of my life, before concentrates became available, were filled with bouts of extreme pain from haemarthrosis into various joints and muscles – pain which went on for days, sometimes weeks. I was unable to attend school, and had no formal education as a child. The only treatment at that time was whole blood, which was mostly ineffective. My earliest memories are of dark Victorian hospital wards, 'cut downs' into veins, and long periods on 'Balkan' beams to straighten joints, and plaster casts. I spent an average of four to six months per year in hospital or in bed at home, at this time. As a result my knees and elbow joints are ruined, and I have been on crutches since the age of seventeen. My last severe bleed was in 1966, into the ilio-psoas muscle, I almost died –being saved by a revolutionary new treatment: pig AHG (No I didn't get swine fever!). Following that I was in a caliper for three years, and my leg muscles never recovered. I know that without Cryo-precipitate and Factor VIII treatment, I would be most probably long dead by now, or so severely damaged that life would be not worth a candle!

Despite the damage I suffered previously, with the advent of Factor VIII I was able to work as a full time teacher for nearly thirty years, something that would have amazed my poor parents, who unfortunately did not live to see my improved quality of life. I was also able to take up my old childhood hobby of collecting & studying insects, going on quite strenuous expeditions into the countryside with other entomologists. For the first time, I spent holidays abroad and drove my car for long distances in France etc. Without the, albeit, infected, Factor VIII treatment I could not have done any of this: I would probably never have seen my children grow into adults, nor had anything like (despite all the pain and suffering) the same quality of life.

The case for taking/not taking treatment depends, it seems to me, on ones perception of RISK: what is the risk, using one of the 'new' (available since 1994) Recombinant Factor treatments, of contracting some new virus/prion etc, compared to the risk of suffering permanent (possibly fatal) damage from continual haemorrhages?

Nothing in life is without risk: do you drive a car; drink alcohol (to excess), smoke, and take 'recreational drugs'? Are these risk free? Oh yes, such activities are of our 'own choice', they give pleasure: ask someone dying of lung cancer, a stroke etc., whether they think the pleasure from smoking was worth the risk!

The use of human derived blood products always involved risks: to inject such compounds into the blood stream was bound to risk infection by various bacteria, viruses etc. Yes, the medical professionals did not inform patients sufficiently about such risks, and were not vigilant enough (at least in the UK) to have insisted on heat treatment when it was first suggested in the late 1970's early 80's. Never the less, I believe, lessons have been learned (at least in Wales, Scotland, Ireland etc.), the recombinant factors now available, plus the new recombinants, which contain no human material (I am now taking part in the trials of one of these), if one can never say involve NO RISK, do reduce that risk to a very, very small factor in the equation.

Let us hope that such treatments, and eventual treatments using genetic control, will end forever the threat of treatment born infections, and all the medical professionals learn to take patients truly into their confidence, in regard to the perceived risks involved. Then we can look forward to a new and haemorrhage free life for all the new generation of haemophiliacs, and the needless suffering of countless older haemophiliacs et al, will perhaps not have been in vain..

CALL FOR PUBLIC ENQUIRY INTO A GRAVE INJUSTICE !

Dear Prospective Candidate,

Before deciding how to cast our vote in the forthcoming elections we would like to have your considered response to the following information on the lamentable state of affairs with regard to the 150 Haemophiliacs and those with related disorders in Wales, who have been infected with Hepatitis C (HCV) or co-infected with both HCV and HIV from NHS treatment for their condition.

The facts of this matter are as follows:

1. In the years between the late 1970's and the present, a large number of those suffering from haemophilia and various related blood disorders, were infected with hepatitis C (HCV) from the blood products used to treat their condition. To make matters even worse, many of those unfortunate people had also been infected with HIV (the Aids virus) from the same source!

2. In addition at about the same time it became known that a virus, known at that time as non-A non-B hepatitis (later called Hepatitis C), was present in blood products.

3. From the late 1970's, it was known that by heating these blood products to 60 degrees, hepatitis viruses were killed rendering the products safe and that in October 1983 the German Health Authorities had introduced heat-treated products to all haemophiliacs, the British NHS continued to use non heat-treated blood products until two years later!

Haemophilia is a severe, life-threatening, condition, which unless suitably treated with blood products can cause extreme damage to the bones and leave the sufferer disabled. In severe bleeding episodes it can also result in death. The added burden of infection with hepatitis C has a very real affect on people's lives, health-wise, socially, financially and emotionally. One of the greatest difficulties faced with viruses is uncertainty, and there is still no fully effective treatment. Those infected face insecurity and stress due to a reduced income, inability to obtain life insurance, reduced company pensions caused by having to take early retirement due to illness, extra costs such as heating, prescriptions and dietary needs. Equally there is stigma attached to HCV so Haemophiliacs try to keep it a secret from friends and employers because they do not know how they will react. Finally, there is the incredible, often unbearable, strain on relationships from the risk of sexual transmission with the fear that they may infect their partner.

The Aim of our campaign is to call for a Public Enquiry into this whole affair to identi~ what lessons can be learnt for the future so that no one has to live with the isolation and fear that goes hand in hand coping with these viruses.

We would be grateful if you could give us your considered response as a candidate to this matter, so that we can vote accordingly in the forthcoming elections.

CHANGING TREATMENTS

TREATMENT INTERRUPTIONS

Taking anti-H IV drugs has been seen as a life-long commitment. Successful treatment reduces HIV viral load to very low, and ideally 'undetectable', levels. If treatment is stopped, this control is lost and levels of HIV in the body rise again rapidly. Nevertheless, good health1 demanding drug schedules, and worry about serious, long-term side-effects may lead some people to ask their doctor if they can stop taking their anti-HIV drugs. While people with HIV may refer to these breaks in treatment as 'drug holidays', many doctors prefer the term 'structured treatment interruptions', or STIs.

Treatment interruptions have become topical amongst HIV researchers after a handful of people who had previously taken anti-HIV treatment maintained very low levels of viral load even when they stopped their treatment.

Though these reports are worth further investigation, at the moment there no evidence that viral load control occurred as a result of breaks in treatment - the two may be purely coincedental. Because of the lack of proof, and the potential risks, many doctors consider that treatment interruptions should only be undertaken within clinical trials, or where a high level of monitoring and care will be available.

Stopping treatment may undo any positive effects of having taken treatment in the first place. The common response to stopping anti-HIV treatment is for viral load to rise and the CD4 count to fall.

The immediate result of these changes will depend on an individual's state of health at the time. Allowing the CD4 count to fall to a level where HIV- related infections can occur will obviously present the greatest health risk.

Treatment fatigue

The day-to-day realities of long4 term anti-HIV therapy can present many challenges. For some people, the need to maintain high levels of adherence (e.g. by not missing doses), and manage ongoing, unpleasant side-effects may reduce overall quality of life so that the perceived costs of treatment may appear to outweigh the benefits. In these circumstances, a break from treatment may be aftractive.

If you are having problems taking anti-H IV drugs, or with side-effects, discuss this with your doctor or another member of clinic staff rather than stopping treatment alone. They may be able to help solve these problems without needing to stop treatment.

Treatment interruptions before changing drugs

A second possible role for treatment interruptions is to improve the chance that a 'salvage regimen' will successfully reduce viral load. Salvage regimens are taken by people who have used many different anti-H IV drugs before and yet have not been able to maintain a suppressed viral load. People in these circumstances may find that their HIV is drug resistant and that consequently there are few drugs available to them which seem likely to work.

Stopping all drugs for a few weeks or months may cause HIV to lose some of its drug resistance. If most of the HIV which grows back is not drug resistant, then the salvage regimen may have a greater chance of reducing viral load to undetectable levels before drug resistant strains can reastablish themselves. However, rather than disappearing altogether, it's more likely that drug resistant HIV is 'archived' within the body and may eventually reappear once treatment is restarted.

Stimulating an immune response

Treatment interruptions are also being investigated as a means of priming the body to control HIV more effectively. The theory is that the rises in viral load which occur when treatment is stopped may act as a type of 'auto-vaccination', stimulating the immune system to recognise and respond to the virus.

Some experts believe that this strategy will have the greatest chance of succeeding in people who began treatment very close to the time they were infected, i.e. in acute or primary infection. However, this approach is also under investigation in people who have been infected for longer periods and began treatment later in the course of their disease.

Potential hazards of treatment interruptions

Rising viral load and falling CD4 could present a risk of infections or other illness.

Though many people regain lost CD4 cells and re-suppress their viral load once treatment is re-started, these may not fully return to the levels achieved before the interruption.

Some people experience flu-like symptoms during a rebound in viral load.

The rebound in viral load could re-seed viral reservoirs which had been diminished by treatment.

Anti-H IV drugs differ in the speed at which they leave the body, and these uneven, low drug levels can result in drug resistance. It may be unsafe to stop some drug combinations abruptly, particularly those that include efavirenz or nevirapine. Seek your doctor's advice on the drug combination you are taking.

Rather than improving quality of life, cycling on and off treatment may reduce it. The 'habit' of adherence may need to be re-learnt, and side-effects may need to be re-endured with each interruption.