

# Birchgrove

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## Mad Cows and Conferences

### vCJD In The NEWS

On the 21st September it was announced that thousands of NHS patients, especially people with Haemophilia had an increased risk of vCJD. By the following day stories appeared in every national newspaper, including the Times which featured a person with Haemophilia. Letters were being sent out from haemophilia centres, accompanied with DOH information nationally to patients. For members of the Haemophilia Society, letters were sent out to members to try and minimise some people's fears and gave their helpline and updated factsheet for further information.

For many of us this is news we had long feared and expected, for many this devastating news has been a bombshell.

By now product recalls from 1997, 1999 and 2000 all were produced from donors who later died of vCJD. A time period when recombinant had been licensed and was available, but denied to us, and is still being denied to most English patients over 40 years of age.

Over the last years the government has constantly reinforced that blood-to-blood transmission of vCJD is purely theoretical. Now we are all being put on "the at Risk" list as far as public health is concerned, and blood to blood transmission risk of vCJD has now been made public.

Letters sent to patients have expressed that the chances of vCJD developing "are likely to be very low".

If this sounds familiar, then maybe you are confusing it with announcements in 1984 that HIV would only infect 1 in a 1000 of us. Maybe you are confusing this with your doctor's advice that there was a small risk of hepatitis infection. Maybe you are confusing it with your doctors telling you your arthritis drugs were safe.

The list of special precautions that we have been advised to take are almost laughable if it were not for the severity of the issue. We should not donate blood, organs or tissues. As we all have either HIV, hepatitis

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## vCJD In The NEWS Continued from page 1

C, B or a combination of the 3 our blood, tissues and organs are not fit for donation as it is. Why should vCJD make a difference?

We should tell anyone who is treating us for surgery or dental work so that they can make special precautions. However they haven't told us what precautions we should take. Do we have to put our old toothbrushes in our sharps bin now, for example?

If precautions were taken in the first place this situation would not be happening. Again does this sound familiar?

We are also advised to tell our families so they can monitor us for personality changes or clumsiness. Haven't our families suffered enough agonising grief already, without landing this on them?

We now have to wait, if we want to know, for our doctors to find out if we have injected possible infected batches into our veins. But when more blood donors die of vCJD we will have to go through the process again.

We are being forced to have the "AT RISK of vCJD" on our hospital notes, our G.P.'s will all be informed and the UKHCDO database will record our "at risk" category, all without our consent or permission.

How many mistakes are the government and our doctors going to make before one of them actually says sorry, actually shows that they owe a duty of care to us as patients, and treat us with some dignity?

*Paul*

## vCJD -PATIENT NOTIFICATION EXERCISE BEGINS

Health Secretary John Reid today announced further developments concerning variant Creutzfeldt-Jakob disease and blood. He told MPs in a written ministerial statement that an exercise has begun to notify some recipients of blood products about the results of a risk assessment exercise carried out by the Health Protection Agency. The exercise follows the identification last December of the first suspected case of vCJD transmission through blood transfusion.

The results of the risk assessment will be made public at the end of the patient notification exercise. John Reid said:

*"It is important that Parliament is kept informed of developments on this important subject, which is why I have made this statement today.*

*However, it is equally important that the patients who need to know the results of this risk assessment are given this information by the clinicians who care for them, so that appropriate support can be provided. My Department will make a further announcement at the end of this notification exercise."*



## WRITTEN MINISTERIAL STATEMENT-DEPARTMENT OF HEALTH

9 September 2004

### **The Secretary of State for Health: Written Ministerial Statement on blood donation and vCJD.**

#### **The Secretary for State Health (Dr Reid):**

Following my statements to the House on 17 December 2003 and 16 March 2004 concerning variant Creutzfeldt-Jakob disease (vCJD) and blood, I wish to provide an update on some further developments in this area.

My statement on 17 December 2003 informed the House of the first case of possible transmission of vCJD via blood transfusion and the precautionary actions taken. Those actions included measures to protect future blood supplies and contacting recipients of blood from donors who subsequently went on to develop vCJD. A further written statement on 22 July 2004 indicated a second case of possible vCJD prion transmission via blood transfusion had been confirmed.

I also made reference in December to the fact that other patients, including people with haemophilia and other bleeding disorders, would have received plasma products before they were sourced from the United States of America. Although there are now two reports of possible transmission of vCJD via blood, the risk of transmission via plasma products, which will have been derived from large pools of plasma donated from many thousands of people - and therefore heavily diluted - is uncertain. But it cannot be excluded. The CJD Incident Panel (CJDIP) were asked to advise on a case-by-case basis (having adopted a highly precautionary approach) which recipients of plasma products will need to be contacted. This advice has been received and a programme of action has been agreed.

In June 2004 the Health Protection Agency (HPA), on behalf of the CJD Incidents Panel, reported on an assessment of the risk associated with each batch of product and advised my Department on: a) which patients needed to be assessed and possibly subsequently contacted, and b) managing the possible risk to public health of those patients.

In the light of these assessments, the HPA is today initiating a process to notify relevant patients of these developments. The HPA are sending information to clinicians to enable them to trace particular plasma products. The clinicians will then notify any patients identified as 'at risk' as a precaution. Any patients affected should expect to be contacted by clinicians later this month.

Aside from patients with haemophilia or other bleeding disorders, the other main group of patients who may have received significant amounts of affected blood products are patients with primary immuno-deficiency (PID).

Throughout this exercise we have been concerned to ensure that the results of the risk assessment are communicated to patients by the clinicians responsible for their day to day care, so that appropriate supporting information can be provided.

Further details about the risk assessment exercise will not be disclosed until after patients are informed of the outcome. I will make a further statement at a later date, if necessary.

<http://www.wired-gov.net/WGLaunch.aspx?ARTCL=26689>

*A further written statement on 22 July 2004 indicated a second case of possible vCJD prion transmission via blood transfusion had been confirmed.*



# A patient's letter to John Reid

John Reid  
Richmond House  
79 Whitehall  
London  
SW1A 2NS

22 September 2004

**Re: vCJD and plasma products**

Dear Mr Reid

I am writing to you about a letter I received yesterday from my hospital concerning vCJD and plasma products. In 1986 my hospital told me I had tested positive for what is now known to be HIV and in 1990 they wrote to me stating I had also tested positive for hepatitis C. So, to again be reminded that I have a "theoretical" chance of becoming infected with vCJD is irritating to say the least. This information was supposed to be sent to patients before we saw it in the media, I read an article in *The Guardian* on Friday 10 September stating that centres would be contacting patients in the next few weeks so I was aware the letter was imminent. That plan worked then.

I would appreciate your comments on the following points, I have not received a reply from previous letters sent to you but am so frustrated after 18 years of virus warnings and infections that I long for a meaningful government response to this issue.

- In 1990, I was told hepatitis C was not something to worry about. I am now being told the risks of contracting vCJD are "likely to be very low". Why do I not believe you? Who would you trust?
- It was apparent in the 1970's that blood transfusions, especially plasma products made from thousands of donors, carried a high risk of transmitting hepatitis. Why did the government ignore the facts and continue to treat people on a non consultative basis with plasma based products? The old party line that people with bleeding disorders would die if they did not treat is untrue and the technology for detergent washing was available and cheap
- Why did successive governments fail to finance the Blood (now Bio) Products Laboratory properly?
- Over 1200 people were infected with HIV from their NHS treatment in the early 1980's, since then those still alive and in need continue to rely financially on The Macfarlane Trust which is basically an under resourced hardship fund, why? The trust work with what they are given and in my opinion are making progress but they cannot possibly meet the real needs of their registrants with the current funding system which results in an unfair and unequal response to people with bleeding disorders and HIV.
- I have been unable to work for 13 years due to HIV and hepatitis C infections caused by NHS treatment, is it fair or right that my family are constantly worried about financial issues, I would probably be enjoying a full, varied and financially rewarding career had I not been infected with two life threatening viruses.
- Do you realize how depressing the Skipton Fund saga has been for those affected? Firstly you deny widows an ex-gratia payment, then the process drags on and on and on, almost a year between government promises and delivery. The fact that I have received probably a quarter of your annual salary because the NHS infected me with a virus that I have been fighting for over 20 years is an insult.
- Do you realize that Haemophilia Centres who have been instructed to write to patients about vCJD are being flooded with calls from worried patients and parents? They should be used to it by now I suppose but they have been given no extra resources to deal with worried people and their work is bound to suffer. The doctor/patient relationship takes another battering.
- I now have to wait until my hospital check the records of 700 patients if I want to know if I injected myself with plasma product from a person who has died from vCJD. Great. What happens when, as it will, another person who donated blood dies of vCJD? Will the centres have to write to patients again and check their records? Will the Government issue yet more platitudes and reassurances?

- About 18 months ago I requested a meeting with a minister to discuss the situation of Macfarlane Trust registrants. This request was put to Charles Lister in my capacity as registrant representative of the trust's partnership group and I was informed by Richard Gutowski in the autumn of last year that Melanie Johnson did not have a window. Do you think, especially in light of recent events, you might persuade Melanie to find an open window for me? Please.
- I believe recombinant treatment for most bleeding disorders was licensed for use in this country by 1996. At this point a caring and proactive Government should have offered all people with haemophilia a choice of treatment, it did not do so and the present Government have only bought in a roll out of this treatment following long and involved campaigning from those affected and organisations supporting us. The recombinant roll out itself is a mess, using age as the determining factor for access clearly goes against NHS principles which I believe state that no person should be denied treatment on basis of age. The deliberations and stalling that followed meant that the roll out was late and under spent in the first year prompting the DoH to attempt a siphoning off process to the tune of 4 million pounds, a decision which was only overturned following intense pressure from individuals and organisations. This country lags behind most other developed nations in the availability of the safest treatment for bleeding disorders and many of the people who should be getting a choice in April 2005 and 2006 are feeling pessimistic that even this date will be met by PCT's and centres.
- I take exception to the public health measures included in the letter from my hospital which the DoH instructed them to send. I have not donated blood since my HIV infection was diagnosed, I have realized it would not be a good idea to donate organs or tissues after my death and my next of kin is also fully aware of this and I already cannot register with a "normal" dentist because they are scared of my conditions and the service, if offered, is dreadful because of this fear. The final public health measure which I quote: "it would be best if you tell your family about this in case you might need emergency surgery in the future" is quite frankly simplistic and arrogant. Please don't tell me how to live with these scary viruses, real or theoretical, after all the government did give them to me without my informed consent.
- I do not wish the UKHCDO data base to have any information about myself. My current centre director has declined to send any information to them without express written consent because of concerns around the data protection act and I am in agreement with this. I have, on countless occasions, challenged the UKHCDO on this matter and they say they are "doing all they can to comply with the act" while dismissing my concerns.

There are further issues I have about this whole sad and sorry saga that drags on and on but I also have a life to live so will leave those for now. I would appreciate a detailed response to the points I have raised but for me and many others the very fact that the recent letters have been sent to patients means we will not be able to really get on with our lives until the government fulfils it's obligation to grant our community a full and public independent enquiry. Mr Reid, you are obviously a man of some determination and intelligence if you can give up smoking, please use some of those qualities to try and understand how unfair and undemocratic it is to continue to deny an enquiry into this tragedy.

Yours sincerely

*Richard*

# BAD BLOOD

Haemophiliac Robert James is one of the thousands of people who received a letter from the government warning them they may have been exposed to the degenerative brain condition Creutzfeldt-Jakob disease through blood transfusions. He explains what it is like to face the prospect of being infected with a third deadly disease.

*Friday September 24, 2004 appeared on the Guardian on-line*

My friend Paul had a greeting card with a picture of a support group for cattle. One cow says to the group "I'm not worried about mad cow disease", the group leader asks why and the cow replies, "because I'm a helicopter". Paul amended it to "because I'm a haemophiliac" and stuck it on the wall in his office. Paul has been dead eight years now - the Aids virus got him. So how did we go from making sick jokes about British blood in the mid-1990s to me collecting a letter when I got home from work telling me I had a higher risk of vCJD than all the eaters of cheap burgers do.

What is it about being told something you already know which still makes it hard to hear? I work in the NHS on promoting patient involvement and I already knew about the two vCJD infections from blood transfusions. I've always known my haemophilia treatment could carry diseases. It takes blood from thousands of people to make my treatment, giving me the opportunity of a disease from every one of them. I can hardly miss the fact that this treatment infected me with HIV, (I have to take my anti-HIV tablets in 20 minutes) and hepatitis C (don't even ask about the treatment for that). In the 70s some of the people that gave blood to make up my treatment had hepatitis C and in the 80s some had HIV. How many in the 90s had mad cow disease? Lots, a few, none?

The Department of Health commissioned a risk assessment of the chance of me and a few thousand others being infected with mad cow disease from our treatment. In fact I am so much of a nerd that I had already read the risk assessment when the letter notifying me came out. Although I am dubious about some of the assumptions in the assessment I did like the mathematical formula which I could use to calculate the risk of my own infection. Assuming it is actually possible to pass it on in this way, using their worst case scenario I have a more than 100% chance of being infected. That is very jolly. In their other case scenario I do a little better with about a one in seven chance. Then again it could all be rubbish and there is actually no chance of me getting it.

My experience of HIV at least lets me know what the preventive measures to stop possible transmission mean. Aside from the frankly bizarre proposal that I should not give blood, the other bit - about destroying equipment after invasive procedures (cutting, drilling or sticking things into me) - will just be a return to the medical pariah status I had with HIV all those years ago.

So what would I do about this as an NHS professional who works to improve the patient experience? It's hard to think how you could make this a good patient experience. I passionately believe that the most important part of patient involvement is not sitting on a committee, but being in control of what happens to your own body.

But of all people I should be good at this, I mean surely no one could have more practice than me at the "we think you may have got something really nasty from your treatment" conversation. Or does it work the other way, one infection is a tragedy, two is a farce and three just too much for anybody. Both seem true; I can laugh it off as nothing like as bad as being told I had the Aids virus in the mid-80s, and other times I feel I should just give up because if there is a God he or she really must have it in for me. Even if I miss this bug there is bound to be another in the next decade.

We have to stop repeating this cycle. In my job I talk about "clinical governance" the framework for continuously improving healthcare delivery. One of its simplest features is learning from your mistakes, trying to avoid making the same mistake and to change the system to pick up the problem earlier. Patient concerns can be a good early warning system to prevent future major problems.

If a hospital had caused the infection of a patient with vCJD from medical equipment it would be a "serious untoward incident" and be investigated. The main focus would be to ensure the same problems were not repeated on more patients. We have now had three occasions with the same treatment of suspecting that it had something lethal in it and on two occasions we were right. Yet there is no decision to investigate this and prevent me getting a fourth, fifth and sixth "nasty thing in my treatment". I could go on but I have to stop as it is time to take my HIV medication.



# HAEMOPHILIA ACTION UK

## PROTEST AT SCOTTISH PARLIAMENT (7th September 2004)

Scottish haemophiliacs, Andy Gunn, and Bruce Norvill, were arrested at a demonstration outside the new Scottish parliament building in Edinburgh which opened its doors for the first time yesterday. The two men interrupted the first debate and then daubed red paint on the walls of the new building which cost £430 million. They were protesting at the multiple infection of hundreds of UK haemophiliacs with HIV, hepatitis B and C, through their plasma treatment, and the fact that haemophiliacs have now been exposed to the blood of donors who have since died from vCJD, and the government's failure to hold a full and open public inquiry into blood safety. Many haemophiliacs are now dead.

In the case of exposure to vCJD, this was preventable. For years haemophiliacs had fought for the right to be treated with a safe, synthetic product, recombinant. Our group Haemophilia Action UK first wrote to the government and our local Health Authority in Newcastle in 1995, asking for all haemophiliacs to be given recombinant treatment as we were concerned over the possible risk of contracting vCJD via blood products. We were turned down in writing in the Spring of 1996 on the grounds of cost. We know now that Newcastle haemophiliacs had their first exposure to the blood of donors who have since died from vCJD in November 1996. Had the authorities listened to us this would not have happened!

We only found out about my husband's 12 exposures to vCJD after we were sent two leaked documents, one from a British plasma company dated 1997, one from the NHS Executive dated 1998, advising doctors not to tell patients why their plasma products had been recalled. We informed the "Guardian" and Newcastle "Journal" newspapers along with "Private Eye" in 2000, and an item on this subject later went out on the BBC's "Watchdog" programme. As a result of the media articles, doctors then wrote to their patients asking them if they wished to be informed of exposure to vCJD. We were finally told of my husband's exposure to vCJD in 2001.

We are expecting further letters to be sent to recipients of blood products later this month informing them of vCJD risk assessment in relation to blood products. The Health Protection Agency have informed me to-day that this information is not currently in the public domain but we understand from the Department of Health Press Office that there will be a press release shortly and NHS Direct have informed us that a helpline will be in operation from around 22nd September.

Haemophilia Action UK supports peaceful protest within the law, however we fully appreciate that the haemophilia community is at the end of its tether. For years we have had to deal with lies and cover-up over blood safety. We can no longer use our own plasma because of the risk of vCJD.

We cannot rely on plasma from America meeting safety requirements as we are aware of recent safety violations. Haemophiliacs are now litigating against four major U.S. plasma for past infections. Our group was able to set up contact with a U.S. law firm with the help of American haemophilia campaigner group, "Hemophilia Justice", and the first UK haemophiliacs travel to Chicago to sign depositions in October.

Anyone who cares about blood safety and anticipates the possibility of them or their family needing a blood transfusion for an operation, childbirth, accident etc, should write to their MP and put pressure on the UK government to hold a public inquiry into blood safety. UK government feels it is not in the interest of the general public to have a public inquiry into blood safety.

Surely it is in everyone's interest to ensure that UK citizens receive safe blood products. We believe next time it will not just be haemophiliacs that are infected with blood borne viruses and exposed to vCJD but the wider population. vCJD is no longer considered a "theoretical" risk in blood products, but is now considered an "appreciable" risk. You too can make a difference!

With thanks

Carol Grayson (Haemophilia Action UK)

*(Birchgrove would like to wish Andy and Bruce all the best for their court appearance in November, and hope that their actions help towards bringing our issues into the news, without detrimental judicial decisions to themselves. By writing to your M.P.'s and voicing your concerns over blood product safety we can, together, make a difference.)*

*We cannot rely  
on plasma  
from America  
meeting safety  
requirements*

**OPEN LETTER TO CHIEF EXECUTIVE OF THE UK HAEMOPHILIA  
SOCIETY FROM HAEMOPHILIA ACTION UK  
RE : CJD LITIGATION**

Dear Graham,

I understand that you have recently been appointed to work as Chief Executive of the UK Haemophilia Society. I would like to introduce myself. My name is Carol Grayson and I run an organisation called Haemophilia Action UK. My husband Peter is a severe haemophiliac, infected with HIV, hepatitis B and C, through factor concentrates, and more recently exposed to the blood of donor(s) who have since died of vCJD. His brother, Stephen, also a haemophiliac contaminated through plasma, died of AIDs in 1986.

I did not get on at all with your predecessor, Karin Pappenheim, as so often she refused to listen to grass roots campaigners, despite the fact that we had collected information/evidence on blood contamination for many years. I am delighted she has now left. It is through the efforts and information from our group working with the Newcastle "Journal" (refer to their website under "haemophilia" "hepatitis" "CJD" etc), and contacting Lord Morris Of Manchester, that we were able to pressurise the government to hold an investigation, albeit an "informal, internal investigation", into the documents surrounding blood and contamination from the 1970s and 1980s. I recently received a letter from Health Minister, Melanie Johnson, informing me that the results should be out shortly, she is asking civil servants to speed up the process. We anticipate a whitewash! We urge the Haemophilia Society to campaign for a full and open Public Inquiry as little has been learnt from the past contamination of haemophiliacs with HIV and hepatitis C.

Despite offering to submit our own government documents of the era that we acquired, we have not been asked to submit our documents or to meet with the Department of Health on this issue. We fully understand that to view our documents which are extremely damning, would no doubt put pressure on the government to hold a full and open Public Inquiry into the mass contamination of haemophiliacs, referred to in parliament as "the biggest medical treatment disaster in the history of the NHS". It goes on, with the latest fears over the transmission of vCJD through blood and blood products.

Our group has campaigned for the use of synthetic products since 1995. In anticipation of the possibility of vCJD in blood products, we established personal contacts some time ago with families and professionals living or working with CJD. We also have an excellent solicitor and QC, who have supported us and provided their services to us free of charge at difficult times when Legal Aid ran out.

We have had meetings over the last few days with our solicitor to discuss legal action with regard to vCJD. He is now prepared to take a case forward for haemophiliacs and other patients who have been informed of their exposure to vCJD through blood and blood products. I stress that there is no currently no blood test to establish that a person has been infected with vCJD but our solicitor believes there is a case for those exposed to vCJD under the "Product Liability Act". He has experience of using this law and winning with another blood case, although this was not a vCJD case. Blood cases will be dealt with in a different way to cases of vCJD through eating beef. Obviously we cannot go into details of information/evidence our group Haemophilia Action UK has collected over the years on vCJD and blood, we can only say that we believe there is plenty there to worry the proposed defendants. Our solicitor intends to proceed with a class action, the process has started, and we invite anyone exposed to vCJD through blood and blood products to join us in this action.

Anyone interested can do this by phoning Pat Rafferty of Mckeags Solicitors, 1-3 Lansdowne Terrace, Gosforth, Newcastle Upon Tyne, NE3 1HN. Telephone 0191-2131010. Fax 0191-2131704. E-mail enquiries@mckeags.co.uk www.mckeags.co.uk

We trust that you will circulate this information to your members as soon as possible and put this letter on the UK Haemophilia Society website. We will be circulating this letter to other interested groups.

I would just like to inform you that the Haemophilia Society, Government, haematologists, and the original HIV solicitors said we could never litigate against the U.S. plasma companies for past HIV/hepatitis C contamination. "Haemophilia Action UK" did not accept this advice and sought contact several years ago with American haemophilia campaign groups. Through joint international co-operation "Haemophilia Action UK" and "Haemophilia Justice", and with the support and assistance of "Haemophilia Justice", "Haemophilia Action UK" was able to establish contact with U.S. law firm, Lief, Cabraser, Heimann, Bernstein, initially for my husband's case and then this was opened this up for other haemophiliacs. The first UK haemophiliacs will travel shortly to America to sign depositions.

If you need any further information please do not hesitate to contact me. You have my permission to print this letter in your magazine and circulate it to the haemophilia community.

Yours sincerely

Carol Grayson (Haemophilia Action UK)

Contact Haemophilia Action UK at:

kunming@ukonline.co.uk

For further information and articles see:

[cjdvoice@yahoogroups.com](mailto:cjdvoice@yahoogroups.com)

<http://icnewcastle.icnetwork.co.uk> and search for haemophilia or vCJD

The "Sunday Herald" website <http://www.sundayherald.com/44445> contains articles on CJD and the risks to people with haemophilia giving a Scottish perspective on the subject.

(Birchgrove is happy to publish this letter making it available for all our readers which we hope includes Graham at the Haemophilia Society!)

RE: CJD LITIGATION



# Liberal Democrats support a Public Inquiry

## FULL INDEPENDENT INQUIRY NEEDED OVER BLOOD PRODUCTS

At their recent Conference, The Liberal Democrats called on the UK government to follow the lead of other nations and hold a full independent inquiry into the contamination of blood products. Patsy Calton MP, Liberal Democrat Shadow Health Minister, led the call in her speech below.

### SPEECH BY PATSY CALTON MP ON BLOOD PRODUCTS-22/09/2004

Haemophilia is a condition which affects the ability of the blood to clot. Treatment involves using clotting factors, mainly Factor VIII, obtained from donated blood or more often plasma. In this country blood and plasma are obtained from voluntary donations - in some other countries, notably the US, they are and were mainly collected from paid donors.

By the mid 1970s it was known that hepatitis could be transmitted via the blood products being used to help haemophiliacs' blood clot.

It was also known that paid for plasma and blood, from prisons and from populations with high incidences of hepatitis disease, were more likely to be contaminated with disease.

In 1975 the World Health Organisation warned

"Countries with a low incidence of hepatitis should not use whole blood or blood products obtained from source material collected from an area (in) which there is a high incidence of hepatitis"

Also in 1975 the Secretary of State for health expressed a determination to see the UK self sufficient in blood products "within 2 or 3 years" to ensure safer donations were used. We were still importing 80% of the blood products used by haemophiliacs until the mid 1980s.

Attempts were being made by scientists to remove hepatitis infection from collected plasma, and by 1982 a German company obtained a licence to heat treat plasma. The method was not taken up in this country.

In 1983 the first case of AIDS was observed in a UK haemophiliac.

Blood products are prepared by pooling large quantities of plasma from different donors. Again in 1983 a blood specialist calculated that just 4 infected donors could contaminate the whole world supply of factor 8 in a year!

Haemophilia patients were being subjected to a form of Russian roulette where the barrel had just one bullet missing.

Sadly, some argued that diluting the virus from an infected donation in a pool would reduce the risk of infection. It was not so. Surprisingly, John Reid's statement to the House of Commons on 17 December, 2003 about the transmission of CJD produced exactly the same impression: quality newspapers on 18 December played down the risk of transmission because the prions which cause CJD were diluted in pools.

Before a test for HIV was developed, a surrogate test, for hepatitis antibodies in donors was advocated. Some collection centres in the United States used the test, and excluded infected donors, others did not. This country never used surrogate testing.

It was 1985 before all haemophiliacs had access to heat treated factor 8 in England. Even then stores of non heat treated factor VIII was used up before heat treated product was made available. Inevitably, further, avoidable infection ensued.

In Canada a number of reasons for this apparently irrational behaviour, also seen there, were identified in the Krever Report, following an independent inquiry. Here, we still do not know what went wrong, and why existing, non heat treated stocks were not recalled as a matter of urgency and destroyed when it was known they probably carried disease.

In 1987 The Health Minister who had called for self sufficiency in UK blood products 12 years earlier attempted to find out why the resources he identified had not been used. The papers had been destroyed.

## Liberal Democrats support a Public Inquiry *continued*



The Haemophilia society wants a public inquiry into the infection of the haemophilia community with HIV and Hepatitis C. They want an examination of the whole issue of blood product safety and why the decision was made to use US sourced blood products after medical experts had already raised concerns about their safety.

### We know

**Heat treating was not brought in as fast as it could have been.**

**Donor exclusion was voluntary for far too long**

**Unsafe sources of plasma were used for far too long**

**HIV testing of donated blood and plasma was not brought in as fast as it could have been**

**Artificial Factor VIII is still not available for all**

The lack of an independent inquiry means the victims (many of whom are now dead) and their families do not know what went wrong. Compensation schemes finally produced by the UK government have been derisory. Trust in UK blood products has been lost.

Now as we face the new threat of CJD transmitted via blood and blood products we have to know that the mistakes of the past will not continue. Before we can do that we have to know what the mistakes were, who made them - and why.

<http://www.libdems.org.uk/index.cfm/page.news/section.conference/article.7520>  
[www.libdems.org.uk](http://www.libdems.org.uk)

## Thankyous Thankyous

*Birchgrove would like to thank all our contributors to this issue and also thank Richard for putting together SFW.*

*Apologies to anyone who emailed us in September as we had IT problems. Please re-email if you have not received a reply. Please note that last months issue quoted us as the Birchwood group. Only one eagle-eyed reader spotted the mistake. Please help us to keep on our toes. Many thanks to all who make this newsletter possible, especially our new funders, Awards For All.*

## The Conference Season The Conference Season.

Yes just as Labour, Liberal and the Tories go to the seaside, Birchgrove puts its bucket and spade away and goes inland to some conferences. And where we were mentioned in only one of their conferences, see report above, they were mentioned at all of the ones we went to. We did not bother apologise about our lack of intelligence (generally we like put it on show) or try and remember 10 words (school dispirin, more pillows, cleaner overalls, lower taxis, controlled imagination - was that it) but we do ask for public inquiries (you are not a patsy Ms Calton I don't care what anyone else calls you). Firstly there was Changing Tomorrow in Leicester, organised by Babs Evans of the National Aids Trust who many of you will remember as the last HIV worker at the Haemophilia Society, then there was SFTW-R in Stafford and lastly Mainliners 8th International HCV Conference in London. And I bet none of the Political Parties Conferences get written up like these have been.

# Birchgrove raises awareness at UK HIV conference

**'Changing Tomorrow – Am I Doing Something?'** was the largest conference of people living with HIV and AIDS held in the UK 4-7 September 2004. Birchgrove committee members and readers were there to ensure that the community of people living with haemophilia and HIV was not forgotten. So how did they do this?

## **Involvement at a strategic level**

Robert James, Birchgrove Chair, was invited to be a member of the Conference Strategic Steering Group. This committee, made up of organisations and individuals living with HIV, was set up to plan the conference and give guidance to the organisers. Although it met occasionally the communication was mainly via email through the conference organiser. Robert was able to make sure that issues relevant to people with a bleeding disorder were addressed in the programme. For example, Birchgrove reader Stuart Gregg was one of the speakers at a workshop on having a family and informed participants all about sperm-washing. Robert also used his experience of involvement to chair the Patient and Public Involvement sections of the programme.

## **Guaranteeing attendance of people with haemophilia**

The conference partner organisations (UK Coalition of people living with HIV and AIDS, Positively Women, National Long Term Survivors Group and National AIDS Trust) wanted to ensure that participants with HIV reflected the diversity of people living with HIV in the UK and the conference application form had an extensive list of questions. The conference was oversubscribed but everyone with haemophilia was offered a place (4% of the total number of

people with HIV attending). People with haemophilia met other desired criteria too, such as living with HCV and/or HBV co-infection, not living in London, and of course all being 'long-term survivors'.

## **Recognition and remembrance**

Paul Bateman, Birchgrove secretary, arrived at the conference venue early on the Saturday to hang the large red ribbon used to unveil the Woodland stone, along with information about the Birchgrove Woodland Grove and how it was set up. This magnificent ribbon was on display at the front of the main hall throughout the conference and most participants took the time to stop and read the accompanying words.

## **Keeping in touch**

One of the conference aims was to 'create sustainable networks' and Birchgrove readers worked hard to forge links with different communities and individuals. Suresh Vaghela of Birchgrove North chaired a workshop on Faith and Cultural Issues. The group lobbied for more time so the workshop was run again the next day and the outcome is that some people attending have decided to work together to lobby faith organisations to address stigma and discrimination. Birchgrove readers were also able to meet a young member of the Eileen Trust and discuss common concerns, meet heterosexual people from around the UK and make friends with people from African and gay communities.

*Babs Evans, Conference Organiser*

*A Full report of this conference will be available on the UK Coalition web site [www.ukcoalition.org](http://www.ukcoalition.org)*



# Reporting Yesterday - What Were We Doing?

As Babs the organiser of Changing Tomorrow says, Birchgrove readers were involved all over the shop in the conference. Strategising, faithing, sperm-washing, drinking and putting the campest thing at the whole event on display with our bright red ribbon of ribbons - haemophiliacs were at the forefront of it all. I got to sit in on the organising events and probably some sub-committees so tedious that I have blanked from my memory already.

The best thing about the whole event for me was meeting such a variety of people and one Birchgrove superhero who shall remain nameless certainly improved the standing of Birchgrove with African women with a deep conference snog. The whole event seemed happy and the strength of some people in really awful situations was inspiring, such as a woman afraid to visit her kids back home because she might be refused permission to return to the UK and so would no longer be able to send them money home to pay for school and also would die as HIV medicines are not available there. The worst bit was that it took place in Leicester and although I like the city it is where my work's office is and so is the city I have been to most frequently this year.

As mentioned I took part in the organising committee suggesting some topics that never made the final programme such as "How should you hide your buffalo hump on a first date?" and "If I become resistant to Efavirenz can I sell it as an hallucinogenic drug to my friends?" and others that did.

I also got to run a workshop on patient involvement in the NHS. This was really good for me as I got some answers I can use in my job and presented them to a bunch of chief execs in Hampshire only this week. As one person pointed out at the end what did they get out of the workshop other than some magnificent facilitation by the eight other doing it? Hopefully they understood a bit better the way the NHS has organised itself and the means to be involved and push for change within it. I also got to hear some interesting talks and debates from people, a workshop on hepatitis C that was mostly about sex rather than interferon, and got drunk with the sexual health programme manager at the DH. She used to work in HIV in my home town so I had met her before. At one point we nearly had all the haemophiliacs at the event at the same bar table and considered forming a caucas group but decided we'd really rather have another drink and talk about football than have a meeting. As with all such events there were some serious things and the discussion about the legality of sex for positive people which were nicely summarised by Yusef at Something for the Weekend - Reloaded and the bits on new drugs. There are some new ones coming along but it is not like a couple of years ago when a new HIV drug seemed to appear every month. All in all far too little sleep for a weekend and far too much talking and learning for me. I was shattered at the end of it all.

*Robert*

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## Something For The Weekend 2.....

### *Reloaded - A Report*

This residential weekend event took place between 10th and 12th September and was open to registrants of the MFT and their partners. Funded by the Macfarlane Trust and organised by Richard Oakley with help from John Morris at the Haemophilia Society the event was well attended and fully loaded.

The Friday afternoon was a welcoming event with new faces blending in with the old, as people acquainted themselves with the hotel and its facilities. The evening was filled with introductions, dinner, a pub quiz and plenty of bar room discussions.

The Saturday was kick started with a talk on HIV and Human Rights by Yusef Azad from the National Aids Trust which was a thoughtful exploration into the criminalisation of HIV, the right to have children, the right to travel and basic human rights issues that we face.

The Big Debate was a popular session which compared the choices of stopping regular MFT payments in favour of larger single grants. (A full report of this session is below).

This was followed by Peter Stevens from the MFT on the BBQ, as the session was titled "Grill the Chairman". Peter gave a talk about the MFT's role and the changes and obstacles it has faced over the last year and the struggles it has with Government for further funding. He also talked about what the trust have done over the last year with £2.1m spent on Regular monthly payments to 610 people, £1/4million spent on winter

## *Reloaded - A Report*

payments, 1260 single grants paid out totalling £713,000, The setting up of the bereavement project, the continuation of the Partnership meetings and funding events such as The Men Only weekend earlier this year, the bereavement weekend and this SFW2.reload event.

Peter talked about the Long Term Review, the appointment of Martin Harvey as C.E., the launch of the MFT website and the registrant chat room, the agreement to administer the Skipton Fund on condition it was ex-gratia and did not exclude MFT registrants. He also added that problems were involved in moving offices and upgrading their IT and accountancy systems as well as the many staff changes. As many people know Claudette has been off work for some time due to illness and Carol Clisby is also leaving soon. The changes in support services have already started with the appointment of Jude Cohen as Head of Support services and regional support workers are planned to be recruited in the near future.

After his introduction Peter was well and truly grilled by the audience and questions were thrown at him. Most concerns seemed to be about the uncertainty of change, and many people saw the role of regional support workers as spies coming round to check up on us. Peter made his point very clear and said that it was impossible for one support worker to see effectively 400 registrants and the bereaved and dependants. The MFT was committed to improving its interface with its registrants and wanted to improve its service delivery.

Other questions raged about the level of grants, the problems accessing single grants and the hoops people have to jump through, the disadvantages to coming off benefits, and the concerns of ongoing financial support from the trust.

After lunch, where Peter was still being grilled, and the MFT debate still raged, the afternoon's options included a talk on Co-infection issues by Dr. Ranjababu "Babu" Kulasegaram, A partners session and Yoga followed by coffee. Then options included a talk on Patient Involvement, bodybuilding, more sessions for partners and a session for positive women. After this choice there was yet more activities with more yoga for those that wanted to wind down, or a chance to hear Denis Whalley talk about the US litigation currently taking place. Denis talked through the legalities of the action, the progress so far and why it is taking place. Some of the information was hard to swallow for some people there as Denis talked about the reasons that the pharmaceuticals were being taken to court. Denis took questions from the floor and gave his contacts for those that wanted further information.

Throughout the day other options were available for conference attendees, such as a range of massage, facials and complementary therapies, a chance to talk to a financial adviser, use of the Cyber Café, the hotel pool, jacuzzi and sauna and an opportunity to talk to the MFT and Haemophilia Society representatives that were there all weekend. And of course the Birchgrove stand, and "ribbon on tour" was accessible to all. The ribbon has now been seen at events in Swindon, Leicester and Stafford.

The evening was yet more food, a disco and a karaoke. The bar was as popular as ever and people talked about their issues alongside football, religion and politics until the bar shut.

The Sunday started with a lengthy session called "meet the organisations", which began with Graham Whitehead, new Chief Executive of the Haemophilia Society. Graham introduced himself and discussed how he saw his role at the society and outlined the organisation's future plans. Graham hit it off well with the audience. He told a funny joke and also fully supported a public inquiry, before answering questions from the delegates. Gareth Lewis followed this with a talk about the work of Haemophilia Wales and how he saw a new change in direction. Robert James talked about the work of the Haemophilia and HIV Life History project, its progress so far and the possible outcomes of the completed works, which will be held at the national sound archive at the British Library. Stuart Gregg talked about his work as a user Trustee at the MFT and how he was a voice for registrants within the trustee board. Birchgrove were last on the agenda for the early morning session and I talked about the woodland grove and the progress to date and Rob talked about the work of Birchgrove, how the newsletter is put together, our involvement in the world of HIV and our future plans. Robert actively encouraged people to contribute to Birchgrove as it is a platform for our collective views as well as information and support.



## Reloaded - A Report

After mid morning break there was a choice of activities as Babs Evans led a discussion on Employment and Volunteering which, as well as being well attended, started off various discussions amongst the group about individual experiences, tips and general advice. Running parallel to this was Jo Robinson from the THT who gave a talk on Making Babies.

The last session of the event was a presentation of holistic health options delivered by Mel Frankland of Tony's Holistic Centre. Tony's based in Kings Cross give a wide range of medical advice, a holistic approach to health, dietary information as well as being able to supply medicinal cannabis products including tinctures, chocolate and organically grown cannabis.

Richard rounded off the conference with some thankyou's to all the people that made the weekend possible, especially to all the smiley faced volunteers who gave up their time over the weekend. Richard himself was thanked and most people, I think went home happy, a little better informed or just glad that they had an opportunity to get things off their chests with people that understand.

A Sunday carvery was served before the delegates made their way home. Overall an exhausting weekend, and a very full weekend. If anything is learnt from these events, it is that we have very individual needs, are geographically isolated and need this kind of event to meet up, share tips on how to cope with life and broaden our horizons. Many people obviously got a lot out of the weekend and especially some people that had never been to an event of this kind shared things with others that they had never had the chance to do so before.

Look forward to seeing people at the SFW3???

Paul

(A full report of this event will be available via the MFT when complete, and accessible on the MFT registrant secure part of the web site- [www.macfarlane.org](http://www.macfarlane.org) )

## **Mainliners 8th International Conference in London.**

This was a surprisingly quiet affair compared to most years and seemed to lack the spark that the conferences have had before. Perhaps as it was in London and I went home in the evenings rather than stay with other delegates as at the previous ones in Amsterdam, Lisbon and Edinburgh that I missed out. As at Changing Tomorrow there was talk about the outbreaks of sexual transmission that have been seen at HIV clinics and a debate about where prevention work should be focussed. One presentation on the problems of effective prevention for drug users in Scotland was particularly good in showing the circumstances and methods people use in preparing and injecting illegal drugs. Other presentation included the controversial proposals by a group of doctors to stage liver fibrosis by using a number of blood tests rather than a biopsy (it's controversial because most doctors think it far too inaccurate) and to be fair it did often sound more like a sales pitch than a scientific presentation and an explanation of the basics of Chinese Medicine. I will not even try to summarise this as I am sure I will confuse my yin and yang, suffice to say they are opposites but both are needed. One guy called Jeff also described his life on interferon that was funny and all too recognisable to any of you taking it - he seemed to get more symptoms than me and I thought I had had hundreds.

## **Tony's Holistic Centre**

For holistic health advice and natural medicinal cannabis products for patients with MS, Arthritis, Glaucoma, Cancer, HIV/AIDS and Chronic Pain

For further information please contact Tony's Holistic Health Centre, 1 Omega Place, Kings Cross, London N1 9DU Tel: 0207 8375223 email [tonysorganics@hotmail.com](mailto:tonysorganics@hotmail.com) or visit [www.thcweb.net](http://www.thcweb.net)



## The Big Debate- SFW2

### **"Single payments only and an end to regular payments by the MFT?"**

#### **FOR**

Robert started this debate by saying this was to be light-hearted and in no way should the results of the final vote be used to justify any changes to the way the Macfarlane Trust operates. Putting forward the argument that regular monthly payments were doing us more harm than good. The drip, drip, drip of cash each month wasn't enough to do anything with, and was only preventing us from becoming empowered. What had been great to get when they started was now just what we used to live on. The money should be making us feel happiness and that only single payments did this now because they felt like extra money. Rob suggested that by scrapping the regular payments attention could be given to single grant applications, which would be for medical need and needs relating to our health, so that the people most in need could access this. Rob also suggested that as the monthly payments were such a pitiful amount anyway why not scrap them, pool the money and give the whole amount out to a selected few each month by lottery. This would mean that months would go by when you don't get anything or one month you might win £1,000s. A lottery for money to go with our lottery for life.

#### **AGAINST**

Gareth stole a coarse fishing expression, by starting his reply with "The Glorious Sixteenth". A Date in every month when we can breath again. The sixteenth of every month was in our diaries, it was the day we paid off our mortgage payment, the day the direct debits went out, the day we start to eat well again, the day you could make a dent on the visa card bill.

The sixteenth was the day that every MFT registrant knows they have a choice. They don't have to go cap in hand, or go and get a letter from their doctor or try and prove how their health is affecting their finances and decisions. Gareth added that to scrap the monthly payments the single payments would have to be huge to compensate as they keep him going through life.

#### **DEBATE FROM THE FLOOR**

Why can't we have both and continue, There's nothing wrong at the present. The present situation makes us dependant. People didn't mind being dependant as it was keeping them going. System is unfair, as single grants still and always will be given to best letter writers, and people with better relationships with their doctors and nurses, and those that don't mind grovelling.

One person asked if the MFT would give him a pay off, get an actuariary to forecast how much he will cost the MFT if he lives until he is 75, and give him the lot up front now. The person said he would be happy to forfeit and cancel all contracts with the MFT and his relationship with them. He just wanted to have the cash now and clear off and do what he wants with it.

This caused more debate than the debate itself, and calculators and figures and scraps of paper were being passed around the excited crowd.

It went to vote and to scrap the regular payments only one person voted.

To retain the system of regular payments 39 people said yes. To the new question of, "if given one enormous amount of money would we all just go away quietly", this was unanimously in favour of the big wad of moolah.

However when someone had actually worked out what the figure would probably be, this caused even more change of heart. A figure of £170,000 was offered as average amount a 40-year-old registrant would cost in monthly payments and winter payments over the next 35 years. Figures were calculated that even in a high interest account this would only give an income of less than £5k per year. Was it worth it to lose the ongoing support?

It went to vote again and this time 15 people voted to take £170,000 and say goodbye to the MFT, and 17 were against. Some people didn't vote; some clearly didn't know what to vote for, some hadn't managed to get their arm down in time from the last vote, and some people voted for everything in the excitement.

This was a fun exercise to find out some of the MFT registrant's views and was a lot less costly than the recent long-term review.

*Paul*

**By Ernest Newboy**

I should be used to it by now, the excitement, the anticipation, the sickening fear that I might make a perfect twat of myself, rather than the half-baked twattish routine that constitutes my default performance. But this time round, lurking just beneath the surface dread is a slight twinge of ... bravado. A feeling that perhaps the challenge is worth the while, a sense that the worst is still to ...

But I'm getting ahead of myself, an understandable trait for a dead keen Newboy. Once we're safely ensconced in the bar on Friday afternoon, an old hand – who, for all the usual reasons, shall remain nameless – insinuates himself into myself and Mrs Newboy's presence and begins to regale us with tales of conferences past. Shifty looking geezer, always on the edge of his seat pretending to be enraptured by your every word, even as he's scanning the room for his next target. Having enlightened us as to his central role in greatest health and social crisis of our times – for which read all us people with haemophilia getting dumped in the honeypot of HIV – his voice drops a decibel or ten as he gives us the scoop on the real purpose of the weekend. It is, he tells us, a government conspiracy designed to solve the compo-seeking haemo problem once and for all. Mrs Newboy, aghast, splutters into her pint of stout. She wants to know if MI5 are involved.

"It's worse than that," says the old hand. "A covert operation by mid-level officials as the Department of Health. The plan is to lay on shindigs like this and encourage us to drink more than is good for us. Our livers being already bugged and whatnot. Ship in a lorryload of prozzies masquerading as masseuses, and a Machiavellian quiz master to drive us to distraction, and they'll thin our numbers dramatically."

Being a sceptical sort of bloke, I begin to pooh-pooh the notion but he raises a hand to silence me. "Mark my words," he says. "It's called Killing with Kindness – or, as me old dad used to say, giving the sponging bastards enough rope."

By this time, the effects of my third pint are beginning to kick in and, as Mrs Newboy will testify, my bullshit tolerance levels act in inverse proportion to my alcohol intake. I make a quick getaway to the toilet, leaving herself to make her own escape. Having spent two hours in the sauna hiding from the conspiracy theorist, I run into my wife again at dinner. "You're not looking too good," she tells me, sending a shiver down my spine.

"What is it?" I ask her. "Have I come out in a rash? Lost a lot of weight all of a sudden?"

"You look kind of parboiled." It's only about halfway through the evening pub quiz that the underlying significance of her words hits me.

By that stage, our ten strong team has been winnowed down to two, myself and the Cap'n. Even Mrs Newboy has disappeared. I voice my concerns to the Cap'n. He nods wisely, taking everything in.

"Still," he says. "If it happens to every other team, we might be in with a shout of winning."

His optimism is misplaced. We do disastrously. In a pub quiz of ten teams, we're lucky to finish eleventh. The Cap'n though, is still smiling. I admire his fortitude, but am puzzled by his shit-eating grin till I see he's hogging a spliff the size of London's new Gherkin tower. In the interests of reason I relieve him of the fiendish thing.

"You think it's part of the plot?" I ask him, in between selfless tokes. "You think the questions were rigged so as to give us all arassed?"

"Anything's possible, I guess," he says, delivering an adroit slap to the side of my head while deftly snatching the spliff from my grip. Alone at the table, reflecting on the warnings of the old hand, I notice just how much the room has emptied out. There's a sick feeling in the pit of my stomach as I stumble up to my room. Martin, Mick, Alan, Gareth ... all gone. A saving to the department of health of so much a month ... my brain's too addled to do the sums, but I'll bet I tidy amount. Finding my wife in bed does nothing to alleviate my paranoia. She is not, after all, a haemo.

The next day I'm diverted from a talk on human rights by the offer of a facial. It doesn't turn out quite like I expected. I'm escorted from the room with my trousers still down around my ankles, and frogmarched to another darkened room where the smell of burning spices hangs heavy in the air. A pleasant lady called Sandra asks me if I want my feet massaged. Not wanting to let her know I'm on to them, I tell her to do her worst. Forty minutes later I'm reduced to a state of such profound laid-backness that I can't tell where my new Hawaiian shirt stops and the carpets starts. But I haven't squealed. I stare up at Sandra from the floor and accuse of her playing the old good masseuse, bad masseuse routine. She gives me a look that suggests she's dealing with a raving lunatic.

I slip out the door while she's taking a snort of tea-tree oil, and check out THE BIG DEBATE. There's no mention of Iraq, or whether George W. shouldn't step down in favour of his kid brother Chad. Instead, it's a mass brawl over whether the MFT should continue to give us our monthly bread, or force us to apply for single payments. Clever bastards, I think, beginning to recognise the true extent of the plot. Of course when the call goes up for a show of hands at the end of the debate, yours truly keeps his firmly wedged up his arse. I've seen the suit in the corner speaking surreptitiously into his lapel.



# KARAOKE FOR THE WEEKEND

At first I thought he was wiping his nose, but after a while I noticed his lips were moving. It was obvious the guy was taking a head count, putting names to faces. And what of those who weren't in the room? Whose absence suggested that those merciless bastards at the DoH were already implementing their evil plot to rid the system of gimps?

Mrs Newboy turns up at coffeee break looking remarkably sprightly. "Where've you been?" I demand.

"For a makeover," she says.

"Any facials involved?"

"Uh, yes?" She feigns puzzlement and, having already seen 'The Stepford Wives,' I suspect the worst. I fake Mrs Newboy. I abandon her by the hi-tech coffeee dispenser and seek out Richard, conference organiser, to see if he knows what's really going down. I collar him in the men's room. He looks arassed as he tries to pee. Maybe he's self-conscious, or maybe he already knows the truth.

"I'm sorry to have to be the one to tell you, Richard," I say, before burdening him with my concerns.

"Oh for fuck's sake," he cracks. "DVDs, rain, umbrellas, impossible quiz questions, overpriced drinks. You think I haven't got enough on my plate, Newboy, without having it rammed down my throat?"

This seems to me to be an overstatement of the case, but I don't see any opportunity to intervene. "I know the whole world's against us," he says. "But I'm not about to use that as an excuse. If they want blood, we'll just have to give it to 'em. Either that or we'll do 'em tonight at the karaoke."

I knew then, that he wasn't called the Big Schwinging Dick for nothing.

By the time night falls, bringing a welcome cessation to hostilities in which another half dozen haemos have either been throttled in Yogic sessions, been mysteriously disappeared while having their American visa applications processed prior to US litigation hearings, or had their negativivity cancelled out by the positive charge of a room full of positive women, thus reducing them to anti-matter, our forces have dwindled to approx five and a half haemos and one or two partners still sober enough to care. The fightback commences with Andrew's heartfelt rendition of Elton John's 'Your Song.' Alas, he makes the fatal mistake of singing in tune and in time. The agents of darkness vanish him before the lights go up. Another two or three footsoldiers make the same mistake, attempting sincerity and having the lips sandpapered off their mouth in reward. And then, and then, something totally unexpected. First, the parody of a farce masquerading as a shambles that is the wreckage of Mike's rendition of Hank

Williams. The godawful squawking knocks the enemy onto the back foot. There's a sudden look of panic about their faces as they ask themselves whether they might not be dealing with the already dead? And then a partner delivers a body blow with the most exquisitely painful version of 'Delilah' delivered this side of an Abercumfuck R.F.C. Christmas 'Stars Pissed in their Pants' annual fundraiser. The DoH swine are beginning to shit themselves at this stage, as they foist a barbershop quartet on us with their pathetic take on 'Hang on Snoopy' but it just doesn't wash.

Suddenly, the ghost of Gareth appears, storming the stage with Martin, Alan and Mick providing backing vocal. I'm hallucinating this bit, but still, it cheers me up no end. And then, the coup de grace, in the form of Rob's fiercesome 'Paranoid', a savagely ironic take on Black Sabbath that puts the 'lite' into heavy metal. Follow that with the spectacle of Motown, Village People and more country blues danced by an assortment of dodgy ankles, replacement knees and 360 degree rotation elbows, and the night was fast becoming a rout.

It's no surprise then to find that everyone has crawled out of the woodwork on Sunday morning for a seminar on 'How to get shitfaced and still feel good about yourself' delivered by surprise guest Howard Marks. He gives a powerful and moving talk on the logic of spending our hardwon MFT payments on recreational drugs whose legal status is a bit of a muddy hole. Not only will these drugs do us a power of good in terms of pain control, ego-banishment, transforming even the most lifeless dullard into a sparkling wit, and depriving the government of tax revenues with which to wage wars against overseas haemos, but they will, as many of us will testify, remove all sense of personal embarrassment and shame. And they don't fuck your liver up - so I'm told.

The weekend comes to a close with a hearty meal and Mrs Newboy safely embracing yours truly, my head locked in the vice like grip of her arms. As she hustles me out to the car, I catch the eye of the 'old hand'. He winks at me and mouths the single word, "vigilance." I nod back, only too aware now of the government threat to life, limb and habit.

On guard.

*(Dept of Censorship note — all names used in this article have been changed in order to conceal the real identities of those we actually have disappeared. Remember, we are watching you).*

# KARAOKE



# Arthritis Drug Removed for Safety

30 September, 2004 <http://news.bbc.co.uk/go/em/fr/-/1/hi/health/3704640.stm>

**Drug company Merck has removed its arthritis painkiller Vioxx because of data showing an increased risk of heart attack and stroke.**

Patients currently taking the drug should contact their doctor to discuss stopping and switching to alternative treatments, experts said. A three-year trial showed an increased risk of cardiovascular events began after 18 months of Vioxx treatment. Vioxx is used by two million people around the world. In the UK, it has been available since 1999 and is used by 400,000 people.

US regulator the Food and Drug Administration said it would closely watch drugs in the same class as Vioxx (rofecoxib) for any signs they might raise the risk of serious heart problems. These are known as cyclooxygenase-2 or COX-2 inhibitors, which are more 'stomach friendly' alternatives to traditional pain relief drugs called non-steroidal anti-inflammatory drugs (NSAIDs).

**Strokes and heart attacks** Following a number of adverse reports after Vioxx became available in the UK in 1999, the European Committee for Proprietary Medicinal Products looked into the safety of COX-2 drugs. In 2003, it concluded that the balance of risks and benefits of the products remained positive. But it recommended strengthening existing warnings about use in patients with underlying cardiovascular risks. Merck's chairman Raymond Gilmartin said: "Although we believe it would have been possible to continue to market Vioxx with labelling that would incorporate these new data, given the availability of alternative therapies, and the questions raised by the data, we concluded that a voluntary withdrawal is the responsible course to take." RCGP chair elect Mayur Lakhani said: "There is no cause for alarm but if people are worried we would advise them to stop taking Vioxx and use a safer pain-killer, which their local pharmacist will be able to advise them on.

**Advice** "The next step is to make a routine appointment with their GP to arrange an alternative prescription. "Patients should be re-assured that there are several other treatments available for arthritic pain relief." Chairman of the medicines watchdog the Medicines and Healthcare Regulatory Agency, Professor Sir Alasdair Breckenridge, echoed this advice. A spokeswoman from the Arthritis Research Campaign said: "This is a highly unprecedented move. "There had been doubts about Vioxx's safety in terms of cardiovascular risk. "There is no such thing as a drug without side effects, but the risks must have been too high." But she did not think other COX-2 drugs would carry the same risk.

*Birchgrove would like to point out to readers that if using Vioxx it would be beneficial to seek medical advice from your doctor as soon as possible.*

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## SNIPPETS AND BRIEFS

Prisoners' clue to hep C vaccine

30 August, 2004 <http://news.bbc.co.uk/go/em/fr/-/1/hi/health/3591760.stm>

**A group of prisoners who appear to be naturally immune to hepatitis C could lead to a vaccine, Australian researchers hope.**

The University of New South Wales team is studying four prisoners who became infected yet went on to clear the virus with no symptoms. Similar immunity has been found in some Kenyan prostitutes against HIV. The authors told the Journal of Infectious Diseases they hope to mimic this natural defence with vaccines. Professor Andrew Lloyd and colleagues studied 160 prisoners who were free of hepatitis C infection but were at high risk of contracting the virus because of their lifestyles – injecting drug use or tattooing. They collected blood samples from the prisoners on a monthly basis for over a year. Four of the prisoners became infected with hepatitis C during this time, yet they all went on to clear the virus without developing any of the symptoms of the disease. Surprisingly, none of them developed antibodies against the virus. A spokeswoman from the British Liver Trust said: "It's really quite phenomenally important research. "Although the phenomenon has been recognised before, no research has been published on it. This is the first. "It's quite clear that there is a whole cohort of people who do not develop hepatitis C. " She said the findings would be key to getting a vaccine. "Getting a vaccine is the holy grail of hepatitis C at the moment and it looks like this is getting towards that," she said.

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## Life History Project

The Haemophilia and HIV life Histories project is taking shape, and some of the collated interview summaries can be viewed at [www.cadensa.bl.uk](http://www.cadensa.bl.uk)

*A feedback day for participants in the project is planned to take place on Saturday January 22nd, appropriately at Swindon close to the woodland grove. There are a few places still available on the project and representation is particularly sought after from Scotland. If anybody is interested, especially north of the border, in getting involved in this project please contact Sian Edwards on 01273 644030 or email [s.i.Edwards@brighton.ac.uk](mailto:s.i.Edwards@brighton.ac.uk)*

## **Haemophilia Society**

Information, advice and support.

Tel: 0800 018 6068

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

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

## **The Macfarlane Trust.**

Financial support for PWH HIV/HCV

Web based chat room for registrants.

Tel 020 72330057

Web site: [www.macfarlane.org](http://www.macfarlane.org)

## **National AIDS Manual**

Provides up to date factual treatment

Information, free publications+website.

Tel: 020 7627 3200

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

Web site: [www.aidsmap.com](http://www.aidsmap.com)

Website for latest news and conference reports, searchable treatment database.

## **HIV and Hepatitis.com**

Online publication about treatment.

Web site: [www.hivandhepatitis.com](http://www.hivandhepatitis.com)

## **The UK Hepatitis C Resource Centre**

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

Tel: 0141 353 6969

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

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

## **British Liver Trust**

Information, advice, support and campaigning on all aspects of liver disease, viral hepatitis, publications and web based details.

British Liver Trust, Portman House, 44 High Street, Ringwood, Hampshire, BH24 1AG.

Tel: 01425 463080 Fax: 01425 470706.

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

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

## **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>

## **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)

Website: [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)

## **+ve**

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)

## **National Helpline Numbers**

### **HIV i-Base**

HIV treatment information and support.

Tel: 0808 8006013 Mon-Wed 12-4pm

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

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

### **National AIDS Helpline**

0800 567 123

24 hour helpline offering advice on HIV/AIDS

### **Terrence Higgins Trust**

0845 1221 200

Mon-Fri 10am-10pm Sat- Sun 12-6pm

### **AIDS Treatment Phone line**

0845 947 0047

Mon + Wed 3pm-9pm Tues 3pm-6pm

### **Positive Line**

0800 1696806

Mon-Fri 11am-10pm Sat/Sun 4-10pm

### **Immune Development Trust**

Offers 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

telephone 029-20372719

### **Birchgrove North**

c/o Body Positive North West.

Lawrence House.

City Road.

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M15 4DE

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## DISCLAIMER

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

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## 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.

Q & A with Macfarlane Trust CEO, Martin Harvey - 7.00pm, November 3rd, 2004 at Freshwinds, Birmingham

Changes are happening at the Macfarlane Trust. Since the appointment of a new CEO just over a year ago, the MFT has undergone an office move, staff reshuffle, office guidelines revision, a new website, and the introduction of The Skipton Fund to mention but a few. It is now looking to the future, particularly with the introduction of Regional Workers in place of the resident office Social Worker, new business cases to be put forth regarding widows and dependants, and modifications to the Trust's governance structure brought on by the introduction of Skipton.

This will be an unique opportunity to meet the Chief Executive of the Macfarlane Trust, Martin Harvey, to hear about his visions for the Trust, and to put your questions, concerns and feelings to him about the proposed changes and what they mean to us as registrants.

The event is being held on 3rd November 2004 at Freshwinds, Freshwinds House, 22 George Rd, Edgbaston, Birmingham B15 1PJ ([www.freshwinds.org.uk](http://www.freshwinds.org.uk)). Nearest train station is Five Ways. Limited parking available. We aim to start at 7.00pm.

If you would like further details, please contact either Mark Simmons (0121 627 2353) or Andrew Evans (07717 471 460 or [andy@design-graphix.net](mailto:andy@design-graphix.net)), otherwise we will see you there. Also contact us if you cannot make it on the night, but would like a question put to Martin.

We look forward to seeing as many people there on the night as possible. Remember, it's your Trust... be a part of it.

Birchgrove would like to thank all our contributors to this issue and also thank Richard for putting together SFW.

Apologies to anyone who emailed us in September as we had IT problems. Please re-email if you have not received a reply.

SKIPTON - the bush kangaroo - an everyday story of ex-gratia payments.

The story so far... Sonny, a nauseatingly cute haemophiliac with freckles is stuck deep underground a mountain of debt. He can see no way out of the hole he has dug for himself with a mini bulldozer from B&Q and is calling for help. However just in the nick of time Skipton the bush kangaroo has come bouncing into view. Sonny hears something shift in the bowels of the Department of Health. What could it be, a bird, a plane, a civil servant and then that familiar sound, "tsk, tsk, tsk a haemophiliac wanting money again". It must be Skipton the bush kangaroo Sonny realises. "Skipton, Skipton - can you hear me? I need help." The thud of Skiptons bouncing feet like the sound of a twenty-eight page form in a large white envelope landing on a doormat is all that Sonny can hear. "Can you get me out of this hole Skipton? I promise I'll only buy Matalan clothes, drink lemonade and go on holidays to Southend in future if you help me?" Sonny waits, hoping and praying that Skipton may go off and find help. But all he hears is 'tsk, tsk, tsk Then the sound of hooves and dramatic classical music and Sonny realises he might be saved as it must be 'Macfarlane the Wonder Horse' and they do single payments...

Did Sonny get out of his mountain of debt? Will he be left to fend for himself until one of the new regional support workers for Macfarlane is employed? Will Skipton have a change of heart and issue a follow-up payment? What will they call the fund for infection with vCJD? Write to Bob the Bleeder with a question or I'll have to make up an answer to these questions for the next issue.

