

Birchgrove

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Jan/Feb 2005

Dear, dear, dear...

"leave no stone unturned....."

Any of you who have followed the Scavenger Hunt for medical notes will resonate with this article; you will have become private detectives in your own right. Though it might seem a year too late, there are haemophiliacs out there who, believe it or not, have yet to join the U.S. Litigation. There are others who are still somewhere along the trail in pursuit of their missing notes. For their sake, and for what's left of my sanity, I am writing this article which may provide some suggestions and useful information.

The search for medical records for the US Blood Factor Litigation has become all but an obsession for many of us, taking us to some unexpected places. Does anyone even know how the storage of NHS medical notes got into such a mess? Perhaps it's because of our previous attempts at legal action? We now find ourselves in the situation where bits and pieces of our notes have ended up with different records departments or are lurking deep in the archives of various solicitors. Notes have even been found with specialist doctors who were consulted by legal firms in a private capacity. The mysteriously-founded UKHCDO is suddenly revealed as the great storehouse of missing chronological batch numbers. The continual occurrence of misplaced notes has added weight to the suspicions of the growing confederacy of haemophiliacs who believe that either the Government or the pharmaceutical companies have tried to vanish the 1980-85 pages from their medical notes, but even HMG's sanitisation sweep overlooked the elusive UKHCDO.

I decided to take a proactive approach; to be persistent. I wrote to every hospital I had ever been to: 6 in all. I quickly came to terms with the fact that it was going to cost me some money, but it would be worth it in the long term. I knew I would have to 'jump through the hoops' as it were, sign release forms, go chasing things up. I was prepared to pay whatever it cost. I discovered that the maximum fee of £50 was payable across each different NHS Trust, although if there were only a small amount of notes they charged me less. I wrote letters to Doctors,

hospital records departments and previous solicitors. I tried to make the letters clear and concise, and in every letter I included my name, Date of Birth and any NHS hospital numbers. I followed them up with friendly telephone calls, and even personal visits which sometimes helped. I tried hard to be diplomatic and calm. I wrote to my G.P. and even my opticians! From the outset of my search I made it my personal motto to leave no stone unturned.

Who would have thought that such a seemingly simple task could take so long and be so complicated? It became clear that my original notes were in bits - all over the place. For those haemophiliacs like myself who had moved around the Country from one centre to another, the downside is that there are more NHS Trusts to chase up, but the upside is that as the notes are more spread out, they are much less likely to have been misplaced as one batch, and the chances of turning up volumes of notes are increased. This was certainly true in my case. I told myself, "Be creative. Have you really tried everything? Try not to make assumptions...". Although most searches will be conducted on your name and DoB, if these fail to uncover notes NHS numbers may become useful. G.P. notes will contain

Continues on page 2

Contents...

This issue seems to be all about writing to people, asking for your medical notes, asking for a public enquiry, asking to be let of jail, asking for free medical treatment even asking you to join a bulletin board. We have English letters, Scottish letters, all we need now is a French one - but you have probably had plenty of them over the last 20 years...

FREE DVD WITH THIS ISSUE- Woodland Open Day

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|-------|----------------------------------------|
| 1-3 | Leave no Stone Unturned |
| 3 | The Future of Birchgrove |
| 4-5 | A Gunn to the Head of Politico's |
| 6-7 | A Reply from DoH |
| 8 | Letters hear from you |
| 9-10 | The MFT and in the News |
| 11 | Woodland Open Day-DVD |
| 12 | Diary Dates |
| 13-14 | Snippets and Briefs |
| 14 | Skipton Update - Deception in Medicine |
| 15 | Contacts, Information and Support |

correspondence received from your Haemophilia centres, as well as old NHS hospital numbers, which will help the paralegal nurses who will fill in the gaps and put together your complete case notes. Make a note of any reference numbers and use them on every subsequent request for medical notes that you send out. I discovered 4 different NHS numbers. Medical records release forms can either be obtained from Anderson Eden or from LCHB: Heather A Foster, Lieff, Cabraser, Heimann & Bernstein, LLP. Embarcadero Center West, 275 Battery Street, Suite 3000, San Francisco. CA 94111-3339, USA. International telephone number: 001 415 956 1000. E-mail: hfoster@lchb.com

Who would have thought that such a seemingly simple task could take so long and be so complicated? It became clear that my original notes were in bits - all over the place. For those haemophiliacs like myself who had moved around the Country from one centre to another, the downside is that there are more NHS Trusts to chase up, but the upside is that as the notes are more spread out, they are much less likely to have been misplaced as one batch, and the chances of turning up volumes of notes are increased. This was certainly true in my case. I told myself, "Be creative. Have you really tried everything? Try not to make assumptions...". Although most searches will be conducted on your name and DoB, if these fail to uncover notes NHS numbers may become useful. G.P. notes will contain correspondence received from your Haemophilia centres, as well as old NHS hospital numbers, which will help the paralegal nurses who will fill in the gaps and put together your complete case notes. Make a note of any reference numbers and use them on every subsequent request for medical notes that you send out. I discovered 4 different NHS numbers. Medical records release forms can either be obtained from Anderson Eden or from LCHB: Heather A Foster, Lieff, Cabraser, Heimann & Bernstein, LLP. Embarcadero Center West, 275 Battery Street, Suite 3000, San Francisco. CA 94111-3339, USA. International telephone number: 001 415 956 1000. E-mail: hfoster@lchb.com

There were some surprises. I discovered that haemophilia centres retain their own set of notes as opposed to the hospitals' medical records department. These notes are usually the current ones and they keep these to hand in case there is an emergency. Any medical notes older than, say, 10 years appear to be stored in paper format in the hospitals' medical records department.

My current haemophilia centre - the Royal Free Hospital - was the first to uncover a

plethora of notes, although there were some awkward glitches in obtaining the release of all of these notes. Large portions of the notes being held at my current Haemophilia Centre contained the correspondence of previous NHS Trusts that I had once attended. My current Haemophilia Centre was NOT permitted to release any parts of these notes that related to my care at these previous hospitals. Whether it was a courtesy to other hospitals or a legal constraint, for me it was a bureaucratic nightmare. My Doctor eventually managed to get around this by writing to the previous hospitals to ask them to authorize the release of the notes and I, myself, wrote to those same hospitals to give my consent for notes relating to them to be released.

I am aware that there are some haemophiliacs that would like to join the litigation in the U.S. who haven't, as yet, embarked upon obtaining their medical notes. Recent developments in the lawsuit, in particular the preparation of patient profile forms (PPFs), have put the emphasis on proving exposure to American blood products. The lawyers initially require a list of batch numbers of concentrate received by us rather than a full set of medical notes per se. Due to the large numbers of misplaced notes, litigants were forced to look in places where they hadn't initially thought to. This revealed the database of batch numbers held by the UKHCDO (United Kingdom Haemophilia Centre Doctors' Organisation). Your first port of call should be this database. There is a £15 fee for retrieving your notes. Contact Lynne Dewhurst at: UKHCDO, Haemophilia Department, Manchester Royal Infirmary, Oxford Road, Manchester, M13 9WL. Tel/Fax: 0161 276 5052. E-mail: lynne.dewhurst@cmmc.nhs.uk

I remembered hearing that it might be worth contacting the solicitors who handled the original attempts at legal action, namely J. Keith Park & Co. What I discovered there was really surprising - they had retained 73 crucial pages of my medical notes on microfiche. This was a good find; these pages had unique information within them which somehow had become detached from my main notes. I paid a nominal fee to have the pages expanded onto A4 printouts. J. Keith Park & Co may well have other haemophiliacs' notes on microfiche. Current contact address: J. Keith Park & Co. Solicitors, Alabama House, 6 Rumford Place, LIVERPOOL, L3 9TL.

The most bizarre find was at a hospital I had never even been to in person! At some point during the 1990's, J. Keith Park and Co. commissioned an independent specialist Doctor to make an assessment of

THE FUTURE OF BIRCHGROVE

This year, 2005, marks 20 years since we were diagnosed with HIV. This is a landmark in itself, in that many of us are still living. A concept that was far from view for most of us and our loved ones. Birchgrove was born out of this tragedy as a self help support group for people with haemophilia infected with HIV and their families. Originally based in Cardiff, Birchgrove grew into a national organisation with many regional support groups across the UK.

Over the years, our numbers have fallen due the 800 plus deaths in our community, but Birchgrove has continued as a voice for people affected by our issues. This has been by a quarterly newsletter, which over the years has commented on political shenanigans, given medical reports and information, a platform for reader's views and a voice to our community. The Birchgrove committee and readers have been involved in countless conferences and projects, including the completion of the Woodland Grove project in 2004.

Times have changed over these 20 years and so have many of our issues. The support we get for the complications in our life varies incredibly across the UK, and nationally the advent of information technology has revolutionised many people's lives.

Registrants of the MFT can interact through the MFT Chat room and Bulletin board, and planned changes to the MFT's support network has come with promises from the Trust to adapt more appropriately to our diverse needs.

Medical information can be accessed at home via the internet as can many sources of HIV support and information. Something that was not on offer in the early days of Birchgrove as a newsletter.

At present Birchgrove is funded by Awards for All, National Lottery funding, which expires in August 2005. The present committee and editorial team of Birchgrove has been consistent for the last 4 years and those individuals lives have changed dramatically too in that time period. We have to ask the question, is the Birchgrove newsletter still needed in today's world? If so does it have to be quarterly?

We also have an issue of data protection, which was not a legality when Birchgrove started up. Although all details of all our readers are kept confidential, to the present committee, can these details be passed on to any one else?

Would a web based Birchgrove be the way forward so that information can be communicated easily and quickly rather than out of date information by the time the Quarterly editions are printed and posted? If so who would want to do this?

During 2005 we will be considering the need and the possible future of Birchgrove.

We welcome your suggestions and comments. Birchgrove is run for you the readers and people out there that enjoy the read, contribute to the content and get something out of it as a means of support and information.

Please get in touch and tell us your feelings about the Future of Birchgrove.

my health with regard to HCV. They asked Dr. Hawkins at the Chelsea and Westminster Hospital to study my medial notes. Somehow Dr. Hawkins had been sent original portions of my notes, not photocopies; he had retained a unique set of my notes containing pages that had previously not been seen by lawyers in the U.S.!

When you are notified that some notes have turned up they usually photocopy them for you, and you will receive an invoice of up to £50. When you send your cheque, remember to ask for a receipt. Take a copy of the receipt and send it to the lawyers in the U.S. To help with the cost of postage LCHB have a Federal Express account number that should be made use of: If there is anyone who still needs to send medical notes to LCHB in the U.S. who wants to send them directly (by-passing Anderson Eden), then you may do so using Federal

Express on LCHB's own account number 118696026. Just call FedEx and when they come to your house to collect the parcel, quote the above LCHB account number and tick the third party box. LCHB only reimburse up to 100 euros, no more than that. The attorney representation agreement actually states that LCHB front the hard costs of the litigation, but they have a right to recoup those costs. If LCHB pay us now for our medical records, upon the lawyers obtaining a positive recovery in a settlement or at trial they will deduct these expenses from our gross awards. LCHB, in essence, will be re-paid those funds if they are advanced to us now.

All in all, I ended up writing 25 letters over 8 months and I must have paid the full £50 fee 6 times over, along with some smaller fees. The total bill must have come to over £350. I also paid substantial postage costs before I knew that you could use the FedE

Putting a 'Gunn' to th

1) Lord Jenkin

Dear Lord Jenkin,

Thank you for replying to my letter of 4th.

I appreciate that you will not have been able to take copies of all your ministerial notes with you when you left office in 1981. However, we do know that there was a "Hepatitis Reporting Scheme" during the years you were in office (79-81). I have seen copies of minutes where the Haemophilia Centre Directors from 1981 were asked to "continue with the reporting of 'suspect' products and batches using the forms provided and also take samples of deceased haemophiliacs' livers for analysis". In light of this I don't think it is unreasonable to ask you to take the necessary steps to obtain copies of this reporting scheme. I expect being a Lord and a former Health Minister, it should not be a problem for you. No-one can argue that we do not deserve to know the truth.

I do appreciate that this was 25 years ago as you say. Incidentally, it is exactly how long I have been infected with HIV and Hepatitis C. I am also sorry to hear that your memory is failing you now that you are nearing 80 and I can empathise, because although I am only 30, I have already had AIDS related cancer and I am beginning to suffer from AIDS related dementia as a direct consequence of the American Blood Products that you saw fit to give to the haemophiliac children of this country. These products were banned in America and the W.H.O. wrote throughout the 1970's that they were extremely dangerous and should not be used. To say that you did not know exactly what virus' were in them is not an acceptable reason for their use, it is only an excuse and a very flimsy one at that. Thank you for proposing to write to Lord Warner to ask if these documents still exist but you will understand my scepticism as Lord Warner has already given false information in session, saying that the Irish Hep C compensation scheme was as a result of admitting blame after a public inquiry (this is completely untrue). Whether it was intentional or not I do not know, but it really is bad show for someone of his position and on such a serious subject to give misleading information in the House of Lords.

As you say these matters are covered by strict protocols affecting former Ministers, but I wonder where these strict protocols were when they were shredding David Owen's Ministerial notes? The outcome of that internal inquiry shall be coming soon although I do not hold out much hope as it's akin to the mafia investigating the mafia.

The documentary we are making is going ahead and I would say that yes you did have a part to play in these matters ie you were the Health Minister when I was 5 years old and being loaded with AIDS and Hepatitis.

I would like all of the documents relating to blood products and blood safety during your time in office. I think at the very least we deserve the truth.

I have informed the media of the contents of this letter and they are also eager to hear your reply.

Merry Christmas, it will probably be my last.

Yours Sincerely,

Andy Gunn

Highland Representative of the Scottish Haemophilia Groups Forum

Chairman of the Highland Group of the Haemophilia Society

2) Jack McConnell (for Southern readers he's Scotland's First Minister)

Dear to whom it may concern,

I was the person who after appearing at Edinburgh Sheriffs Court and pleading guilty to Malicious Mischief and being fined £100 for throwing water soluble paint over the new Scottish Parliament on it's opening day, disrupted the First Minister's Question Time one hour later.

I had this question for Jack McConnell, although in not as many words - Why are the haemophiliacs who were infected with HIV, Hepatitis C, vCJD and a host of other virus' still waiting for a public inquiry? Over 5000 UK haemophiliacs alone, not including those who received blood transfusions, were infected and everyone of them still alive wants a public inquiry. When 1 person dies, as in for instance, the case of the Asian prisoner put in a cell with a racist, or when 5 people die in a train crash it is carried out, but when hundreds of Scottish haemophiliacs die "there isn't the need".

It would bring closure for many people knowing exactly what went wrong and also it would be good if there were people at fault for them to stand up and be responsible for their actions.

All we want is the truth and justice, not more money or heads to roll for the sake of it. I think we are entitled to that?

Is it not the case that Jack McConnell etc are doing what Westminster tells them and even though they could help this small vulnerable part of society, they will not. Of course, why would you jeopardise a lucrative career in politics for the sake of bringing justice to a few hundred dead people and their families? That's practically nothing of the electoral vote and there's a lot of money and prestige at stake.

They are a disgrace to Scotland and the human race in general.

Yours Sincerely

Andy Gunn

Highland Representative of the Scottish Haemophilia Groups Forum

Chairman of the Highland Group of the Haemophilia Society

heads of the politico's

3) All the rest

IT'S A MYSTERY

How is that when a perfectly healthy man climbs onto the roof of the Scottish Parliament building to protest and causes much disruption, puts people in danger and resists arrest till the last minute, he is released on bail, but when another man, who is a haemophiliac with Hepatitis, AIDS and Cancer protests in an peaceful way putting no-one at danger and does not resist arrest, he is put in the cells for the night even though he is bleeding internally and is not a danger to anyone?

It's a mystery!

It is up to the individual how they express themselves. I would never tell anyone how to voice their feelings and neither would I accept anyone telling me how to conduct myself. I would however draw the line short of violence, but anything up to that in this instance I would say was fair game. In the short time I have become involved in the campaign for justice I think there has been progress made, with the Hep C compensation and the recombinant etc, but I think it falls far short of what we should have. ie proper treatment for everyone regardless of postcode / age etc (its not like they can't afford it), proper compensation on a par with the gravity of what's happened to us (again money is not the issue, and don't let your health minister tell you that he'll have to switch off a baby's incubator in order to give you ex-gratia payments) and finally an independent investigation of what happened and for those responsible to be made accountable for their actions. I do not think we are being unreasonable in asking for this and in fact think that it's the least we deserve. So how to go about getting it?

I agree with Margaret Thatcher on one thing, we shall never see justice unless it's through the courts and not for lack of trying, I think the political process holds no answers for us. We need lawyers, so we need money or legal aid. The government took court action to prevent us getting legal aid. None of us have large amounts of money. Frank McGuire in Glasgow is trying to push for a judicial review but needs £15,000 to safeguard the families involved. We can't even raise that although I think it should be number one on the agenda as I would say it's probably our best hope of getting into the courts in this country. I know it's only for Scotland but as with Hep C compensation it may have a snowball effect. If anyone can contribute the £150 per person as many have done in Scotland it would be appreciated.

Other than that, the other option is to use a percentage of our winnings in the US to take a class action forward in the UK although this is speculative.

In the meantime I think we should be stepping up the campaign. The time for letter writing and political protocol has come and gone. Too many of us have died. Civil Disobedience is what should come next and I think it should escalate each time we are refused. So, there have been various protests over the years and I think it's time to start chaining ourselves to the railings again, leaving our cars parked outside parliaments, throw water soluble paint, shout at politicians from public galleries (it's like your first self infusion, you think it'll be terrible and it takes guts but afterwards you realise it wasn't so bad) they wont arrest you, just drag you out. Hire a hot air balloon and fly over London with a banner...? ...Suggestions on a postcard!

I was told there that on average 1 haemophiliac has died per week over the last 20 years. Why don't we have 1 haemophiliac thrown out of a devolved parliament for calling for a public inquiry every week as well? With the media it's about creating a hook that will pull them in, they need a gimmick, a new angle that is why I tried to sell the last one on simultaneous protests at all the devolved parliaments.

I don't know what anyone else thinks but these are just my views.

Strength in numbers and all that

Cheers

Keep on rockin!

Andy

If you would like to sponsor the Haemophilia Fighting Fund more details can be found at this contact.

Haemophilia Fighting Fund

Frank McGuire

Thompsons Solicitors

285 Bath Street

Glasgow

G2 4HQ

0141 221 8840

A reply from the Department of Health

In the last issue we printed a letter sent by Richard to the DH about one or two issues that he felt quite strongly about, nothing major just the odd terminal illness, funding of recombinant and one or two other issues. Well customer services have sprung into action and with some judicious cutting and pasting of previous replies an answer arrived. I don't know who Marcus Giddy is and nor did I know that the DH even had a customer services centre but if nothing else Marcus must now know more about Haemophilia and blood products than probably anyone else in customer services.

7 December 2004

Dear Richard,

Thank you for your letter of 22 September to John Reid about vCJD and plasma products. Due to the volume of letters Mr Reid receives and his daily commitments, he is unable to reply personally to each individual letter. Your letter has been passed to me for reply and I apologise for the long delay in doing so.

I was very sorry to read that you have been infected with HIV and Hepatitis C and I can only begin to understand the impact that this had on you and your family. The Government takes the issues around haemophilia and blood products very seriously, and has great sympathy for anyone who has suffered harm as a result of NHS treatment. Ministers do understand the hardship and great distress that people with haemophilia and their families have suffered, first from HIV and then from hepatitis C, and deeply regret that so many people were infected through blood products.

You refer to reading about the patient notification exercise on 10 September in the Guardian. This is because on 9 September the Secretary of State for Health John Reid announced details about the patient notification exercise. It was announced that the Health Protection Agency would be sending information to clinicians to enable them to trace particular plasma products. The clinicians would then notify any patients identified as 'at risk' as a precaution. You will be aware that a further announcement was made on 21 September.

Having been infected with both HIV and hepatitis C, I fully understand the concerns that you have about contracting vCJD. Ministers have been completely open about this area. When details emerged of the first possible case of transmission of vCJD by blood transfusion in December 2003, the Secretary of State for Health alerted parliament and the public at the first opportunity. Prior to the first case reported last year the risk of vCJD transmission through blood transfusion was a theoretical one. In the absence of a screening test for vCJD, the Government have introduced a range of precautionary measures.

With regards to the recent patient notification exercise, the Health Protection Agency and the Department of Health worked closely with clinicians and patient groups. It is very uncertain whether any recipients of plasma products could have been infected with vCJD via this route. The programme of patient notification is a highly precautionary action following recommendations by the independent CJD incidents panel. The purpose of this is to minimise any chance of infection. This measure was considered necessary by clinicians and patient groups.

In your letter you refer to the transmission of hepatitis through plasma products. Our understanding is that during the 1970s and 1980s, before clotting factors were virally activated little was known about hepatitis C. Although it was known as 'non A, non E' hepatitis, it was not specifically identified as hepatitis C until 1989. The technology to make blood clotting products free from hepatitis C in sufficient quantities to treat people with haemophilia in the UK was not possible until the mid 1980s and it was not until 1987 that there was positive proof of means of eliminating the virus. As soon as the technology became available to make blood products free from hepatitis C, the NHS introduced it.

With regards to the Macfarlane Trust. The Government provides the Macfarlane Trust with £3m per annum This is available to enable the Trust to make regular payments to 'registrants and their dependants on the basis of their health and financial circumstances. In addition, one off grants are made for specific needs that are generally health related. We consider that this is sufficient funding to meet the needs of registrants.

In your letter, you express disappointment that the hepatitis C payment scheme has not been extended to dependants of those who have died following inadvertent infection with hepatitis C. This was not an easy decision for us to make. It is important to stress that the underlying principle of the payments is that they should be targeted to help alleviate the suffering of people living with the virus.

The payments are not designed to compensate for bereavement, although I fully appreciate the hardship and pain experienced by families who cared for loved ones who eventually died of the disease. I realise that this is little consolation for the families.

The scheme ensures that we are able to make value for money payments while not adversely affecting the rest of the health service. We consider that the payments are fair and reasonable and will go some way to help improve the lives of those who have been inadvertently infected. Turning to your comments about the roll-out of recombinant treatment. I am sure that you are aware that very soon after the additional funding for recombinant was announced, the Department of Health set up a working group to provide advice on the strategy to roll out treatment for adult haemophilia patients. It was on the advice of the working group that the decision was made to phase in the roll-out by age. The roll-out did commence later than officials had hoped, this was because data had to be collected to facilitate the roll out, in addition PASA (NHS Purchasing and Supplies Agency) had to negotiate a national tender. Commencement of the roll-out was further delayed by a legal challenge which had been raised in judicial review which argued that the DH's 1998 Health Service Circular (HSC 1998/033) on recombinant products for children was in breach of the Disability Discrimination Act. Pending judgement on this point commencement of the roll-out was delayed. The judgement finally granted on 8th December 2003 did not support the challenge and the roll-out then continued as planned.

You are correct to say that a £4m cut was proposed by finance colleagues to the recombinant budget in this financial year. However, as you know this cut was re-instated and funding was duly allocated to Primary Care Trusts. I would like to assure you that Ministers remain committed to the roll-out of recombinant for all adult haemophilia patients. Our aim is that by March 2006 the vast majority of haemophilia patients will be receiving recombinant treatment.

In response to your request for a public inquiry. Ministers have considered very carefully the call for a public inquiry. They do not accept that any wrongful practices were employed and does not consider a public inquiry is justified.

You have also requested a meeting with Melanie Johnson. The Minister is unable to meet with you at the moment. However, I have been advised that Officials will be seeking to arrange a meeting with yourself and the Chairman and Chief Executive of the Macfarlane Trust in the new year.

I know you will be disappointed with this reply, however I hope you consider that we have responded to the concerns that you have raised.

Yours sincerely,

Marcus Giddy

Customer Service Centre

Hello fellow nutters,

Thank you for the latest edition of Birchgrove mag.

Well your conference sounds as if it was a ball even if everyone was reeling from number crunching/ alcohol amongst other substances!!! Sorry I missed it, but struggling to get my epielpsy under control and keep my sight. Think my son's half joke about a white stick for Christmas might come in handy after all. N the go faster striped Zimmer frame , obligatory here!!!! When the 1st round of letters were sent out by out treatment centre and my now ex was informed he'd received infected blood plasma from a donor who went onto develop vCJD, he was walking around mooing for a while 'til I pointed out I was the MAD cow of the family so he could find his own sound, no way could we have 2 mad cows in the same household, too much for our kids to deal with!!!!!! At least that's how I saw it. More recently he received another letter identifying yet another contaminated batch had been given to him, so does that mean he's got a 200% chance "theoretical or not" of getting vCJD? Maths was never my strong point, not sure I had any academic strong points come to think of it. Unless you count ROBBIE WILLIAMS BIOGRAPHICAL info????? maybe not, but he's a bit gorgeous!!!!!! I can sing Angels along with the rest of 'em plus most of his songs really n wiggle about too!

I wish everyone the best in their tireless campaign to get something done in sensible recompense for all those bleeding sufferers, as a Nurse in a former life we were taught this " THE HOSPITAL SHALL DO THE PATIENT NO HARM"! make of that what you will, the hospital meaning the whole environment and staff. So I'm left wondering if an amendment has been made along the lines of " Except for Haemos" as the list we were constantly shown during out training started with the Minister for Health and the smallest lowest down word said PATIENT. I recall stating so that's how the money is distributed, which didn't go down too well with my tutors! Always was a pain in the arse, so nothing new there then.

The dept of health is a vast machine to tackle as its always someone else's fault, as was proven when ex was haemorrhaging big style following surgery to remove wisdom teeth and the anaesthetist cut the back of his throat during the procedure, as is often the case NOTES " WENT MISSING" so the offending person remains a mystery to this day, this was in 1984 and the haematologist was literally by his bedside pumping him full of CRYO to stem the tide (no use at all) but saying she had to warn him of this virus possibility, as he was choking n throwing up and basically trying to live as our son was 8wks old at the time, he was more bothered about getting out of hospital alive. But he'd never heard of this virus (HIV) and just begged them to do something. Was he going to sue for malpractice was the question on their lips? This was early 1984 roughly when

the issue about the supposed window when nobody was quite certain as to when the BIG ISSUE became public knowledge I can state clearly it was known about at least 9 months BEFORE being made public. I can testify to notes going missing when i was caring for patients in ITU when a cock up occurred and we had to try and put some poor unsuspecting patient back together again. Might be worth checking your own notes, they are yours to read after all, to see what is " MISSING" in your own records.

I wish everyone good health, a Happy Christmas and a merry New year or whatever you prefer. Personally if I can stay awake long enough I will be pissed for the whole 2weeks, depending on medication! AND IM desper8 to go clubbing having had NO life for over 6 months at all, bugger the strobe lights just want to be awake long enough to live my life for a change. That would be a cool way to end a shitty year and i want to PARTYYYYYYYYYYYYYYYYYYYYY!!!!!!!!!!!! had to give up work for 3rd time thanks to neuro probs, must be the mad cow thing rearing its ugly head again. Anyone got a spare eye so I can see properly again with both eyes, send it my way oh and if you find a spare brain cell send it my way too.

Greetings whatever,

A Seasoned Reader

With Thanks.....

Dear Birchgrove

I write with thanks after being in receipt of my first Birchgrove newsletter which I read with much interest and humour. After attending "Something for the weekend" I thought the write up was excellent and after meeting several of "the characters" mentioned it brought back some funny memories. SFW..reloaded was my first meeting with any other person with haemophilia and at 36 years old I wish it had come about sooner.

Regretfully, (to my knowledge), I am alone in my area when it comes to someone like ourselves to talk to, and I have been particularly depressed.

I am waiting for a knee operation, and needless to say I was overjoyed to receive the news that I was probably vCJD+ too. Oh well may as well go for the hat trick. I wonder how much the government will palm us off with this time.

One good thing did come from the Stafford weekend however as I was not aware of the case being brought against the American Drug companies and I managed to sign up with only days to go.

Anyway I just wanted to express my thanks to yourselves and all who helped put the weekend together and all the people who made me so comfortable, especially G and the welsh crew.

Big G- A New Reader

**Letters
hear
from
you!
(Say
it
out
loud...)**

the Department
of Health are
miffed that we
are still alive

Andy Gunn, political six shooter, is not best pleased with the suggestion of regional support workers.

The Macfarlane Trust, which was set up to help Haemophiliacs infected with HIV is changing the way it operates and is going to be means testing us to make sure "the people who need the help the most get it". Almost certainly there will be people who are sicker than others, but it is also true that no-one will be any less sick as a result of long term HIV infection, so why should anyone accept less money from the Trust? Many of us are more sick, so we should be talking about a raise in benefits, not a cut. Also, I would think that most of us, if not all of us, have to now take anti-HIV medications, which have many side effects that affect the quality of our lives and even though for some, the outlook is not as grim as it might've once been, to suggest that we are coping so well that we could handle a drop in our benefits is just plain preposterous and to suggest that the people who would travel the country deciding who gets what, should be paid from our fund, is just adding insult to injury.

It is a disgrace and is happening because the Department of Health are miffed that we are still alive and they are still having to pay us money when they thought they were buying us off with a few small monthly benefits that would've ended when we died within the space of a few years. How unlucky for them,

If anyone comes round my house looking to ask me questions about my income and trying to cut my benefits, they will get a frying pan over the head quicker than they can say 'can't cook, won't cook'.

Comprende?

Andy Gunn

Macfarlane Trust Partnership Group.

The MFT Partnership group had a representative at a recent DoH meeting who has given a report of his experience. View www.macfarlane.org.uk and view news pages.

IN THE NEWS

CHARGING FOR OUR CARE?

Did you know that the Government has introduced new charges into hospitals which mean that many people living with HIV will no longer get free treatment and care? The Government is also planning to introduce these charges into GP surgeries. Those affected include failed asylum seekers (who would have had a right to treatment until their claim was rejected) and people that do not have legal residency status (such as visa overstayers).

The Health Committee of the House of Commons is going to hold an investigation in January into the charges for HIV treatment and care introduced by the NHS for people without ordinary residency status. The National AIDS Trust is arguing that there should be no charges for HIV treatment and care (see our paper 'Eligibility for free HIV treatment and care' on the NAT website www.nat.org.uk). We would be very grateful for any experiences of refusal of HIV treatment and care, with some information on the consequences, either from those who have been refused treatment or from people who know of those who have been refused. We are also keen to hear from people who feel that they have been treated or questioned inappropriately in relation to their residency status when attempting to access treatment and care. Please email Yusef Azad (yusef.azad@nat.org.uk) Director of Policy at NAT. Cases will be referred to anonymously.

For more info:
National AIDS Trust
T: 44 (0) 20 7814 6729
F: 44 (0) 20 7216 0111
www.nat.org.uk

people living with
HIV will no
longer get free
treatment and
care

IN THE NEWS

DARTS CHAMP BACK ON DECK

TOWNSVILLE'S Tony David hopes to shake off a recent major health scare in a bid to claim his second title at the 2005 Lakeside World Professional Darts Championships in England starting tonight (Australian time).

David, who as a rank outsider became the first Australian to win the world championship in 2002, suffered a serious complication relating to the blood-clotting disorder, haemophilia, from which he suffers. Shortly after arriving in London to begin his preparation for the event, David and his family in Townsville were sent into a panic when he developed an ankle bleed and the monofix clotting factor he uses to stop the bleeding failed to arrive at a London hospital from Australia. After being given authorisation from a Brisbane-based doctor to take alternative medication, the situation then became much more serious when soon after David, now bleeding from a separate cut, developed an allergic reaction. "He said: 'I'm close to dying'," his father Alf David recalled of the stressful phone conversation he had with his son just days before Christmas. "He had this rash around his throat and he couldn't breathe." However, a swift dose of antihistamine followed by the arrival of the monofix in London helped David return to health and the 37-year-old began putting in long hours of practice in the lead-up to the nine-day event. The 2002 Townsville Bulletin Sportstar of the Year is rated a 20-1 chance to claim his second title and takes on Englishman Tony Eccles (50-1) in his first-round match tonight.

(Well how do we read this? British clotting factors are rubbish? Or was he a wuss for getting scared by a reaction hundreds of us used to get from cryo?? Whatever it was he did not do well at the darts, going out in the first round.)

GRAHAM AND THE GANG HAVE LEFT THE BUILDING!

HAEMOPHILIA SOCIETY MOVES.

No longer will you be speaking to Tom in Euston Road. He will now be sitting in Hatton Garden, slightly nearer his beloved Arsenal. Hopefully this will act as a jinx on his team as none of the committee support the Arse.

And if you need to go there the nearest tubes are either Farringdon on the Hammersmith and City/Metropolitan/District lines or Chancery Lane (Central line). The office is at the Clerkenwell Road end of Hatton Garden on the corner of Hatton Garden and Hatton Wall.

The Haemophilia Society
Petersham House
57a Hatton Garden
EC1 8JG

The Freephone number will not change and the Society can be contacted on 0800 018 6068 as usual. The website and all email addresses at the society also remain unchanged.

THE MACFARLANE TRUST BULLETIN BOARD

The Trust hosts a bulletin board for all registrants. In order to access it you just need a password and your Macfarlane Trust number. Passwords are freely available via the Trust and the site is managed by a registrant known secretly as "The webmaster". It is accessible only to registrants so you can put all your secret fantasies about Martin Harvey on it and he won't ever know. Pictures can also be placed on the board but so far few the only ones there are of a guy in uniform. (One for the shiksas).

The MFT website also features News-Member Utilities-Forms for Feedback- Trust Information- All of the Trusts Newsletters in PDF format- Sections on: Financial Assistance- Staff and Trustees- Welfare benefits- And the bulletin board and chat room where any registrant can communicate with others wherever they live.

Contact MFT 0207808 1170
or email admin@macfarlane.org.uk for your username and password.
www.macfarlane.org.uk

David, now bleeding from a separate cut, developed an allergic reaction. "He said: 'I'm close to dying'," his father Alf David recalled

Birchgrove Woodland DVD – Free With This Issue “THE OPEN DAY”

Enclosed with this edition of Birchgrove is a free DVD of the Woodland Open Day which took place on Sunday 23rd May 2004. This event saw the culmination of a ten year long project marking the Birchgrove Woodland Grove in Swindon. On the day over a hundred people attended and the event was extremely powerful and moving. A video was used by one of Birchgrove's readers which was used to put together this DVD of the days speeches.

We must stress that on the day we did not have the intention of producing this, and people were not given an opportunity to say whether they objected to being filmed. However nobody on the day objected to the video being used. We took the decision to fund this DVD from surplus funds raised from the woodland fund raising. This means that we have had to put the idea of installing a bench in the woodland on hold for now.

This DVD was first shown to a select audience at the "Something For The Weekend ...Reloaded" event in Stafford in September 2004. Amongst the audience were people who had attended the event, people who had not, and people who knew nothing about it. It was a moving experience in real life, but the recording relayed to people watching it the emotions and energy. For this reason we thought it was important to let the wider affected haemophilia community have an opportunity to witness a very special day who didn't have the chance to attend. For those that did attend we also thought this was a very special keepsake of a special day. We also thought it would be a valuable tool to show to others that you feel close to, to help them understand that this situation has affected many different lives in many different ways.

Whatever your relationship is to the world of haemophilia and HIV this recording is undoubtedly emotive, sad and extremely thought provoking. It is now a piece of our history.

This DVD has been produced for these reasons and that as recipient of this we hope you will treat the identities of people on the DVD with respect. It is not intended for copying, reproducing, transmission, broadcasting or for sale.

Birchgrove would like to thank Alan, Sarah and Mark, the people behind this DVD, for filming on the day, hiring studio time to cut and edit and reproduce. Without them this would not have happened and as a result we have a tangible piece of history and a moment we can all share, whether we were there or not.

Paul

A Vision of a Birchgrove Woodland.

The vision of a Birchgrove Woodland site was first muted several years ago. Paul Jenkins and Gareth Lewis had the seed of an idea, nurtured it, that has now grown into the impressive and tranquil site that is now the Birchgrove Woodland situated at Stratton, Nr Swindon.

It was 10 years ago that I became involved with the woodland project when Gareth and Paul Jenkins delegated responsibility for the scheme to Cady Khudabux and myself as the workload for the Birchgrove group was getting heavy. After working some years on the project Cady had to relinquish his role due to ill health, a year or so later my health dictated that I also should take a break from the project. Paul Bateman took over the reigns and has seen the project through to the present day along with the Birchgrove Woodland committee.

The DVD film of the opening day at the grove will be a lasting and poignant image to commemorate such a very special day. Sadly both Paul Jenkins and Cady are no longer with us. The film is dedicated to them, and the hundreds of haemophiliacs infected with HIV who have tragically died over the years and to those still living with HIV.

My thanks go to my daughter Sarah and her partner Mark Adams who have been a constant help and support with the production of the DVD.

Alan Burgess



PRESENT:

Men Only ... Vol. 2:

An event for men with a bleeding disorder and HIV

Friday 13th to Sunday 15th May 2005



Nottingham Royal Moat House Hotel
Wollaton Street, Nottingham,
Nottinghamshire, NG1 5RH
www.moathousehotels.com

NOTTINGHAM

- looking after yourself
- talk to other reigistrants
- renew old friendships + make new ones
- pool + health suite
- talk with the trust
- positive living workshops
- complementary therapies



Registration Fee: £20 per person (£10 for people on income-related benefits)

For further information please contact:

Richard

email: richard@macfarlane.org.uk

Jude

Telephone: 020 7808 1175
email: jude@macfarlane.org.uk

Roz

Telephone: 020 7808 1176
email: roz@macfarlane.org.uk

LIVING WITH HIV

NAM- by Michael Carter

Living with HIV was published in November 2004 and is an up to date guide of the issues around living with HIV. The book has been written by people with direct experience of living with HIV and pools and shares information, knowledge and insight. For anyone living with HIV or wanting to have a comprehensive understanding of the issues around Living with HIV this book is for you. It is also free to anyone affected by HIV. Please contact NAM for your copy. NAM Lincoln House 1 Brixton Road London SW9 6DE

0207840 0050

info@nam.org.uk www.aidsmap.com

CO-INFECTION GUIDELINES

The updated guidelines for HIV and Hepatitis treatment in the UK are now available on the BHIVA website (www.bhiva.org). Treatments for coinfection with hepatitis B+C are included and both have been reformatted in the style of Anti Retroviral Therapy guidelines. There are clearer definitions of when to treat and with what, what to avoid and updated clinical trials and references to help patients with some of their decisions.

FACING UP TO IT-

Bio-Alcamid as a facial filler to treat lipoatrophy. Visit the body for more info. www.thebody.com/tpan/novdec_04/bio-alcamid.html?m72h#

CAN'T GET A VISA FOR THE US - WHAT ABOUT WHITSTABLE?

Birchgrove has been asked to let our readers know about a holiday opportunity in Kent between the beautiful islands of Canvey and Thanet. Seriously, this bit of the country is close to Canterbury for Cathedrals, tea shops and haemophilia centres and Herne Bay for sea clean enough to swim in, country walks, or those of us over 30 country hobbling, and carnivals.

The caravan is in Swalecliffe, near Herne Bay and Whitstable. It is run by the mother of a Haemophiliac, who used this caravan for many years when it was managed by Contacts. Last year rather than let it close she and her daughter took it over. They still have some regular clients who go every year for their holidays as it is so nice. The caravan is suitable for disabled adults and children and is a six to eight berth, with own beach and club house. The site is very family orientated.

Its open from March till October and you can find out more about Herne Bay at www.hernebayonline.co.uk and the official guide at www.Canterbury.co.uk

If you are interested please contact:

Mrs B I Robinson at barbara.robinson80@ntlworld.com

BHIVA IN DUBLIN - APRIL

20-23rd April 2005- The British HIV Association (BHIVA) is to hold its 11th Annual Conference in association with British Association for Sexual Health and HIV (BASHH), at the Burlington Hotel in Dublin Ireland.

For more information visit www.bhiva.org or www.bashh.org

HEPATITIS C - RECOMPENSE FOR PEOPLE WITH HAEMOPHILIA INFECTED WITH HEPATITIS C

Skipton Fund: all new applications and enquiries should be made directly to the Skipton Fund helpline: 020 7808 1160/email: apply@skiptonfund.org.

Approximately 5800 applications are now being processed but the pace is reported as getting much slower as over 50% of applications are being returned to doctors as they have not been completed properly. The Skipton Fund staff are now announcing that they are able to work within the 28 day window as originally planned.

Continued over...

SECOND STAGE APPLICATIONS FORMS

These are now available on request from the Skipton Fund for those who have made a successful first stage application and believe they have developed cirrhosis or liver cancer.

Please remember if you are entitled to the Part 2 payment, or you think you might be, you must contact the Skipton Fund and give them your reference number from Part 1.

There have been no changes in the Government's decision to refuse ex-gratia payments for the dependants of those infected with HCV who are now deceased.

APPLICATIONS TO THE SKIPTON FUND FROM PEOPLE WHO HAVE CLEARED HCV SPONTANEOUSLY.

An article written by John Morris, Services Development Manager at the Haemophilia Society, looks at patients who have been exposed to HCV but are not eligible for HCV ex-gratia payments. The full report is

available on www.haemophilia.org.uk

If applicants feel they have had a period of chronic infection despite currently being PCR negative, they should discuss this with their doctor. If their application has been rejected, it will be because the answer their doctor gave to the question about radiological and pathological evidence was 'no'. If applicants disagree with this statement they need to take it up with the doctor who signed their form. If the doctor agrees that such evidence exists, a second application should be made in preference to using the appeal process.

It must be stressed that chronic-phase clearance is very rare and the most likely scenario is that applicants were informed of their HCV infection at some time in the 1990s on the basis of a positive antibody test. When PCR testing was introduced towards the end of the decade, this usually confirmed that no such chronic infection had ever been present.

Doctors Telling the Truth or Deceiving us - Want to have your say?

I'm a PhD candidate in Medical Ethics at Imperial College, London (under the supervision of Professor Raanan Gillon, a retired GP and Emeritus Professor of Medical Ethics, and Dr Tim Rhodes, a social scientist). My research is on truth-telling and deception in medicine and attempts to answer the question

"should doctors ever deceive their patients?". The project is funded by the Wellcome Trust and has been approved by the Oxfordshire Hospital Ethics Committee.

As part of the project, I am conducting empirical research on doctors, patients and members of the public to find out what these groups think about deception in medicine, and why. I then plan to compare the views and reasoning of each of those groups and attempt to reconcile (or at least reduce!) any differences between them. Over 60 doctors have so far participated in the study but I now need patients. This is why I come to you for assistance.

The questionnaire is entirely anonymous and consists mainly of scenarios in which deception is a realistic option. Most of the respondents so far say they have found the questionnaire thought-provoking.

For details of the project and to have a look at, or (better still!) complete the questionnaire, please go to www.medicalethicist.net/deception.htm, click on 'patient' and plug in:

Username: patient Password: ethics33

I sincerely believe that this project could help improve current practice and policy regarding disclosure of information to patients.

Many thanks for your help and please don't hesitate to contact me if you have any questions about the project.

Kind regards,

Daniel Sokol

Medical Ethics Unit, Imperial College Faculty of Medicine, St Dunstan's Road, London W6 8RP

tel: 01865 200 671 website: www.medicalethicist.net

Haemophilia Society

First Floor
Petersham House
57a Hatton Garden
London
EC1N 8JG
Information, advice and support.
Tel: 0800 018 6068
Email: info@haemophilia.org.uk
Website: 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

National AIDS Manual

Provides up to date factual treatment
Information, free publications+website.
Tel: 020 7627 3200
Email: info@nam.org.uk

Web site: 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

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
Web site: 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
Website: 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
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
www.positivelywomen.org.uk

Hepatitis Resource Centre

Tel: 020 7378 5496
Email: admin@hepccentre.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
Website: www.positivenation.co.uk

+ve

Monthly publication about HIV and quarterly
issues about hepatitis
Tel: 01895 637878
Email: andrewb@akitonet.co.uk
Website: 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
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
www.idt.org.uk

Haemophilia Wales

1st Floor 100 Whitchurch Road.
Whitchurch,
Cardiff,
CF14 3LY
telephone 029-20372719

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birchgrovenorth@hotmail.com

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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 inn fear and isolation.

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

Haemophilia and HIV Life History Project

On the 22nd January a feedback day was held at Swindon for the participants of the Haemophilia and HIV Life History project. Over the last 12 months 30 life histories have been recorded and held at the British Sound Archive Library. The feedback day is an opportunity to share the experience of involvement within the project and to discuss plans for the future. A report of the event will be reported in the next issue. Interview summaries can be viewed at www.http://cadensa.bl.uk

Birchgrove would again like to thank all the people who have contributed to this newsletter, and who make this possible. We would particularly like to express our gratitude to all the kind comments we received over the Christmas period, especially in relation to our work with the Woodland Grove in 2004.

We wish all our readers a very happy and healthy new year.

Bobthebleeder? Can he fix it?

No he can't! Pull your socks up and sort your own life out! He is away looking for some inspiration to write another column. All suggestions of problems, jokes, get rich quick schemes to [Birchgrove1@hotmail.com](mailto:birchgrove1@hotmail.com). Please accompany them with your bank account and/or credit card details so that he can steal your money, pay off those persistent bailiffs, landlords and dealers and stay on holiday a bit longer.

Skipton the Bush Kangaroo Quiz

For those of still waiting for the answers to the questions at the end of the last issue they were in order - No; Yes; Not unless you are really, really, really, ill and 'The vCJD Trust' (it already exists) and sadly is not called the Hannibal Trust.

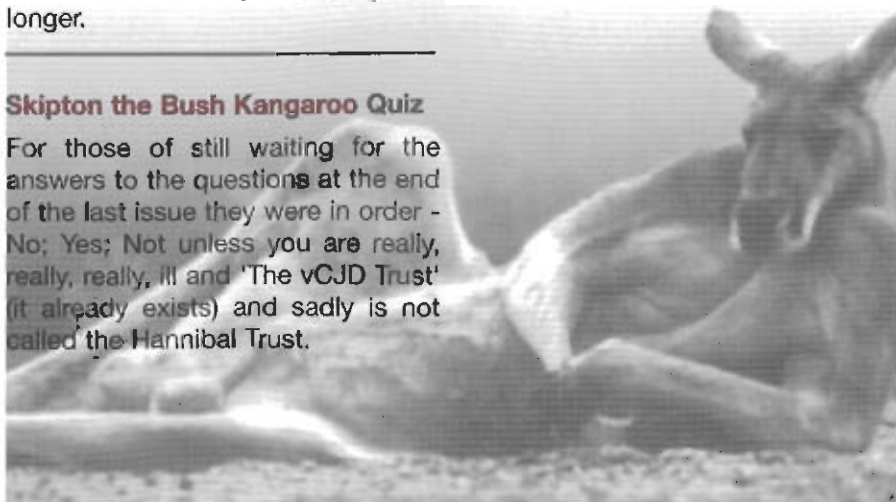
"Leave no stone unturned..."

Continued from pg 3

account number. It's worth remembering that unless you're a named Plaintiff at the spearhead of the U.S. Litigation, then so far the emphasis has been on obtaining a comprehensive list of batch numbers and brand names received to date. For a fee of £15, you can request a search and printout from the UKHCDO database that will most probably turn up some crucial data. Don't hesitate to contact the lawyers in the USA to ask if a list of batch numbers and product details would be sufficient for the time being. If every approach fails, try writing to your MP and ask them to help locate your notes. As a last resort, you might also try contacting the Press to draw attention to your plight.

by Andrew March

[Editor's note - when you write to the UKHCDO they do not send you the notes direct but send them to your haemophilia centre who give them to you. This is to ensure they are only given to you and not someone claiming to be you, however if you are uncomfortable about your haemophilia centre knowing you have requested records you can have them sent to another doctor. I asked Lynne Dewhurst to send them to my HIV doctor at his clinic in a different hospital as it was more convenient for me to collect them there which she was happy to do. And all 5 of the hospitals I wrote to were happy to include copies of letters and reports sent to them by other hospitals unlike Andrew's case]



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AWARDS FOR ALL
National Lottery
(a bit like our lives)