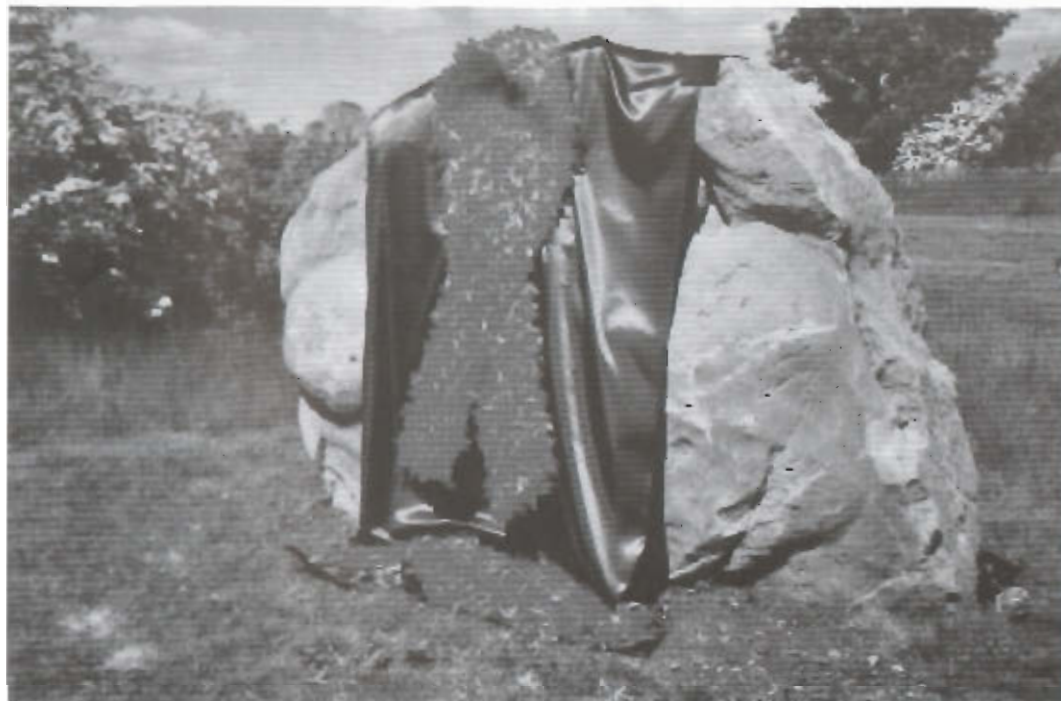


Birchgrove

P.O. Box 9755
Solihull B92 9WA

Issue 12
August 2004

Woodland Open Day



On Sunday 23rd May 2004 Birchgrove held an Open Day at the woodland grove at Stratton Wood near Swindon. The inscribed stone, which was installed last year, was officially unveiled and the day gave an opportunity for many people to come together and share their personal experiences.

It was a beautiful day in many ways. The sun shone all day, the trees in blossom and Forget-Me-Nots, in flower amongst the trees added to the occasion.

A wonderful large red ribbon made from hundreds of small red ribbons covered the stone, which was hand made by Linda, Gaynor and Anne. At 1pm a number of invited speakers gave short talks and some poetry about how HIV had affected their lives, which was emotionally charged and poignant. Gareth gave a speech about how HIV had affected him and the people he had known and what the woodland meant to him and others. Gareth then introduced other speakers starting with Mary Dykes, former Haemophilia Social worker at Cardiff UHW, who spoke about her involvement in setting

continues on pg2

Contents...

2-4	Woodland Open Day
5	Skipton Fund
5-6	DOH Reply
7-8	Skipton, Scotland and the Lords
9	Life History Project
10-11	Men Only
12	BHIVA Report
13	Recombinant Cut
14	CJD
15	US Litigation
16-17	Diary Dates-Snippets + Briefs
18	Skippy and Apologies
19	Contacts, Info + Support

Woodland Open Day

continued

up the meetings and introductions of the very first meeting of Birchgrove and the people she had known in those early years. Janet, a mother, read a poem about her feelings and her son. Robert ended the speeches with a moving short talk and a moment of reflection of some of the lives represented within the woodland.

After the speeches the large ribbon was removed, laid on the ground, and the stone unveiled. This was an emotional moment and comfort was found in the solidarity of those present. Some people laid flowers at the foot of the stone, some hugged strangers or loved ones, and cried, and a mother lay a small teddy bear next to a tree.

Around 150 people attended the event, consisting of people with haemophilia and HIV infection, their brothers, sisters, sons, daughters, mums, dads, wives, friends and loved ones, many bereaved, and all were there for the same reasons.

People had an opportunity to talk empathically with others, and to share the day as well as their sandwiches and drinks in the sunshine. Many people expressed that the day also brought a sense of closure, healing and acceptance and a realisation that they were not alone.

Birchgrove had a gazebo at the event with a photo display of the stone being installed, newspaper cuttings and back editions of the newsletter, which were very popular. There was also, more importantly, a "Thoughts and Comments" book where people had an opportunity to put their feelings into words.

Birchgrove would like to thank all the people involved in making the day a success especially the dedicated volunteers and The Woodland Trust.

the Swindon Evening Advertiser.

There were no representatives from any pharmaceutical companies or the Haemophilia Society at the event.

After last years fundraising for this event, there is still some money left over which will be used to purchase a bench in the wood near the stone later this year.

My involvement in bringing this project to closure has been one of the proudest, rewarding and most fulfilling parts of my life. I would like to thank all the people that have been supportive and hope that you all visit the wood and see the trees grow for many years to come.

The wood is open to the public all year round and can be visited at any time.

If you would like a copy of Birchgrove's Woodland Special newsletter with maps and information about the grove please contact Birchgrove.

Paul Bateman

BBC Radio Swindon and Wiltshire covered the event for their Sunday Breakfast programme and an article also appeared in

Thoughts and Comments recorded on the day.

Thanks for opportunity to see this lovely woodland. This special place for us to visit.

In memory of our son Michael who passed away aged 25 years, 9 years ago this week.

Time to think of people I miss.

Memories of a beloved son who died in 1993 aged 34 years.

Loving everlasting memories John 1997. Never forgotten.

Missing both of you, Thinking of you both.

A fantastic setting in this peaceful woodland. What a lovely way to remember all the people I have had the privilege to meet over the years that are no longer with us.

Remembering our good friend Dave and the good times we shared.

This day, these friends and this moment is by far the proudest event I have ever been involved in.

Philip, always loved, always remembered.

In loving memory of Duncan, a lovely day in a beautiful setting.

These trees thriving and strong for me and my family are a fitting tribute to a husband, father, brother, who's spirit is strong like these trees, although his body has been weak for him. We love you.

Many thanks for a pleasant afternoon in a suitably beautiful place.

Er cof am eirn dau ewythr annwyl- Duncan a Matthew

Just simply wonderful, peaceful and quiet.

A lovely way of remembering our friends and relatives.

In loving memory of Martin in this very peaceful woodland.

Wonderful tribute to brave people, both with us in spirit and body.

Remembered forever, always in my heart.

Dad, I love you.

A beautiful place to put the stone.

A splendid memorial to a splendid bunch of guys, including my son Toby.

Thankyou for the invitation to this beautiful wood- it is a fitting tribute.

Always be thinking of you Dad.

Today, Tomorrow, my whole life through, I will always love and remember you. God bless baby boy.

Ten years on and finally the grove is complete. It was great to be here on the day- A sad day, to think of those that didn't make it- I thought of you.

To all my friends at Birchgrove. Thankyou for giving so much of yourselves to us. I'll never forget today. You did a great job from start to finish.

Just glad to be here, will come again. To all, both with us and those sadly not.

This has been a very special day for us as a family. It brings it home to me as a mum, the enormous tragedy that has happened.

What a beautiful, peaceful place to remember. The stone is beautiful. Remembering my husband. All the people I have met today have been wonderful. Thanks for all the work by the Birchgrove group.

A lovely and special day- thanks for all your hard work over the years...my thoughts are with everyone involved over the years.

Woodland Open Day

Some Responses to the Open Day

Dear Friends

I am writing to let you know what a lovely day it was on 23rd May, we had such a good time as a family. I felt the ceremony was so moving.

When I arrived I didn't know what to expect. My first reaction was, what am I doing here, I didn't know anyone. I felt out of place.

When the ceremony began and people began to tell their story, their experiences, their poem, their individual tragedy, I began to relate to them. I too knew what that felt like, I had that happen to me, I knew the sadness and pain in my own life. I realized that I had every right to be there. It happened to my son, my family.

This day will live with me for a long time. It was a memorable day and one that was also a means of healing, acceptance and a realisation that I am not alone.

Thankyou once again from
GM

Dear Birchgrove

I'm so glad that we had the opportunity to come down for the unveiling of the stone. It was a beautiful sunny day and the emotion was certainly felt. It was a lovely way of spending the 9th anniversary of losing Michael, and I would like to thank all concerned in making this happen.

With love to you all

L+P

Best wishes to all involved and for bringing it to fruition after all these years. Hearing about the project brought back many memories, good and bad ! I'm sure Arthur Bloom would have approved. A real 'Birch Grove' (sorry about the pun).

Dr Simon Davies (ex Cardiff Haemophilia Centre)

Dear Birchgrove,

I was really pleased to be able to play a part in the Birchgrove dedication and to help bring to a conclusion the idea that was born so many years ago. It was a lovely day and well worth the journey. That ribbon looked magnificent and must have taken a lot of hard work to create.

Cherril Deans - Woodland Trust

Dear Birchgrove

Thank you for organising such a lovely occasion on Sunday. It was so nice to meet you and share in the success of all your efforts in creating the Woodland Grove.

Peter and I were most impressed with the

organisation and attention to the needs of those attending - the weather was perfect too. It was a lovely day, shared with others who have a common cause, that gave us something quite unique, emotional yet joyful but mostly, I felt, inspiring.

You have worked so hard to achieve this memorial and I'm sure it will be appreciated and enjoyed by not only those of us who are directly connected but the local community as well. Congratulations and thanks to all those involved.

Kind regards

Pat Hamilton

A POEM-

Today

By Janet Smith

I will look at this stone and remember
many faces are coming to me
The fun and the joy of just seeing them
Is a wonderful memory for me

This stone is a symbol of unity
Of great strength from one and all
For the wonderful work of the Birchgrove
group

Mainly Gareth, Haydn and Paul

And Gareth my darling I thank you
On behalf of my little boy
For the love and support that you gave
him

You gave him so much Joy

You gave him your time and your laughter
You shared in his pain and his tears
You gave him what ever he asked for
You gave him seven wonderful Years

Now this beautiful woodland memorial
Has brought us all together again
And as we all stand here together
it's time to remember them

But not just those that have gone before
us

But the men that continue to fight
This stone is a symbol for all of us
it's solid, steadfast and upright

So when I look at this stone and
remember

The planting of 1200 trees

In decades to come

the Trees will be strong

As they grow with our memories.

SKIPTON FUND

The Skipton Fund, set up to manage the UK wide ex gratia payment scheme for people infected with hepatitis C from NHS blood products, went live on 5 July 2004.

Claimants can apply by completing a registration form and questionnaire. Registrants of the MFT already infected with HIV and Hep. C should have already received a separate form to complete.

Birchgrove readers have already commented that the DOH lack compassion by asking for the information of the "dead person" rather than the deceased in the second paragraph in the how to complete the form. Confusion has also arisen from the 4 separate sections on the back of the form for your Doctors to complete. This is apparently another "red herring" designed to confuse and stall us, and you only need one box completing by one doctor. The helpline also did not have hours of opening or when commencing, which has frustrated some callers. The MFT have reported that there were complications with the telephone service provider which were only resolved at the last minute. This is why parts of the form had stickers over the phoneline.

In addition to people who have cleared the virus as a result of treatment, those who have cleared it spontaneously after a period of chronic infection will be eligible for payments. It will be assumed that people who have developed hepatitis C after being treated with Factor VIII or Factor IX concentrates were infected as a result of that treatment. Applicants will not be asked to sign any waiver. The scheme will not reimburse legal costs incurred in making a claim or in appealing against a decision by the Skipton Fund. The scheme does not include widows or dependants of anybody already deceased before September 2003. The scheme does not compensate anybody for their infection.

The second payment for people who have cirrhosis, end stage liver failure or have undergone transplantation will be sent out separately on request from the Skipton Fund once initial payments have been processed.

The Skipton Fund

PO Box 50107, London, SW1H 0YF

Tel: 020 7233 0057

Email: apply@skiptonfund.org

Website: www.skiptonfund.org

Department of Health press release

www.dh.gov.uk/PublicationsAndStatistics/PressReleases/fs/en

DOH RESPONSE To Birchgrove-

On the 12th May Melanie Johnson MP, Parliamentary Under Secretary of State for Public Health, replied to Birchgrove's letter, on behalf of John Reid (see last issue) regarding the Hep C ex gratia payment.

Dear Birchgrove

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 hepatitis C, and deeply regret that so many people were infected through blood products.

(What about Hep B, CJD or Parvovirus Mel?- Editors note)

You have expressed disappointment that the payment scheme has not been extended to dependants of those who have died following inadvertent infection with Hepatitis C.

(Who has proved this was inadvertent Mel? We would love to know- Editors note)

This was not an easy decision to make, but I think 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.

(We think it is important to stress Mel that our underlying principle is to get to the truth behind what has happened to us and not fob us off with small change- Editors Note)

The payments are not designed to compensate for bereavement, although I fully

continues on Pg 6

DOH RESPONSE To Birchgrove-

continued from Pg 5

appreciate the hardship and pain experienced by families who cared for loved ones who have died. I realise that this is little consolation, but I hope you can understand that the healthcare budget is not unlimited. *(What about the criminal injuries compensation budget Mel- maybe the DH should look there? Editors note)*

I believe that the scheme strikes the right balance and ensures that we are able to make value for money payments while not adversely affecting the rest of the health service. *(Is this like the value for money skid row blood products you gave us 20 years ago? Editors note)*

The payments are fair and reasonable and I hope that they will go some way to improve the lives of those who have been inadvertently infected. *(Actually Mel, it will buy a Ford Mondeo, or pay off debts that we have already incurred trying to stay alive. Editors Note)*

In response to your comments about the payments in Ireland and Canada, you will be interested to know that during a debate in the House of Lords on 25th March, the Parliamentary Under secretary of State for Health, Lord Warner, made clear the Government's official position on this issue. I would not like to add to this response, the reference in the Official Report, can be found under column 796 of the Lords Report for 25th March 2004. *(You May be interested to know Mel, that Lord Warner's references were factually incorrect-see last Birchgrove newsletter article from Malcomson Law-, and didn't make the issue clear at all- Editors Note)*

Since the announcement of the scheme officials have held meetings with a number of charitable organisations including the Haemophilia Society and haemophilia groups in Scotland and Wales, The Hepatitis C Trust, The Macfarlane trust and the Primary Immunodeficiency Association. We chose to meet with these groups because of their involvement in the setting up of similar schemes and/or because of their large representative constituencies. *(Does this mean you chose not to invite Birchgrove? Editors Note)*

We have also considered the views of other groups and individuals through correspondence. *(And how many of those thought your scheme was fair and reasonable? Editors Note)* We would be pleased to consider any further views you may have in writing. *(OK readers get your keypads and pens out- DH Richmond House, 79 Whitehall, London SW1A 2NS. Editors Note)*

I am aware that some people would like the Government to set up a public inquiry into this issue. We have great sympathy for those infected with Hepatitis C and have considered the call for a public inquiry very carefully. *(We are sure you have, and you know what's at stake. Editors Note)* However, as previously stated, the Government does not accept that any wrongful practices were employed and does not consider that a public inquiry is justified. *(We have never had the opportunity to investigate whether wrongful practices were employed, and we believe that a public inquiry would give us some justice. Editors Note)* Donor screening for Hepatitis C was introduced in the UK in 1991 and the development of this test marked a major advance in microbiological technology, which could not have been implemented before this time. *(Do you know when the major advance in the technology of heat treating and solvent detergent viral inactivation was developed Mel, and the time span it took to use it on the products we injected into our veins? Editors Note)*

Yours

Melanie Johnson MP

Birchgrove would like to thank Mel J for her response and the understanding shown by the Government and the DH but we know what we really, really want.

SKIPTON FUND, Scotland and Lord Morris in the News

SKIPTON FUND, Scotland and Lord Morris in the News

Thursday, 6 May BBONLINE

Legal challenge over Hep C cases

Bereaved families of Hepatitis C victims who contracted the disease through contaminated blood, are taking action against the Scottish Executive.

The families want judges to rule that Scottish Health Minister Malcolm Chisholm is breaking human rights law by refusing to hold a public inquiry.

At least 550 Scottish NHS patients were infected by the virus in the 1970s and 1980s. Mr Chisholm said he would consider the legal argument before making comment. The lawyer for the bereaved families, Frank Maguire, said the action was necessary as there are still many unanswered questions. Referring to the system which administered blood products, Mr Maguire called for a public inquiry to clear up doubts.

Inquiry call

He said: "Does it have systematic faults? Does it have institutional problems? How does it communicate with each branch of its service. "Has something gone wrong there which may occur in the future with CJD or HIV? We don't know. "If there is a systematic failure or institutional failure and a lack of communication and a lack of action by these authorities, then that is of public interest." To date there has been an internal inquiry into how contaminated US blood products came to be used in the NHS. But victims said that this had not answered key questions on why blood products in Scotland were treated differently to those in England.

The victims also said that it was unclear what Scottish doctors did when they knew there was a problem and why victims were not told about infection until years later. Mr Chisholm has stated that he will not sanction another inquiry unless new evidence comes forward. On Thursday, Mr Maguire said that, legally, the health minister does not have that choice.

Hep C victims use payouts for new legal fight

Sunday Herald www.sundayherald.com

John Reid faces court battle over "bad blood" scandal

By Liam McDougall Health Correspondent

Government payments to patients who contracted hepatitis C through NHS blood transfusions will be used to fund the legal campaign for a public inquiry into the scandal. Lawyers acting for patients said yesterday that they are prepared to take UK health secretary John Reid to court if he refuses to call an inquiry. Scores of patients have agreed to apply to the government scheme, offering ex-gratia payments to victims, and then plough part of their compensation into a "fighting fund" to pay for the court battle.

"Has something gone
wrong there which may
occur in the future with

CJD or HIV?

We don't know".

Legal watchdog probes advice for hep C victims

Sunday Herald <http://www.sundayherald.com/43646>

THE law watchdog is investigating claims that NHS patients infected with the hepatitis C virus have been warned off talking to lawyers by the Scottish Executive.

Glasgow lawyer Frank Maguire has complained to the Law Society of Scotland that the Executive has been telling his clients they "will not need legal advice" before applying to a compensation scheme. He accuses the Executive of acting inappropriately as it set up the Skipton Fund which will determine who will receive payouts of up to £45,000.

It comes after the Sunday Herald revealed that the Executive initially planned to force patients to sign a waiver preventing them from suing the NHS or government ministers if they received a payout. This has now been withdrawn.

"This application has to be filled in by the patient and may then go to a number of specialists around the country before being submitted to the fund," he said. "People can decide themselves whether they need to seek legal advice or not. A government body should not be seeking to dissuade anyone from taking legal advice."

An Executive spokeswoman said: "The only information claimants are required to provide is their name, address and permission for their doctor to provide medical details to the Skipton Fund. Therefore, we advise that claimants do not need to seek legal advice."

Lord Morris in the House

Blood Supplies and Safety 20 Apr 2004 : Column WA29

Lord Morris of Manchester asked Her Majesty's Government:

Further to the Secretary of State for Health's press release of 16 March on blood donations and vCJD, what specific steps the National Blood Authority will take to address the reduction now envisaged in the supply of blood available for transfusions; and what is their current assessment of the level of risk of vCJD infection to which people with haemophilia were exposed between 1980 and 1998.[HL2022]

Lord Warner: The National Blood Service (NBS) has in place an advertising and marketing plan to encourage new donors to come forward and existing donors to give blood regularly. The NBS relies on voluntary donors, and the plan aims to recruit new donors and encourage regular donation amongst existing donors and those who have not given for a while.

In addition, we are working with the NBS to produce a revised approach to the Health Service Circular 2002/09 Better Blood Transfusion-Appropriate Use of Blood. This is to ensure that the safe and effective use of donor blood and also alternatives to its use are fully considered.

The Department of Health commissioned Det Norske Veritas (DNV) to undertake an assessment of the risk of exposure to variant Creutzfeldt-Jakob disease infectivity in blood and blood products. This analysis was published in 1999 and considered the potential risks posed by United Kingdom-sourced plasma products. This covered all recipients, including haemophilia patients. The risks could not be quantified, due to major uncertainties as to what infectivity plasma derivatives might carry and about the prevalence of the disease amongst UK donors. An updated risk analysis by DNV has recently been published, this is available at <http://www.dnv.com/consulting/news-consulting/RiskofInfectionfromvariantCJDinBlood.asp>.

Hepatitis C and HIV Inadvertent Blood Infection:

Payment Schemes 20 Apr 2004 : Column WA30

Lord Morris of Manchester asked Her Majesty's Government:

Why widows of haemophilia patients who have died of hepatitis C infection from contaminated National Health Service blood products are to be excluded from help under the proposed ex gratia payments scheme, while the widows of patients who have died from HIV infection are included in the existing payments scheme for that infection.[HL2241]

Lord Warner: Unlike the Macfarlane and Eileen Trusts, which administer schemes for those infected with HIV, the ex gratia payment scheme for those infected with hepatitis C as a result of National Health Service treatment with blood or blood products, known as the Skipton Fund, is not a charitable trust.

The Skipton Fund has been designed to make lump sum, ex gratia payments to those living with the hepatitis C virus and has not been designed to compensate for bereavement. For these reasons it is distinct from the HIV payment schemes.

"we advise that claimants do not need to seek legal advice."

The Haemophilia and HIV Life History Project

The Haemophilia and HIV Life History Project is recording 30 life stories of people with haemophilia and HIV. The interviews will be archived at the British Library and various options are available to participants to restrict how they are accessed. All participants receive a copy of their own recording and written text of the interview.

Themes from these recordings will be used in educational seminars and publications in order to enhance public understanding and appreciation of this major social, political and medical event. Interview summary's can be viewed on line at [www.http://cadensa.bl.uk](http://cadensa.bl.uk)

If interested in being involved please contact Sian Edwards, Senior lecturer in HIV, Institute of Nursing and Midwifery, Brighton University, Falmer, Brighton, East Sussex, BN1 9PH- Tel 01273 644030 email s.l.Edwards@brighton.ac.uk

HIV Life History Project- Telling My Story

When I first heard about the Telling Your Life Story project I was instantly interested. I had lots of reservations, but I wanted to be involved. I wanted to have the opportunity to have my story be part of history, along with others in similar situations. To be given the chance to be able to tell how haemophilia and HIV infection has affected our lives, without Government interference and distortion of the facts or truth, is not only unique, but everlasting. I also wanted my story to be there for the people I can't tell at the moment. Maybe it is for them to listen to in decades to come, whether I am still alive or not. My nephews and nieces who are too young to know the truth about my life right now, the people I want to tell about my infection, but I haven't got round to, and to all the strangers in future decades who turn up at the British Library and want to be informed about a piece of medical and political history that affected 1250 families.

Finding 2 days without interruption that suited Sian and myself was the first hurdle. The second was my preparation for this as the interview date loomed near. I phoned a few friends who I knew had already took part in this project. Their advice was very valuable, but conflicting. "Just go for it, you know the story, its your life" or "Make detailed plans of what you want to say beforehand" for example. We talked about the fact that there is always something you miss. It's a one off chance to do it and it's important to get it right. It's strange what you thought you had forgot, but remember, and how remembering exact dates of when things happened get blurred.

Sian put me at ease right from the start, and the recording was very easy and comfortable, in my own home, the answer machine on, a "Do not disturb" sign on the front door and a pot of fresh coffee. Sian led the interview by asking open questions and asking me to expand on areas she thought were important, and so we set off on my life story.

Over 2 days I went through, and talked about, my childhood, my family, my friends, my relationships, my illnesses, my frustrations, my anger, my passions, my pain, my loves, my ambitions, my struggles and my coping mechanisms amongst many other subjects.

What I didn't expect was the emotion that it all evoked. I didn't expect to break down and cry. I talked about things that I hadn't thought about in years. It made me very sad and it made me feel that I was doing something that was extremely important and necessary. I had to have breaks during the interview, as did Sian. I had to get some fresh air, a walk in the garden, clear my head, have another coffee.

After the first day I was emotionally drained and hardly slept at all that night, with my head full of thoughts and full of people that I once knew but are no longer here. People that were part of my life once, but are part of my life story now.

Day 2 and we started mid morning, with the bulk of the taping done the first day this was not going to be such a long session, which I was pleased about.

We continued where I had left off the day before, and I expanded on issues I had talked about the day before but wanted to add to. I talked about the future, a topic some years ago that only went 6 months ahead, and I talked about my reasons for being involved in this project.

Throughout this, Sian was extremely supportive and understanding and explained everything carefully and compassionately. I felt like a huge weight had been lifted from my shoulders when this was over. I no longer had this huge secret hidden away inside me, it was for all to hear at the British Library. I felt like I had a life-times worth of psychologist and counselling sessions in one go. I felt that I had contributed, along with others, to a piece of history. Our history, our truth.

Overall, an emotionally draining, but worthwhile experience that for 2 days of my life will stay alive forever.- Paul

I talked about things that I hadn't thought about in years. It made me very sad and it made me feel that I was doing something that was extremely important and necessary

Men Only - A Cautionary Tale

by Maurice Zeta-Morris

It takes me a little under four hours to get to Solihull, a sentence which, under any other circumstances, would be enough to induce a fatal aneurysm. Snow had fallen overnight on the hills along the Heads of the Valley road, and charming as this scene might have been, I can't say I really noticed any natural beauty. Which is not to say that the phrases 'Heads of the Valley road' and 'natural beauty', don't go together like 'hand in glove', or 'Mormon ménage à trois', just that my head was too frazzled from trying to keep four wheels on the road and juggernauts out of my passenger seat.

Arrived at the Renaissance Hotel about 4.00pm and found some familiar faces congregating in the bar. Look, this was a 'Men Only' weekend - where else do you think they'd be hanging out? It wasn't that type of 'Men Only' weekend, though at times, particularly when the thin line between consciousness and stupidity became blurred by drink, it was hard to tell. Foolishly, I offer to buy a round. Anyone who says positive haemos are a bunch of layabouts sponging off the state should consider how much we contribute in tax on alcohol. And cigarettes. And texting. Good job some recreational habits still fall outside the taxman's remit. After a number of drinks - and a credit check by the barman - I began to unwind from the drive. I went up to my room, hurried through the ritual of the three S's, sprucing myself up to look my best in case I vomit in my own lap later in the night. Mother Zeta-Morris taught us young ZMs to always be well turned out, no matter what the circumstances.


For dinner they'd hived us away into one corner of the restaurant. Hearing us say Grace, I can understand why. Of course it's possible that what we were saying wasn't Grace at all, though John Morris seemed convinced it was. Dinner was, as usual, a raucous affair, except for the relatively new phenomenon - to me at least - of the dinner conversation by text. I'd always thought the 'art' of texting was limited to those between the ages of seven to twenty. Now, I'm not a great reader of age, but I'm damn sure there was nobody in our mob under ten and precious few younger than twenty. I wouldn't have minded so much if it had been the more pimply among us whose thumbs were tippity-tapping like a pornfreak frantically trying to get the webcam to show the money shot, but alas - it was the more grizzled of our fraternity who indulged themselves. Maybe it was to do with recapturing their lost youth.

Dinner was followed by a quiz which some people - ZM included - took far too seriously. It's not sour grapes, but our team - MP, MM, GI and MZM - has evidence, in

the form of hidden surveillance footage - of dirty deals done between the winning team and certain, allegedly 'neutral' officials. How else do you explain the absence of questions on Cardiff City F.C.? Or Deep Purple circa 1971-75, the classic years? Or the qualitative difference between a King Edward and a Maris Piper? Bitter - yes, we'll have another round, at a fixed rate of 5% taken over a five year term. Thank you very much.

A little later, one of our erstwhile commandants - PB - led a raiding party on what I thought was a wedding bash in the hotel's function room. I was up for the foray, assuming the object of the mission was to carry off a number of virgins for our 'Men Only' delegates to make sport with. Turned out it was some charity do, black gown, white balls, and lots of salving of middle class consciences by bidding for items you'd never dream of cluttering up the house with. Unless of course, you were PB. I wish I could do justice to the love between a man and a guitar, but until you've seen it for yourself, it really is impossible to convey the depth of emotion, of passion, one man can feel for someone else's instrument. So enthusiastic was this passion that a third party - the young woman who had become the guitar's new owner - became concerned lest PB acquire carnal knowledge of said instrument. There followed much to-ing and fro-ing, tugging and shoving, to the extent that I'm now a firm believer in the illicit pleasures to be found for everyone involved in a ménage à trois between man, woman and a white stratocaster.

After much amusement watching one of the old stalwarts - okay, it was GL - act as peacemaker between two worse-for-the-drink charity donators indulging in an impromptu boxing match - more like handbags after the ball - the remnants of the haemo mob shambled off to the bar. Very nice woman there, more than delighted to serve us and very appreciative of PB's spontaneous jam session utilising stools and bar table as a drum kit. Amazingly, PB's rhythm was faultless. It was about then that the night began to catch up with me. This seems to me a fundamental of a good 'Men Only' weekend - the ability to maintain mental and physical equilibrium and verbal coherence throughout a long night. This seems to me a fundamental of a good 'Men Only' weekend - the ability to maintain mental and physical equilibrium and verbal coherence throughout a long night. You know it's time to hit the sack when either (a), you can no longer speak; (b), you can speak fine but you can't understand what it is you're trying to say; or (c), GL starts to sound amazingly rational and you can't help but agree with everything he says.



Saturday morning comes as a shock. Not that I woke up, but that I managed to stumble down to the dining room while breakfast was still being served. Juiced-up, coffeed and cerealed, I use my uncanny homing instincts to find - not the bar - but the seminar room. But of course, being real men, the rest of them have started without me. So I take advantage of the massage I'm offered. Very nice woman, full back massage and though I'm tempted, I decide not to embarrass her - or myself - by enquiring into the possibility of extras. Making my way back to the seminar room, I give serious thought to attending the next partnership meeting, if only to table a motion to get Swedish relief massage offered to the delegates at the next 'Men Only' event. Check your programme notes for 'Something for the Weekend 2' in September.

After a coffee break we had the first part of a seminar on the health and fitness of positive haemos. Apparently, our equivalent of Mr Universe was due to give us a demonstration but he had to cancel at the last minute. Apparently he had a bleed. This was either a supreme irony or Christ Almighty was trying to tell us something. Of course he was - he was screaming at us - "For the love of fuck, you're goddamn haemos - start pissing around with weights and such nonsense and see what happens - you get a bleed." Much the wiser for this harsh lesson, we had a subdued lunch and were entertained afterwards by Martin Bedford who regaled us all with jolly tales of the sorts of things that alcohol was doing to our livers and tobacco to our lungs. Happily, he didn't mention dope. Or maybe he did and I was just too stoned to notice. Anyway, it was a - shall we say 'sobering' - but entertaining session. The mood amongst the delegates was on something of a downward spiral, but luckily, Gwent's very own MP and the Emperor of East Anglian Drinking were on hand to raise our spirits by steering us pubwards as we ventured out into welcoming Solihull.

Ensnared in the local pub, I noticed an unattended bag at the next table. Most of our group missed it, apart from AB, AM and PH who all looked a little pasty-faced at the sight of this potential Weapon of Mild Irritation. Taking control of the situation, I led a relocation to another part of the bar, putting a pillar between the bag and our little group of heroes. The pillar, two young woman at a table between us and the suspect package, and MP - who had his back to the bag - would absorb the blast impact should the bloody thing explode. It didn't. But I like to think that if it had, my reading of the threat of the WMI would have saved countless people from becoming inexplicably annoyed.

Back at the hotel to get smartened up for the possibility of pulling, but more likely

spewing, we took a short taxi-ride to a local Indian Restaurant. Food was more than acceptable, though the professor who booked tables for thirty odd people on a 1st floor accessed by a spiral staircase, was possibly not drawing on his full intellectual capabilities. Not when you consider that one of our group was wheelchair bound and at least half of are to spiral staircases what elephants are to the Bolshoi Ballet. Still, the crack was good, even if RO nicked my bloody nan.

We returned to the hotel via the pub we'd visited earlier in the day. Emboldened by drink and curry, MZM too it upon himself to try and charm entrance for the whole 'Men Only' bunch into a club. For once, the old charm didn't work. Suave and sophisticated as we may have looked - and sounded - I fear that once we began to move, our assortment of limps, totterings, stumblings and shufflings gave the game away. But honestly shir, not one of us has been drinking. Well, only a little. Following this slight embarrassment, we found ourselves in the hotel bar where one by one, we became fewer, until finally there was just a hardcore of MZM, GL, RO, PB, PH and a couple of others whose names - or initials - were no doubt filed away in those brain cells which passed away overnight. The conversation took a turn for the cerebral as pondered the real meaning of the term 'men only'. RO's suggestion that the term could be defined as embodying a measure of 'Pooficity' was given serious consideration for 5 seconds before being treated with the ridicule it deserved. Maybe that sort of thing is acceptable for a Cockney Geezer, but we were true Men Only, and proud of it. As the night wore on our party shrank even further, till we were one prick short of ménage à trois. Time to call it a night.

The morning was a little fuzzy, but miraculously I made breakfast for the second day in a row. Like always, it was something of a downer saying so long to guys who've managed to suspend their sense of embarrassment and shame for a weekend. It always strike me as ironic that the positive benefits to be had from the pleasure of such company should be countered by the debilitating effects of our excesses. No doubt there's a lesson to be learned. Probably several, but I'll leave you with just one. When trying to weigh up the positive benefits to mind, body and soul against the negatives of attending a 'Men Only' event, just remember that you're damned if you do and damned if you don't. But the first is a Hell of a lot more fun.

(This article was intended for the last edition of Birchgrove but missed our print deadline. We thought it was valid in promoting a balance within the newsletter and maybe encourage others to realise that attending these events isn't all that bad. Or is it? - Editors Note)

BHIVA 10th ANNIVERSARY CONFERENCE

Held at the City Hall Cardiff between 15th and 17th April.

Three days in Cardiff at the most prestigious HIV conference in the UK, attending on a BHIVA community scholarship for Birchgrove, I wanted to find out what's new in the world of HIV and ensure that I could remind as many people as possible that we still exist and have our corner to shout about.

This 10th Anniversary BHIVA conference was a landmark as Prof. Brian Gazzard stood down as Chair of the organisation and handed over the leadership to Dr Margaret Johnson.

The Conference was a mixture of heavy content lectures, a tight schedule, lots of people to talk to and meet, lavish banquets, Rodin sculptures, Welsh Choirs and free pens.

Amongst the schedule I was particularly interested in Brian Gazzard's comments regarding "Long term management of Patients- what have we learnt"- Brian talked about how perceptions to treating patients have changed and how patients' perceptions of living with HIV has changed. Setting strategies for 30 year treatment programmes. Emphasis was put on the drugs themselves and how their durability is an unknown concept. They work, but for how long? Treatment strategies over this long-term period should consider more importantly the tolerability and toxicity of the medication, as well as its efficacy. There was no doubt that long-term treatment meant lipid problems for many patients and how this impacted on the patient's life. Brian stressed that we needed more data on metabolic effects of HAART. It was stressed that patients should have more choice in the drugs they take, try and impose a NRTI sparing regimen and to switch patients with high lipid levels to alternative medication. Overall it was refreshing to see such forward thinking.

HIV and Hepatitis C was discussed during the conference and through abstracts, but overall the treatment news is not as good as people hoped a few years ago. It was stressed the need to prioritise the treatment of HCV in coinfected as there was accelerated progression to cirrhosis in this patient cohort. That the impact of HAART on the liver should be closely monitored and was an added risk factor. Normal indicators for stopping HCV therapy such as PCR response and tolerability should be used in co-infected as in mono infected.

Trials noted lower response rates of people with HIV in treatment of HCV. One reason may be the lower doses of ribavirin given to HIV+ patients due to anaemia and AZT reactions. For treatment to be effective the full dose therapy must be used, but overall 48 weeks may not be necessary for all genotypes such as 2+3. It was discussed how much patient choice there was to continue treatment for longer.

Results from the APRICOT (Roche product) trial were presented. This was the largest recent study of 868 co-infected patients. Discontinuation of treatment was around 15%. The most reported side effect was fatigue (40%). CD4+ cell counts dropped by around 140 cells but went back up at end of treatment. 40% Sustained Viral Response is the highest achieved so far in any co-infected group.

Regarding adherence and resistance there were study's that reported using an electronic pillbox with patients. Results showed that risks of resistance are higher in serial missed doses. However, one study found that even highly adherent patients on P.I.'s (protease inhibitors) failed with resistance.

It was discussed how the adherence relationship is different with types of drugs. The half lives of drugs differ and missed doses could end up with a patient effectively being on mono-therapy, for example using one drug with a long half life alongside two drugs with short half lives.

Early trial data about resistance may not turn out to be the same when the drug has been in use for some time, so do not rely on old information. Some drugs are more prone to resistance than others. Some drugs are still effective, even when resistance has developed.

SMART (Strategies for Management of Anti-Retroviral Therapy) which will be the largest international HIV study, following 6,000 patients over 6 to 7 years, was launched. This study will compare the long-term clinical consequences of two strategies of antiretroviral management and study the cumulative effect of HIV drugs over many years. Data we do not have and which is essential for long-term management of our condition.

By Paul

(with thanks to Babs Evans)

A full report of the conference can be found at:

<http://www.bhiva.org> email bhiva@bhiva.org Tel 020 8369 5380

The BHIVA Secretariat 1 Mountview Court 310 Friern Barnet Lane London N20 0LD.

Now you see it - now you don't: £4 Million Cut to Recombinant Budget Birchgroves Response

Health Secretary
The Rt Hon. John Reid MP
Richmond House
79 Whitehall
London
SW1A 2NS
16 July 2004

Dear Mr Reid,

Re: The unmentioned £4 million cut to Recombinant Clotting Factor Budget

We were appalled to discover that the funding that began only last year to ensure that recombinant blood products would become available to all adults with bleeding disorders has already been cut. Finance Directors of PCTs were written to only six months ago on January 7th 2004 about the £88 million extra funding for this programme and it has been cut already. To withdraw £4 million pounds from the programme and without even the courtesy of making it public is both seedy and cowardly. How different from the press release of the announcement of the original £88 million (now only £84 million of course). If announcements and press releases are written to trumpet good government policies and the spending of money then at the very least unpopular ones or the withdrawal of the promised monies should be made public as well.

The question of blood safety is one close to our hearts, lungs and joints as the human factor VIII that we inject into ourselves is pumped around our bodies. To be blunt human blood products are an extremely efficient way of passing new and undetectable diseases on to people whose blood does not clot and the diseases that we collected from this treatment have mounted up as the decades have passed. The main reason the rest of Western Europe switched to recombinant was to overcome that unavoidable issue. Birchgrove, itself, began as a group for people with haemophilia and HIV and even though 800 have died we have become a group for people with haemophilia, HIV and hepatitis C who are also being monitored for signs of variant CJD. (After the death of a person of vCJD who received whole blood from a donor with the disease CDSC are hoping the same will not happen to the recipients of human clotting factor products made from donors who then died of vCJD).

To deny the promised recombinant factor product or at the very least delay the receipt of it to those who want it whilst simultaneously monitoring us for signs of vCJD would be a sick joke were it not a (theoretical) risk to our health and lives.

Robert James
Chair- Birchgrove

At the time of going to press we have been informed that this cut has been cut and we have got our £4 million back. Birchgrove suggests you inject your recombinant quick before they take it away again. Especially as a second case of transmission vCJD from a blood transfusion also made the news in July. The recipient had died of something else but their post mortem showed signs of vCJD in the person's spleen. See news.bbc.co.uk/1/hi/health/3916285.stm

Second case of vCJD 'via blood'

A second case of a possible transmission of vCJD via a blood transfusion has been revealed by the Department of Health.

The patient died from causes unrelated to the disease, but a post mortem found the vCJD agent in their spleen. The patient received the transfusion in 1999 from a donor who later developed vCJD, according to information from the National CJD Surveillance Unit. The CJD Support Network said the news confirmed its worst fears.

Infection route

In December last year, the first reported case of a patient who died of vCJD after receiving blood from an infected donor was revealed. The case was thought to be the first person-to-person transmission of vCJD in the world. The patient had received blood during an operation in 1997 developed variant CJD and died six years later. At the time, Health Secretary John Reid said in a statement to the House of Commons, "This is possibly not a proven causal connection - it's also possible that both individuals acquired CJD separately. "This is a single incident, so it is impossible to be sure which was the route of the infection. However, the possibility of this being transfusion-related cannot be discounted."

In response to that case, the government banned anyone who had received a blood transfusion since January 1980 from donating blood in the future. It has now said it will extend the ban to cover a larger group of transfusion recipients from August 2. Potential donors who are unsure if they have had a transfusion and those who regularly donate blood components will be covered by the new restrictions.

Blood rules

Announcing the extended measures, Mr Reid said: "We are continuing to follow a highly precautionary approach. Although

people may have concerns about the implications of this announcement, I would emphasise again that the exclusion criteria are being tightened because of a small but unquantifiable risk". "People should continue to have a blood transfusion when it is really necessary." He added: "Any slight risk associated with receiving blood must be balanced against the significant risk of not receiving that blood when it is most needed."

Shadow Health Secretary, Andrew Lansley, supported the government's "highly precautionary" approach. But he said: "It is important to assess to what extent the process of leucodepletion - the removal of white blood cells in blood used for transfusion - has contributed to reducing this risk. The second possible case of transmission in the department's announcement concerned a transfusion in 1999 but it doesn't make clear whether it was prior to the implementation of leucodepletion in October 1999."

Paul Burstow, Liberal Democrat health spokesman added: "The government must ensure that people prevented from donating are reassured about the risks involved. Ministers must be ready to take urgent steps to encourage blood donation if the blood supply is affected by today's announcement."

Latest figures show 142 people have died so far from probable or confirmed vCJD

Since 1997 all cases of vCJD that are reported to the National CJD Surveillance Unit and diagnosed as having 'probable' vCJD, are passed on to the National Blood Service which searches its blood donor records. If the patient has given blood, subsequently any stocks of that blood are immediately destroyed.

Blood products, such as clotting factors, have been prepared from plasma imported from the USA since 1998. And white blood cells (which may carry the greatest risk of transmitting vCJD) have been removed from all blood used for transfusion since 1999.

(Editors Note- Birchgrove would like to note that as Mr Reid states "We are continuing to follow a highly precautionary approach", and that "People should continue to have a blood transfusion when it is really necessary", the policy on access to recombinant clotting Factors contradicts both these statements. The current recombinant policy also goes against patient choice, which Mr Reid seems to talk so much about in the press. If the DoH want to take a highly precautionary approach to the risks of vCJD, Birchgrove suggest that finances to enable recombinant to all people with haemophilia, irrespective of age or past code, are made available immediately. Maybe then John we might start taking you seriously. Injecting blood derived clotting factors is NOT really necessary.)

Countries suing the pharmas

www.ireland.com/newspaper/ireland/2004/0702/3638429281HM3DRUGFIRMS.html
Irish Government-Attorney General seeks advice on suing drug firms

The Attorney General has sought legal advice on the prospects of suing pharmaceutical companies which supplied contaminated blood products to Irish haemophiliacs after a US law firm offered to take the case on a "no foal, no fee" basis. **Joe Humphreys** reports.

The State has instructed a separate US law firm to advise it on the implications of accepting the offer made by Lief Cabraser Heimann & Bernstein last year.

The Minister for Health, Mr Martin, said yesterday that the Government was awaiting the independent advice before making a decision on whether or not to embark on foreign litigation. This advice was due in a "relatively short" period of time, the Department said.

The news emerged yesterday during a meeting between Mr Martin and the Irish Haemophilia Society (HIS), which has accused the Minister of reneging on a promise to establish an inquiry into the role of drug firms in the infection of 260 haemophiliacs with HIV and hepatitis C.

Mr Ray Kelly, an executive committee member of the HIS, whose son, John, was among 86 haemophiliacs killed by contaminated products, said it was a disgrace that the State hadn't "the bottle" the take on the drug companies.

"It appears the political will is not there either to hold some form of investigation, which would be our preference, or to conduct litigation," he said.

But the Minister said he was satisfied he had taken every appropriate step to ensure the Government and the HIS had the best-quality advice available before embarking on any foreign litigation.

In a separate development, Mr Martin said he hoped to bring proposals to Cabinet by September on the establishment of an insurance scheme for people infected with HIV and hepatitis C. However, he said this was dependent on legal advice from the AG.

Patients suing the pharmas

"Second Generation" Blood Factor Concentrate Products Liability Litigation MDL No.986, United States District Court for the Northern District of Illinois.

Most people who are part of this litigation should by now have received and completed a Plaintiff Profile Form or PPF for the claim they are bringing as part of this litigation. It is essential that the information in this is as accurate as possible as this will assist in efforts to obtain compensation.

Plaintiff's have been advised that proceedings are at the discovery stage at present and some people have been asked to prepare for a possible trip to Illinois to give their evidence.

For further information contact.

Lieff, Cabraser, Heimann + Bernstein, LLP can be contacted at Embarcadero Centre West, 275 Battery Street, 30th Floor, San Francisco, California 94111-3339, USA.
 Tel- (415) 956-1000 email mail@lchb.com www.lchb.com

Birchgrove has also been informed that some people from Britain are going to the states in late September early October to give depositions. Let's hope they do not get stopped at passport control!

(The UK contact for further information on this is Denis Whalley or Lynne Wilson at Anderson Eden Solicitors, Tel 01772 272 081 or email lynne.wilson@andersoneden.com or denis.whalley@andersoneden.com)

INHIBITOR SUPPORT GROUP

The second meeting of the Inhibitor Support Group run by Max Medicom with sponsorship by Novo Nordisk will take place on : 2 October, 1pm at The Renaissance Solihull Hotel, Warwick Road, Solihull B91 1AT. For further information contact Kate Bleby on 01252 702739 or email:kate@maxmedicom.com. Anyone affected by inhibitors and a bleeding disorder is welcome.

Supporting Children and Young People Living with HIV- National Childrens Bureau

Wednesday 8 September 2004- Newcastle + Wednesday 6th October Birmingham (1-5pm)

Aimed at people working with HIV+ children and young people.

Further info- email training@ncb.org.uk or call NCB Conferences and Training on 020 7843 6441/1906

International Hepatitis C Conference

23rd and 24th September 2004- Imperial College London

UK Hepatitis C resource Centre. 276 Bath Street. Glasgow G2 4JR Tel 0141 353 6969
nrowan@mainliners.org.uk

BHIVA Autumn Conference

10th Anniversary Conference- Friday 8th Saturday 9th October 2004

Queen Elizabeth II Conference Centre, London

Subjects covered in the programme will include a Resistance symposium, Hepatitis B/C co-infection Survey, Transplantation, Lipids, metabolics and cardiovascular risk factors. New approaches to simplifying therapy, developments in salvage therapy and avoiding long term toxicity.

Anyone interested see www.bhiva.org email bhiva@bhiva.org Tel 020 8369 5380

BHIVA Organising Secretariat. 1 Mountview Court. 310 Friern Barnet Lane. London N20 0LD

Hemophilia 2004 World Congress, Bangkok, Thailand 17-21 October 2004

World Federation of Hemophilia.

See web site for further details, or contact at

1425 René Lévesque Blvd. W., Suite 1010. Montréal, Québec. H3G 1T7 Canada

Tel.: +1 (514) 875-7944 Fax: +1 (514) 875-8916 E-mail: wfh@wfh.org

Changing Tomorrow- UK Conference

Leicester Saturday 4th - Tuesday 7th September.

A full packed programme of events over 4 days solely aimed at people living with HIV and AIDS and not the professionals.

The major themes of the conference include Long term survival on anti HIV drugs, Patient and Public Involvement in the NHS, The global situation and update from World Aids Conference Bangkok July 2004, Criminalisation of HIV transmission and creating sustainable networks of people living with HIV. The conference is now full but some day places are available for those living nearby.

If interested please contact Babs Evans PPI Project Coordinator, National Aids Trust, New City Cloisters, 196 Old Street, London, EC1V 9FR

Tel 020 7814 6729

Email- babs.evans@nat.org.uk

Something for the weekend 2

Reloaded

Friday 10th to Sunday 12th September 2004

Best Western Tillington Hall, Stafford.

Open to anyone with a bleeding Disorder and HIV, registrants of the MFT and Partners of both. The weekend will include activities such as general socializing and meeting people to share information, knowledge and support, Health and fitness, finding out about organizations and what they can do for you, Complementary therapies, HIV and HCV treatments update, HIV and Human Rights, a Cyber Café, Facilitated workshops on requested issues, exploring issues around making babies, Getting back into full time life, patient involvement, body building, one to one appointments and entertainment.

Contact Richard Oakley oakleyrichard@hotmail.com

Or John Morris at The Haemophilia Society 0800 018 6068

This event is funded by the MFT

SNIPPETS AND BRIEFS

NEW CHIEF EXECUTIVE FOR HAEMOPHILIA SOCIETY

Graham Whitehead, who was formerly the chief executive of Hampshire Deaf Association, is now the Society's new chief executive as from the 24th July. His previous roles have included Principal of the Royal National Institute for the Deaf's residential college and Regional Director for Southern England. Prior to these posts he was involved in a variety of educational establishments as teacher, community education development officer and manager of a residential education centre. Originally from Nottingham, Graham has worked in various parts of the country and now lives in Hampshire. He is a keen armchair sports enthusiast, and enjoys the theatre and music events when time permits!

Birchgrove wish Graham all the best in the driving seat at the Society and hope that he will be "all-ears" to the concerns of the Society's members. We hope that Birchgrove readers will shout out loud about what the Society should be and could be doing for them.

Birchgrove have requested a meeting with Graham to discuss the HIV services provision within the Haemophilia Society and the on going funding and support to Birchgrove.

MFT WEB Chat Room- www.macfarlane.org.uk

Do you want to contact other registrants of the MFT? The web site enables registrants to enter a secure site where they can email, leave messages and replies to others. This is a forum for your topics whether you want to contribute or just hear what people are concerned about. To do this MFT registrants need to contact the MFT by email or phone asking for a password to enter the secure part of the site. Once in, you can change your password to your own choice, and use this whenever you want.

Be a Friend of NAM

As record numbers of people are living with HIV, demands on NAM's services are increasing daily. To continue to meet these demands NAM are asking for any financial support anyone can offer through "Be a friend of NAM" with a regular monthly donation or one off gifts. If you or anyone you know is in a position to support NAM please contact NAM Lincoln House 1 Brixton Road London SW9 6DE or Tel 020 78400050 or email info@nam.org.uk

Want to make your views count

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

SKIPTON - the bush kangaroo

Hello sport, I'm Skipton the bush Kangaroo, Bob the Bleeder asked me to explain a bit about myself while he is away on holiday. First I'd like to take this opportunity to correct a few myths about myself for y'all.

My parents are Macfarlane and Eileen and I did not come from an unholy union between a couple of Scotsmen called Reid and Chisholm.

I am a cosmopolitan kind of kangaroo with god parents in Cardiff Bay, Holyrood and Stormount (although my Northern Irish God parents are always arguing and hardly ever there).

I live with my parents at a secret location in London as we don't want you coming to visit us.

I will be giving out presents of £20,000 to some of you but only if you can complete a detailed questionnaire and a pint of blood, extra cold.

I will also be offering a reward of £25,000 for people who can send me a piece of their cirrhotic liver. (Photos, ultra sound scans, Hider scans, or blood aren't enough) I am hoping to cook it for my friend Hannibal with some flava beans and a nice chianti.

I'd also like you to know that I am NOT, repeat NOT charitable like my ma and da and I don't care if you are in hardship!

Bob the Bleeder is on holiday with his brother Tom at the South Pole

Apologies, Corrections and unclaimed Prizes

A) In the last issue of Birchgrove we printed a letter from Malcolmson Law without reference to the source or permission to print. We were not informed by the person who sent it to us that source and permission were required so Birchgrove would like to credit this information and ownership to Carol Grayson and Colette Wintle, who are long time campaigners for haemophilia issues. Birchgrove did not intentionally plagiarise this information or print it without knowledge of the source, but put it in with the intention of informing, and benefiting through knowledge, the haemophilia community. Birchgrove would like to take this opportunity to thank Carol and Haemophilia Action UK for all the hard work in campaigning over the years especially in the formation of the US litigation currently taking place.

C) Haemophilia Wales- Please note that Haemophilia Wales telephone number is 029-20372719 rather than the old number we printed in the last issue. We apologise for any inconvenience caused.

un-P) Last issue- Blood Money- We would like to point out that the last issue was incorrectly numbered Issue 10 April 2004, when we also printed issue 10 News Update in Jan 2004. This issue, August 2004, is now numbered 12. If this has left anybody in confusion as to where Issue 11 went then see Issue 10 Blood Money. This was an intentional mistake with a lifetime's supply of Stella Artois as a prize for the person who noticed this first. As nobody reported this error the prize has now expired. Please stay alert and help us to keep on our toes too.

Birchgrove welcome your contributions, and would like to thank all the people that contribute to the newsletter and the feedback we receive.

Haemophilia Society

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

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@akitanet.co.uk
Website: www.howsthat.co.uk

National Helpline Numbers

HIV i-Base

HIV treatment information and support.
Tel: 0800 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

Birchgrove North

c/o Body Positive North West.
Lawrence House.
City Road.
Hulme.
Greater Manchester
M15 4DE
birchgrovenorth@hotmail.com



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.

Some of The Birchgrove readers
and long time contributors to the
woodland project, after the
unveiling of the stone on May
23rd.

The Woodland Grove is now
complete, and a new bench will
be installed later in the year.
Anyone can visit the wood at any
time.

Editorial Team

**Mick Mason, Paul Bateman
& Robert James**

DISCLAIMER

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

"BIRCHGROVE" is published by
Birchgrove Group,

P.O.Box 9755

Solihull

B92 9WA

E-mail:

birchgrove1@hotmail.com

THE BIRCHWOOD NEWSLETTER IS
FUNDED BY THE HAEMOPHILLA
SOCIETY