



# Birchgrove

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## the drugs issue...

*The following article is a transcript based on an interview which was carried out with the assistance of a Birchgrove member. We asked him if he had any experience of recreational drugs before HIV?*

I'd smoked dope before that, I'd smoked dope quite regular. I'd go out with the boys, I was a big drinker then, drink a lot, get into trouble through drinking, drunk and disorderly, fighting, snorting a bit of speed on the weekend, going night-clubbing, dancing my bollocks off all night. You're whizzing away, that would be Friday and Saturday nights. But when I was in hospital I was a bugger for the painkillers. I was addicted to painkillers, but I wouldn't go out looking for stuff on the streets once I was out of the hospital. When I was in there, I was on it, I wanted to be on it, but when I came out, I could stop it. I had a positive side to me, even though I had a problem, I could still sort it out.

When I got told I was HIV, I was on the ward and when I came out I felt alright, until a couple of months went by, and then I thought "Fucking hell, I'm going to die". So I thought, "let's go out big". I started taking a lot of speed, not only weekends, but taking it daily. Into a paranoia state, and I couldn't sleep. I was thinking about dying and HIV, "Oh my God," I thought.

A couple of years ago, I didn't want to live, I wanted to die young, but not with HIV. I wanted to die through another cause, drugs probably, but not with HIV. I didn't want have the headlines out on me "He's dying of AIDS", you'd hear things on the news, the local headlines, haemophiliac dying of HIV. It'd be on the news, an iceberg falling into the water, and I thought "Fuck this, I've got to get out of this world, I gotta get out of here, I can't handle this no more, my heads going". I started taking a lot of speed. Speed kept me awake, and the only way I could come down from the speed was to whack

some sleeping tablets, loads of sleeping tablets. I thought I like this side of it. I like the sleeping side of it.

I started getting into the sleeping tablets, buying them, buying palfium, then buying morphine tablets on the street. You get in so deep, you see people who can get heroin for you. Start taking it, then you start getting it yourself, going to who they're buying it off and on down the line to who they're buying it off, until you get to the main source. Then you buy it in bulk, enough to last you. There was just nothing positive to stop me.

But after the HIV, I started taking as much as I could get. I used to get palfium from my GP or dexamoride, very, very strong, much stronger than pethidine, about the same strength as morphine.

Pethidine was no good anymore, I'd started to abuse it, it was just blanking everything out of life. I thought I can cope with this, I can handle this, but I couldn't handle coming down and being back to HIV. Well, they just wouldn't work anymore, so my GP put me on palfium, I'd been on and off them in the hospital, morphine, palfium. When I was in the hospital it was hard to get enough pain relief. But, in the end, I did cry wolf and when I was in genuine pain they didn't want to know. So I had to go to my GP and he'd give me palfium and that, but in the end he wouldn't give me no more.

The morphine was nice, but pethidine was bloody horrible, it's a chemical, it makes you go doodle alley, it doesn't last two seconds. But heroin is the real McCoy. My contacts for amphetamines were no good for heroin so I had to go travelling, Bristol, London, there are people up there who know where to get it from.

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Inevitably, any discussion focussing on drug use and abuse is bound to provoke strong opinions. What is interesting in terms of the HIV/AIDS debate, is how much the polarised viewpoints one normally associates with recreational drug use has spilled over into the arena of therapeutic and prophylactic drug treatments. Of course, certain clinical drugs have always provoked controversy, the tragic consequences of the use of thalidomide in the '60s, or the more recent scare about certain forms of contraceptive pill. But in the case of AIDS, there are so few effective therapies, that almost anything that appears to offer hope is seized upon as a possible life saver.

Remember the early feedback from the AZT trials? The initial indications seemed so compelling, seemed to indicate that it could prevent a progression to AIDS. Remember the clamour for positive people to be allowed access to the drug before the completion of the trials? Were the medical establishment right to believe that it is morally wrong to deny access to a drug that seems to have such positive benefits? Or were they equally guilty of clutching at straws?

Whatever the subsequent findings, the Concorde Trial has left a bitter taste in the mouths of many. And what have we been hearing recently? A new set of endorsements for the early Delta Trial results, a new call for positive people to be able to access combination therapy, and all this despite the trials going ahead without a control group. I am beginning to get that déjà vu feeling.

Many people might throw up their hands in horror and exclaim, "Drugs! haemophiliacs don't do drugs." But most haemophiliacs are used to regularly injecting themselves with factor VIII, a form of dependency which few of us like to acknowledge and with long-term side effects from which few of us have managed to escape. Some haemophiliacs have also been exposed to a vast range of recreational drugs including alcohol, cannabis, amphetamines, barbiturates, heroin, ecstasy etc. and this is alongside the prescription drugs such as the pain relievers, pethidine and DF118's, antibiotics such as Septrin and Fluconazole and anti-virals such as AZT, ddi, and ddc.

Whilst we neither endorse or condemn any of the drugs under discussion in this newsletter, we believe that drug use is an issue of common concern and that there is much to learn from people's individual experiences. We hope that we have presented these views in a rational and readable form and that the issues involved will encourage wider discussion amongst those who are concerned about the welfare of positive haemophiliacs, their families and friends.

## THALIDOMIDE DRUG "MADE IN WALES"

Following media reports over the last few months that the controversial drug, thalidomide, was being used in trials to treat HIV and AIDS related illnesses, Gwent drug company Penn Pharmaceutical, is to begin producing the drug for use by HIV sufferers in the United States. The Tredegar based firm is reported to have signed a major contract with US corporation Celgene, which could pave the way for a massive clinical trial involving tens of thousands of people using thalidomide. The agreement will make Penn the sole supplier of thalidomide to Celgene, which has gained approval for its project from the US Food and Drugs Administration, which controls the sale of medicines in the United States. Penn's managing director, Dr Roger Jones, said thalidomide had been found to help in preventing HIV sufferers developing full-blown AIDS. The drug is said to act as a suppressant to the production of cells in which the AIDS virus develops.

Thalidomide is also said to help ease the pain of sufferers of rheumatoid arthritis, leprosy and ulcers, but is perhaps best remembered for the terrible side-effects inflicted on the newly born infants of mothers who had taken the drug as a supposed treatment for the effects of morning sickness.

"We have been working with thalidomide for about nine years, we probably know more about it than its original manufacturers," said Dr Jones. "We have made it available in the United Kingdom to selected patients with conditions where it can be of help. The Americans want to learn what we have learned and under this agreement, bootleg thalidomide coming to the States from such countries as Brazil will be stopped. We will be the sole suppliers. HIV positive people in America are being advised to take thalidomide and if they want to they can get involved in a clinical trial. The FDA is planning to get every Aids patient in the States into an open clinical trial."

However, Dr Jones sounded a note of caution when he said, "We cannot just be euphoric about this deal, because of the suffering that has taken place previously, because of thalidomide." He added, "We have to think of the terrible suffering it has caused, but hopefully it can now be put to a positive use."

*"The really bad lot of it started when I had the money from the Trust, that was a bad patch, that's when I went right off the rails."*

The really bad lot of it started when I had the money from the Trust, that was a bad patch, that's when I went right off the rails. Through the week I could manage on small doses of heroin, like £10 bags here and there, and a lot of temazepams - sleeping tablets. There were tons of them where I live. At that time the doctors were giving them out like smarties. So I started injecting temazzies to get the same buzz, breaking it down with water over a flame. I used to buy the works from the chemist, the syringes and stuff for factor 8 was no good. You have to have 1ml syringes with the needle already attached to them, you buy the works in a pack of twelve from the chemist.

On the weekends, I'd spend a couple of hundred quid on heroin. Then again, if there was nobody about because somebody had been caught, or if they were laying low because somebody had died through it, there'd be nothing about. So I'd go on a bit of crack, freebased cocaine, cocaine that's been purified to get a 100% buzz. It's not morphine, but it's enough to get you going, it makes you feel like a superstar, you could take on the world then. HIV was nothing, nothing, that was the thing.

Through the week, I'd be sleeping most of the time, sleeping all the time, day and night taking sleeping tablets. By this time, its taking me 10 to 15 sleeping tablets to get off to sleep. At the weekend I'd get smashed out of my brains. Friday night would come on a Thursday afternoon and I go and pick up a couple of mates. We'd all be in my car and we'd go off, travelling about, picking up here, picking up there, seeing what we could score. If we couldn't score one place, we'd score at another. When you get involved you seem to score anywhere, it's like going up the shop to buy a paper, except you've got to go further. We'd stop in service stations on the way home and do it, sat there blown out of our brains. And when we got back, we'd go to somebody's house and we'd shoot up all night.

*"I wouldn't go up the hospital anymore, I wouldn't even go if I had a bleed. I'd just hope it would stop on its own, I was in a hell of a mess, that's why my knees are in a mess now. I just didn't want to go there. It's funny though, I didn't seem to have many bleeds at the time and if I did, I'd rest up, I'd be sleeping all day and when I finally woke up it would be alright."*

I wouldn't go up the hospital anymore, I wouldn't even go if I had a bleed. I'd just hope it would stop on its own, I was in a hell of a mess, that's why my knees are in a mess now. I just didn't want to go there. It's funny though, I didn't seem to have many bleeds at the time and if I did, I'd rest up, I'd be sleeping all day and when I finally woke up it would be alright.

When I did go up the hospital I was usually pissed up, drink, amphetamines, head gone, go in there, say I'd been in a fight or something. I might only have a scratch, but I'd say I wanted something more. I'd want painkillers and when they refused to give them, I started arguing, started aggro about it. I can't remember, it's just blanked out now, it's embarrassing to look back on it and think "Christ, how could I have been like that?" To even think of doing the things I done.

There was one night, I was living in a caravan then, nice place, bought it myself. I had it all comfortable, had a three piece and that. And one night, I thought, "Bollocks, I want to finish with it, finish with it all". I'd really had a guts full. I was on a methadone prescription then, from the CDT. I'd been out and then I'd had my own stuff, I also bought a load of tablets. I ended up taking a bottle of temazzies, I had a couple of joints and a chase of smack. It's funny, I usually injected it, but this time, on the silver paper, I had a chase of it. I remember falling asleep and waking up in the morning, about five o'clock, freezing cold, absolutely freezing cold, shivering like hell. I thought, I feel weird, really, really weird. Out of it, but not out of it like I'd always been in the past, as if I'd gone too far, too far and I couldn't get myself back together. I remember phoning up my mother and saying, I can't walk, I can't walk. I'd got no legs, as if somebody had cut my legs off.

She came over to the caravan and the ambulance had to break in to get me out 'cos it'd gone too far. I remember coming to the hospital and being up on the ward. Then I can't remember anything more, until the following week, when I woke up in intensive care. I'd nearly ended it, another 10 minutes I had left to live, they had to rush me into intensive care with oxygen on and everything. I was in intensive care for a couple of weeks, on life support for about a week I think. And I knew from the day when I woke up in intensive care, that I'd never go back to it, I knew. I been out of it ever since, I would never go back to it, never ever go back to it.

***The next issue of the "Birchgrove" newsletter - "Rock and Roll" will actually be on the theme of death and dying. We would be pleased to publish people's views, experiences and recollections. Please send any and all contributions to the address below.***

The views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group. The Birchgrove is a forum for discussion and seeks to encourage debate on the issues that affect people with haemophilia and HIV. We would encourage anyone who may have strong views regarding any of the items published in this newsletter to write to the Editor: "BIRCHGROVE" is published by:

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# THE BEST HOPE YET

Every time I visited my haemophilia centre I was always told, "You should consider starting on AZT, it's the best hope yet!" After each visit, I went home and thought it through. I always arrived at the same decision that it wasn't for me. But eventually, I gave in to the continual pressure that AZT was my only option. In fact, I had little choice but to take the treatment. On the 13th of February 1992, I finally said "Yes" to AZT. I was prescribed 1200mg daily, with an initial course of six weeks and told to come back for my next prescription when I had finished those.

At first, I didn't think that I had any problems at all. But very gradually my memory began to let me down. Trying to recall telephone numbers that I called regularly became almost impossible. If I wanted to ring someone, half way through looking up the number, I'd forget who it was that I wanted to call. Small things that we all take for granted, such as making a cup of tea, became impossible. I'd get to the kitchen and put the kettle on, then I'd go back to the living room, sit down, desperate for a cup of tea, but having totally forgotten that I had already put the kettle on. On more than one occasion, my girlfriend managed to stop me from burning the house down.

As time went on I became so lethargic and washed out that I no longer cared about my failing memory. While halfway through my second prescription of AZT, I caught a cold which wouldn't seem to clear up. So I found myself seeking help for my general ill-health. Luckily, I was seen by a doctor whose knowledge of HIV came from outside a haemophilia unit. He knew exactly which test to do before advising me to stop taking the AZT. He also asked me to come back the next day for a blood transfusion, because I had become so severely anaemic.

It was almost three months before I bothered to go back, and by this time there was a new consultant. He was more than happy with my T4 cell count which had improved dramatically since my last test. When I explained the problems that I'd had, and that I'd stopped taking AZT, he suddenly realised that my improved cell count was due to stopping the treatment, rather than a benefit of it.

Upon reassessing the situation the consultant felt that I was an ideal candidate for combination therapy, in this case AZT with ddi, with a smidgen of Seprin thrown in to keep PCP at bay. His suggestion left me fucking speechless! After all the trouble I'd had on AZT, there was no way that I'd even consider taking it again, especially not in combination with some other bloody wonder drug!

Marijuana has been used for thousands of years as a medicine. According to a recent report in *Nature*, ashes from a fourth century tomb near Jerusalem suggest that marijuana may have been used in ancient times as an inhalant aid in childbirth. As an herbal remedy, it is well documented in cultures as diverse as the Chinese pharmacopoeia of 2727 BC and 16th century BC Egypt.

In the 20th century marijuana has been used for a variety of indications, including controlling nausea, arresting glaucoma and spasticity, and increasing appetite. Other anecdotal evidence has shown marijuana to provide symptomatic relief of HIV-related agitation, appetite-loss, spasms, chronic pain, and depression.

Because marijuana, like most herbals, is a complex substance, many users of marijuana argue that the synthetic form (Marinol) is only marginally effective when compared with the smoked variety. Smoking marijuana provides its own dangers, however, because many PWA's suffer from poor lung function. Potential heat irritation or damage to sensitive lung tissue in persons with pulmonary problems can be ameliorated by use of a water pipe or use of herbal teas. Fungal and bacterial infestation (salmonella, for example) of mouldy herb can be easily dealt with by heat-treatment for one minute in a microwave oven. This is done by those who distribute marijuana to the PWA community through an informal network of ad hoc buyers' clubs.

Some 35 studies have been conducted on the effects of marijuana on the immune system. Based on these studies, the *Journal of Psychoactive Drugs* determined marijuana has no significant effect - negative or positive - on the immune system, cell mediated, or humoral immunity.

Because of its classification as a controlled substance, little research on the use of herbal marijuana has been done on PWA's. We do know from long experience that the substance is nontoxic and is active, since it is widely used to alleviate nausea caused by chemotherapy (such as AZT, ddI, ddC, and drugs used in the treatment of opportunistic infections). And it is commonly used for appetite increase from its widely-known property in recreational use of causing the "munchies."

# Portrait of a piss artist

Early in 1994 my centre director informed me that the non-A non-B Hepatitis virus had now been identified as Hepatitis C, and that it appeared to be active in my system. Initially this didn't mean a lot to me. I'd long been aware that I'd been exposed to various hepatitis viruses, none of which had apparently caused any lasting damage. But this one was different though, this time there was a payback.

The doctor explained, as best he could, the implications of the disease, detailing the various symptoms, long term prognosis and possible treatments. As I sat there, trying to take it all in - a mere 15% recovery rate from infection, the rest going on to develop a cocktail of chronic hepatitis, cirrhosis of the liver and liver cancer - something else he was saying gradually impinged itself on my consciousness. He was telling me that the best advice he had to offer in combating Hepatitis C was to cut down on, or give up entirely, the consumption of alcohol!

*You're sixteen and already well into your apprenticeship; maybe you can't do all the things your friends can do - soccer, rugby, cricket, boxing, whatever, you name it, you can't do it any longer - but by God you can drink with the best of them. It's a Saturday night and you're out on the town with your buddies. You get the first round in, lagers for everyone, it goes down well, and within minutes its someone else's turn to get them in. A couple of hours pass and you can feel that buzz of confidence and well-being; you belong here, in this environment, with these people; they accept you for who you are, even though they may not necessarily know what you are. They treat you as they do each other and it's that sense of belonging, of not being someone apart, that you begin to associate with alcohol. It is almost as if for those few hours, you undergo a transition from being a 'bleeder', to being a normal, healthy person. For that short period of time, all the physical and psychological problems that stem from your haemophilia, are erased, and you can drink, fight and fuck just as well (or as badly) as any of your peers. The consequences - joint or muscle bleeds, not to mention a sick head - seem almost inconsequential when compared to the few hours of relative freedom that booze permitted you to enjoy.*

No way! That was my first, instinctive reaction. Impossible. After all, drink had never done me any harm, I enjoyed it; it was so inextricably bound up with different aspects of my life, not only the social side. I saw the pleasure I took from drink as being a sort of resistance to, or unwillingness to compromise further to the pervasive influence that HIV had already had on my lifestyle. Having previously changed my diet, incorporated safer sex principles into my sexual relations, committed to a thrice weekly workout at the gym, made a conscious decision to avoid recreational drugs such as dope, speed and so on. I had come to

realise that a line would have to be drawn somewhere if I wanted to retain any sense of identity. And now I was being told - in effect - that if I wanted go on with the same level of health and well-being as I'd previously enjoyed, I would have to let go of something that seemed to be intrinsically bound up with that very identity. "Isn't there something, anything I can do?" I asked, clutching at straws.

*You're twenty-two and it's your wedding day. All your family and friends have turned up and you still feel the need to show them that you're in control, that it's you that makes the decisions that direct your life, and not some lousy genetic mutation. The ceremony over, the party begins. You tell everybody to eat, drink and be merry. You're the centre of attention; people listen to what you have to say, they laugh at your jokes, they wish you well for the future. It feels good to belong, to feel that you mean something to these people, that you have something to contribute.*

*Perhaps you might have a few regrets tomorrow, those knee joints are a little stiffer, but you didn't want to admit that you weren't quite the John Travolta you used to be. Maybe you've started to ask yourself just why it is you need booze to express yourself more freely, but hey, tomorrow you're off on honeymoon and this is no time to start getting introspective. Afterwards, everyone tells you what a great time they had, best piss-up they've ever been to, and everything they say goes to reinforce that latent connection between your sense of self-worth and alcohol.*

The "something else" turned out to be Alpha Interferon, and I was duly offered this as therapy whilst at the same time being informed of the rather hopeless statistic that only 10 - 25% of those who were Hep C positive but not HIV positive would have a long term response to therapy. The prognosis for those with both Hep C and HIV was even more depressing. Still, after listening to the possible side-effects, including flu-like symptoms, I decided to take the treatment for a six month period. Anything, even a subcutaneous injection into my belly three times a week, rather than cut down on my drinking.

*You're twenty-eight, working, mortgaged to the hilt and you have a two-year old child. Your wife works full-time and you only get to see each other in the evenings, by which time you're both too jaded to make the effort needed for meaningful communication. On top of this, you've been living with the knowledge of your HIV diagnosis for three years. Life is, as they say, a bitch. But nonetheless you get by. It is after all, a bit late to admit that maybe you can't cope, that just maybe things are getting on top of you. You've spent most of your relatively short life combating the effects of haemophilia, fighting the idea*

# I WAS TOLD NOT TO WORRY

BY MIKE DIBBLE

On the 2nd of May 1995 I was informed that I had recently been infused with a drug that had been exposed to a potentially fatal contaminant. This is the fourth fatal disease I have been infected with from Factor VIII concentrate.

I have never experienced a life-threatening bleed, and have used pooled factor concentrate on the advice of haemophilia centre doctors to reduce damage to my joints. Prior to 1975, when I had a serious joint bleed, my doctor administered cryoprecipitate, a blood product made from a small number (typically 5), of volunteer donors. Cryo was always effective for me, but it required my doctor to administer it and it made no profits for the blood industry. To the best of my knowledge, properly manufactured cryo has never been associated with the transmission of any disease.

In 1975, I was informed that I would be using a new "miracle" product to control bleeding. This was called concentrated Factor VIII, and was made available only through government-funded haemophilia treatment centres. Factor VIII was made by pooling large quantities of blood. Up to 100,000 units from paid donors went into a single vat, that was then fractionated and divided into individual doses. If any unit was contaminated with a virus, the entire batch would be contaminated. My family doctor told me that he thought the product was dangerous, but that the haemophilia centre doctors were specialists, and should be trusted.

The treatment centres called Factor VIII concentrate a "miracle cure" because patients could be trained to administer it themselves, whereas cryo had to be administered by a doctor. In the late 1970's, I developed hepatitis B, as did virtually everyone else who used the concentrate. Records show that researchers knew that thousands of haemophiliacs would eventually die as a result of hepatitis. The first I knew about this was when the treatment centre informed me that I had developed hepatitis B. I was told not to worry. Nobody mentioned that hepatitis B is frequently fatal; nobody mentioned that hepatitis B could be transmitted sexually.

In 1983, I was making a good living selling advertising by telephone. I read something in a newspaper about AIDS and haemophilia. I asked the treatment centre about it and was told not to worry, the chance of getting AIDS was less than one in a million.

In 1985, I tested positive for HIV. I was told not to worry. Exposure wouldn't mean that I would develop AIDS. I also recall being told that if I brought a suit against the manufacturers, they would be forced to stop making blood clotting products and I would be responsible for the deaths of many children.

By 1990, I had developed full-blown AIDS and was unable to work. Stress was causing a rapid decline in

my health so I bought a holiday home and moved to the mountains. The stress-free lifestyle, mountain air, and herbs stopped the decline in my health, and by 1994, I felt healthier than I had in years. But my blood tests now showed that I had picked up hepatitis C from my Factor VIII concentrate. I was told not to worry. Nobody mentioned that hepatitis C is frequently fatal; nobody mentioned that hepatitis C could be transmitted sexually.

On the 12th of September 1994 the Institute of Medicine held public testimonies in Washington. It was here that I first met some of the mothers and children affected by the blood industry. I had coffee with two women who had haemophiliac children. Both of them had trusted their doctors and felt that they had injected poison into their own babies. One of them no longer had a son, the other had a 14 year old with her, a really nice kid. Although he looked healthy, his mother told me he had almost died a few months earlier, and he had a current T-4 count of one. I found out that his family had been having difficult financial times and had recently been evicted.

When they were leaving, I heard the boy ask his mother if he could stop at MacDonald's for a burger on the way home. When she told him no, that they didn't have enough money, he didn't complain. I had the opportunity to talk to him several times, and not once did he utter a complaint. Here was a young man whose body had been turned into a toxic waste dump, who was dying, who knew that to ever love a woman could be to kill her, and who couldn't even afford a burger. And he never once complained.

I talked to a man who was trying to take care of his small children alone, while dying from AIDS. He had mild haemophilia and had used concentrate once on the advice of his doctor as a "safety precaution". By the time his centre had informed him of the danger, he had already infected his young wife with AIDS and she had died.

I met a woman from Japan who had infected her son with AIDS, as thousands of American women had already done. She demonstrated to me that the contaminated medicine that she had infected her son with was a product that had already been recalled in the United States. The government allowed the blood industry to take hundreds of millions of dollars worth of contaminated products and sell them to Japan and Costa Rica.



BY GARETH JAMES, HEAL TRUST

An overview of the last millennium teaches us that truths and realities about science and medicine have never been fixed or set. As inhabitants of the late twentieth century we now have sufficient historical 'memory' to appreciate that what we believe to be 'reality' during any given era, is neither absolute nor enduring. Our hi-tech world lends immense credibility to the authoritarian voices of our medical profession.

But, however highly skilled we have become at convincing ourselves we are nearing an end point of knowledge, history still predicts that our contemporary medical obsessions will, in time, pass away and join the likes of leeches, daily blood letting and the crude mercury misadventures of centuries gone by. We will move on again.

Already, we can have little doubt that in the virtual-virology world of AIDS, the realities of HIV infection are becoming evermore negotiable. Relentless research efforts, with a clear agenda to pin everything on HIV, have repeatedly failed to bring us to any point of certainty. AIDS has not only seriously called into question the one microbe - one disease - one cure, twentieth century medical ideal, but it has also caused us to question the very ways in which we have chosen to interpret health and the disease process.

In the present day, our experience of reality relies upon, and has developed alongside, language. Even our ability to think is dependent upon the use of language and words in our own minds. As is well illustrated in 'AIDS and its Metaphors' by Susan Sontag, the use of military terminology in the understanding of disease has persuasively shaped and moulded our entire belief systems surrounding health and germs. We now speak of disease with exactly the same language that we use to describe military manoeuvres and political paranoia. This use of language creates and forms our realities.

We speak readily of 'the war on AIDS'. Modern medicine has conditioned us to view the body as the 'battlefield'. Germs are the 'enemy' which 'invade' us and against which we have to mount 'defence' strategies. We are encouraged to hand over responsibility for our well-being to the 'military intelligence' of our medical doctors who 'attack' our disease symptoms with the aggressive 'weaponry' of pharmaceuticals. We even credit microbes with the same human attributes of intention and cunning as we would any national enemy.

Since the birth of the germ-theory, disease has become named in accordance with the microbes found to be involved in the manifestations of symptoms. The upshot of naming diseases in terms of microbes means we have 'actualised' the processes of

disease to the point where we imagine it to be a tangible entity, a 'thing' that we 'get' or 'have'. For example we say that he or she has 'got' cancer, 'caught' a cold or 'has' AIDS - they are all thought of as objects or nouns. The phrase 'he has AIDS' immediately implies that the complaint is external to the person, the person is removed from being involved in the complaint and that the person has been standardised within this system of disease names. However, diseases are not nouns - they are closer to being verbs. Diseases are processes that we do, rather than being things we get. In this sense, it would be more accurate to say that he or she is cancering, colding or AIDSing.

Modern medicine has also succeeded in separating us out into little bits and pieces, limbs, organs, connective tissues, the nervous system, the blood stream etc. Applying the dissection of the body to the manifestations of dis-ease, however, relies heavily on the bizarre assumption that parts of the human body operate independently within our constitution. Modern medicine has also teased apart the mental and emotional spheres of the person from the body and recognises no role for these influences in the development of illness.

Earlier this year, a joint report published by the Royal College of Physicians and The Royal College of Psychiatrists, claimed that a staggering 50% of all illness may have its roots in anxiety and stress. There is now no shortage of studies confirming stress and other psychological influences to have a major role in predicting the outcome of microbial disease. The implications for a positive HIV-antibody test result become self evident. Any medical model which fails to take these factors into account will be fundamentally flawed.

How we choose to treat disease is entirely dependent on the ways in which we decide to interpret it - one stems from the other. In the late 1700's, a German physician called Samuel Hahnemann developed the notion that there may be two ways of treating illness dependent upon this choice. The first is the way of 'opposites' or heteropathy this has now evolved to become orthodox Western medicine. By its very nature orthodoxy distrusts the body's reactions during disease and believes symptoms to be unintentional, purposeless expressions of microbial attack, that signify nothing more than an alien invasion. It prescribes drugs designed to prevent the symptoms expression in the body.

The second way of interpreting disease is the way of 'similars' or homeopathy. This model views the body as the finely tuned end product of millions of years of

Dear Editor,

Many congratulations on your fine publication. I refer of course to the Birchgrove Newsletter no. 7 the issue about Sex. My own feelings about this topic are many, varied and complex, and I believe that you've thrashed out the subject in a fine and scintillating manner without resorting to such titillation as one finds in other, less savoury publications which shall remain nameless - publications such as "Pussy Galore, "Furred Escort", "Rhina Plasticine," and "Trunk Male". Not that I have ever seen such magazines; God forbid.

I found all the articles by turning the pages, they were quite interesting but the photos were too blurred and obscured for my taste. I see the necessity for making them 'artistic', but as they were primarily of a medical nature, I would have thought that in the interest of enlightenment, you could have made them more explicit.

Cybersex sounds like a great idea. Does one have to be on the internet to participate? Or is there a number one can ring? We should have more articles of this sort. I would try sperm washing but I am not sure which brand of washing powder to use? The biological ones all seemed to neutralise the sperm and hanging the little bleeders out on the line sounds like murder.

Keep up the good work and let's have more issues like this, full of controversy and sticking it up Johnny Foreigner.

Jarvis Stewart

Dear Editor,

It was with profound shock and disgust that I scrutinised the Birchgrove Newsletter No.7 "The Sex Issue." Having once been a keen supporter of the aims and work of Birchgrove in the past, with particular regard to its work with children, I must say that I found the contents and tone of issue 7 particularly disturbing. It is unsurprising that many of the so-called articles remained anonymous, and is indicative of the lack of courage of both the authors and you the editor, that you would not put your names to such depraved rubbish.

Never in all my born days have I had to read through a once respected journal, only to find myself knee deep in verbal dung. Do you not realise that children may read this publication? Must they really be subjected to stories about sex with our bovine friends? And what about masturbation? Yes, yes, I'm aware that in your schoolboy minds, the term 'hand jobs' might seem hilarious, but to most responsible adults, it marks a sad preoccupation with the seedier side of a sacred act.

What makes you think that HIV positive haemophiliacs need a 'spiced-up' sex life? Most haemophiliacs I know take a responsible attitude towards sex and practice abstinence in the privacy of their own homes. If more HIV positive people took this line, then we'd all have less to worry about.

The "Birchgrove" has in the past, always followed a sound editorial line, but I detect a change in editorial policy, it has become clear to me that smut, innuendo and provocation have been embraced and manhandled onto the agenda. Why

weren't we, your subscribers, consulted about this? Articles about members splitting during copulation, oral sex, and the condom survey, were all in extremely bad taste. The woman who wanted to leave her husband when she found out he was HIV positive should receive every encouragement as she obviously deserves the chance to make a new life for herself with someone more worthwhile.

If I encounter future articles promoting an immoral lifestyle, I shall have no choice but to cancel my subscription. We, as parents of haemophiliac children have a duty to protect the little darlings.

Mrs P H Jones

Dear Editor,

I was interested to read your recent coverage of the opinion that HIV does not cause AIDS, and the resulting letters. However, I take exception to Garry Davies' suggestion that my reports on the use of co-trimoxazole (Septrin) in NAM's newsletter "AIDS Treatment Update" have been "over-enthusiastic".

"AIDS Treatment Update" aims to present full and balanced information, the accuracy of which is checked by our Medical Advisory Panel. The potential for allergic side-effects to Septrin has been properly reported; indeed, last summer I devoted a front-page article to strategies for overcoming toxicities. The restrictions recently placed on the use of Septrin, which do not apply to its use in treating and preventing HIV-related infections, were also fully reported in "AIDS Treatment Update" last August.

The fact remains that Septrin has been proven highly effective in preventing PCP pneumonia and is associated with longer survival. The choice not to take Septrin can itself have potentially life-threatening consequences, in the form of avoidable cases of PCP.

Perhaps, I could also take this opportunity to mention that "AIDS Treatment Update" is available free of charge to people affected by HIV each month, simply by sending us your name and address.

EDWARD KING

Editor, AIDS Treatment Update

Dear Editor,

Well, bloody, done to you all at Birchgrove, for having the balls to print an entire newsletter on the subject of Sex! Safer sex for the positive person is something that often tends to get overlooked when safe sex literature is produced. Prevention at source, surely makes sense. And the more information and openness that can be brought to bear the better.

Sex doesn't stop just because your HIV positive, but it does take on a different role within a relationship. When you are a HIV positive person you need to carefully consider the effects that unsafe sex could have on your life. The importance of readable and honest information on safer sex for positive



PORTRAIT OF A PISS ARTIST continues...

*"after a while you learn that if you drink enough you can obliterate a whole lot of the pain and a whole lot of the fear"*

that you're a special case, that you need looking after. You've decided how you live and how you take care of your health and that has always been a source of pride. But that HIV diagnosis, that was a real set back. You needed to draw on every resource, every bit of strength you had. It's not always easy fighting the good fight, putting on a brave face, but down the years you always knew you could rely on your old friend, the booze, to help you pull through. Lately though, the way things have been going, the way you've been feeling, all you really want to do is forget. And after a while you learn that if you drink enough, and keep drinking enough, you can obliterate a whole lot of the pain and a whole lot of the fear. You sought nirvana but you'll settle for oblivion.

So I took the interferon and the initial results looked promising. At the same time I did make a vague commitment to cutting down on my alcohol intake, mainly to placate the doctor and my wife. After six months my liver function tests seemed to have returned to normal, but there was no guarantee that it would stay that way after the cessation of treatment. And neither could the doctor say for certain that it was the interferon regime which had brought about the improvement.

A large part of that positive response, he said, might be due to my cutting down on alcohol. In truth, I didn't see it that way, after an initial lowering of my weekly intake, after about three months, I was drinking almost as much as I ever had. The question is, why? Why, given that I had found out as much as I could about the disease, and that every piece of information I came across had spoke of the incompatibility of Hep C and alcohol, why, given my awareness of the long term consequences, did I continue to subject my liver to such systematic and suicidal abuse?

You're thirty-four. You're still surviving, after a fashion, despite having been told you have liver damage due to Hepatitis C infection. Some things in your life have settled into what might be called a pattern of normality. Your relationship with your wife is better than it has been for a long time, and so too with your child. Somewhere along the way, you've attained a level of insight into the way you function as a human being; you've allowed a little honesty to infect the way you look at and respond to the world. You realise now that your friendship with alcohol may be a double-edged sword. Much as it may have given a bolster to your confidence, much as it may have provided a fillip to your social life, and as much as it may have helped you get through some difficult times, there is much that you have lost along the way.

Were you really the guy laying in his own puke at someone's party because you had to go over the top to get people to accept you? Did their acceptance

really matter that much to you? After all, if they were ever going to be real friends they would have accepted you whether or not you were the life and soul of the party. Were you really that weak that you needed an alcohol crutch to get you through the last twenty years?

What surprises me is that my case is not atypical of haemophiliacs. In fact, there are quite a significant number of people out there whose experiences with alcohol are remarkably similar to my own. What does this mean, or what does it prove, if anything? Well, first of all it doesn't prove that if you drink a lot of alcohol over a long period of time, you'll do anything to fight off either Hep C and HIV. Too many people - both drinkers and abstainers - have died along the way. Nor does it mean that alcohol makes no difference either way. The medical evidence is clear that alcohol misuse, whether or not you're carrying a viral load, is definitely bad for you.

Perhaps many of us are relying on alcohol as a means of forgetting the reality of our situation, but somehow, I don't think that's the whole picture. Throughout a lifetime of striving to be as good as the next man, or no different to him anyhow, alcohol is just one tool some of us have employed to shield ourselves from the blurring of our identities, to allow us to blunder through the question of who we really are.

*You have attained this insight, and still you drink what you know is too much for your system. Sometimes, in the privacy of your own thoughts, you ask yourself, what lies behind this? Do I have a self-destructive urge, or do I see myself as invulnerable? Maybe even immortal? Or maybe just fucking stupid? It's late in 1995 and I'm still surviving. Maybe this is some sort of achievement, but I don't feel that it's a big deal. I'm still drinking, and though I drink less now than I used to do, that's as much to do with the fact that I can't physically cope with the alcohol, as it is with conscious choice.*

In my own case, I've spent so long constructing personalities that are not so much me, as representations of who I really am. Take away the scaffolding - the "hale to you me hearty," the bluff, the bonhomie, the bullshit, the piss-taking, and most of all, the booze which for a long time has fuelled it - and what's left behind is...? I don't really know. And that scares me. And that, I suspect, lies at the heart of why I continue to drink. It's not just the enjoyment of drinking, though that is a large part of it, or a defiant laughing in the face of death, but the fear of what might be left behind when all the alcoholic artifice has been drained away.

*"the question is, why? why did I continue to subject my liver to such systematic and suicidal abuse?"*

# SMOKING TO LIVE

*The following is extracted from a report entitled, Smoking to Live, which was first broadcast on CBS News as part of "The 60 Minutes Show."*

Marijuana is not good for you. It's an axiom. But for some people, marijuana could be the difference between life and death. That's what they and their doctors say. The doctors prescribe it and the patients smoke it to live. There are among only 14 people in the United States who have had it prescribed by their doctors. For Ken and Barbara Jenks, marijuana is but one more of the myriad of prescription drugs they must take every day.

I asked them how often do you smoke marijuana? "We usually smoke - well, I usually smoke at least three to four joints a day." And what would happen to you physically, both of you, if you went for a couple of days without smoking marijuana? I asked. "We'd throw up all the time." said Ken, "I would get sick to my stomach, I mean, I can't face eating food - and if you don't eat you get sick, and then you can't take your medicine, its a constant battle to maintain weight - and then I'd start losing weight again." "Having AIDS is like a wasting syndrome, with the virus and everything. The smell of food, just even thinking about food can make you feel nauseated." said Barbara.

Ken and Barbara Jenks are dying. He is a haemophiliac. Eleven years ago, he was given blood contaminated by the AIDS virus. He unknowingly infected his wife. They are both too ill to work. They live on disability, barely able to cope. Without the marijuana, they would probably be dead, or they would have wasted away because of the nausea brought on by their chemotherapy. Before they got marijuana legally, they bought it on the street, or grew it, until last year, when police burst into their home in Panama City, Florida, and got the goods on them: two marijuana plants. "And then they started going through my house, I mean, just dumping drawers and tearing the cabinets up." said Barbara.

The police thought they were onto something big when they found a suitcase filled with syringes and other drug paraphernalia. Ken tried to convince them that the syringes and the pills were prescribed by doctors. He didn't tell them that marijuana was the only medicine that enabled them to take the chemotherapy without being violently ill. "You're talking to somebody that never wanted to take an aspirin for a headache. It's a relief to know that there's something that you can take to relieve the nausea from all the medications that you're on," says Barbara. The Jenks were charged with growing marijuana and possession of drug paraphernalia. In court, their lawyer, John Daniel, tried to prove that for the Jenks, marijuana was a medical necessity.

asked. "None whatsoever, in fact, they even stipulated that in Kenny and Barbara's case it was beneficial for them and that they would die without it," said John Daniel. "But you lost the case because you couldn't prove medical necessity, that doesn't fit somehow?"

"The Judge said there is no such doctrine as medical necessity in Florida, that it's a matter for the legislature to promulgate a statute that says that it is or is not." But the judge was not an unsympathetic judge? "He was a super judge. The sweetest sentence I've had in 20 years of criminal defence work." The judge found them guilty, but sentenced them to 500 hours of community service. Their only task? To look after each other. As decent as the sentence was, the Jenks were outraged that they were still considered criminals. They decided to appeal.

"Kenny and Barbara said, 'Go for it. we're going to be gone soon. There's going to be people following in our footprints and in our pain and suffering, and there needs to be some law made one way or the other on it.' That's why they took it up on appeal". "Why? They're not exactly the wealthiest clients in the world." "No their not, but I'm not exactly charging them, sir."

The Drug Enforcement Agency classifies marijuana as a highly dangerous drug, in the same class as heroin and LSD. And the only way to get it legally is to face a bureaucratic jungle. Applications have to go through the DEA, the Food and Drugs Administration and the National Institute of Drug Abuse. If all approve, the legal marijuana, grown on a government farm in Mississippi, is sent to the patient's pharmacist, a month's supply of cigarettes at a time.

Only 14 people are now able to get marijuana legally from the government. It took Ken and Barbara Jenks almost nine months to get their first prescription. Many doctors are reluctant to make the effort, fearing that the ramifications of even applying for marijuana will affect their reputations. Three years ago, the DEA's administrative law judge, Francis Young, wrote of marijuana, "In light of the evidence, it would be unreasonable, arbitrary and capricious to stand between those sufferers and the benefits of this substance." But the DEA rejected its own judge's opinion and stands firm that doctors shall not prescribe marijuana.

Except, of course, for those few who are willing to go through the agonisingly long process of applying. Desperate patients say they would rather live by buying marijuana illegally than die by playing by the rules. Dr. Ivan Silverberg hears that all the time from his cancer patients in San Francisco. "I have yet to hear of a patient who can't find it. I have heard loud and clear from patients who resent having to go on the street when they're feeling sick, when they're

nauseated, when they've lost 40 and 50, 60 pounds, to try and buy a drug from somebody without knowing whether that drug is adulterated because it comes off the street, of having to face the possibility that the person they're buying it from is an undercover policeman. I think all these things are wrong."

But Silverberg says if he had to fill out that mountain of paperwork every time a patient needed marijuana, he wouldn't have time to treat his patients. "Why has the DEA dug its heels in on this and will not allow the general prescribing of marijuana when you can prescribe much more dangerous, much more habit-forming drugs?" "You're absolutely correct. I think morphine, for example, Demerol, are far more hazardous drugs, in my opinion, than marijuana. I think part of it is an entrenched bureaucracy that doesn't want to admit it's wrong." says Dr. Silverberg.

If marijuana is as effective as the Doctors say it is, why haven't the drug companies tried to get government approval for it? "You can't patent marijuana, it's a plant. They can't make any money. No way. You see, in our country, the way drugs come into being, a drug company gets hold of a chemical, somebody discovered it has some sort of effect, they review it, they decide is it worth trying to do it. They have to invest 100's of million to get it from chemical to drug on the shelf. But then they get an exclusive patent for 17 years, and they can earn a lot of money. How could they possibly do this with cannabis?"

For Ken and Barbara Jenks, marijuana has made their troubled lives tolerable. "Do we look like a junkies?" asks Ken, "I wish we didn't have to take the medication that we're on, I wish we didn't even have to smoke marijuana." "Yeah. It'd be nice to be to be free of drugs and disease, but we're not. I mean, we need drugs. I can't help that. I've been taking drugs my whole life, and it hasn't made a junkie out of me."

"Do you ever agonise over, 'Why me? Why us?'" "At first, at first we did." said Ken "But then it was easier. I mean, I've been dealing with disease since I was six months old, so it was just like fuel to the fire. It was just one more thing." Barbara said, "He blamed himself because I had gotten the virus, and I don't blame him, because he - you know, I love him, he's my husband." "You know, these are the cards you got dealt, you've just got to play 'em or fold."

The Jenks eventually won their appeal and their criminal convictions were overturned. The Public Health Service is not accepting any new applications into the program for marijuana prescriptions and it's considering closing it down entirely, regardless of what patients say.

On the 2nd of May 1995, I was informed that the blood product that I had received a year earlier was recalled because of the contamination with Cruetzfeldt-Jacob disease. CJD is a (formerly) rare disease caused by something called a prion. There is no blood test for CJD, and it can only be diagnosed by an autopsy. I was told not to worry.

In the blood industry, it is a maxim that the larger the product pools, the larger the profits. A single commercial donor who died of CJD in 1994 has put anyone who used pooled blood products after 1954 (yes, 1954) at risk. These products include Immune globulin, Prolastin, Albumin, PPS, NSA, Factor VIII, Factor IX, and other products. The prognosis for Cruetzfeldt-Jacob disease is no visible symptoms for up to forty years, followed by dementia and death.

The blood product authorities are notifying people who may have fresh, contaminated products in their possession, but are refusing to notify those who have already used contaminated products. They maintain that there is no proof that Cruetzfeldt-Jacob disease is transmitted through blood products.

The New England Journal of Medicine states that it "has been shown experimentally to be present in blood", and clearly states that "blood or cerebral fluid must be considered as potential sources of infection". If the experience of 10,000 haemophiliacs is repeated, tens of thousands of Haemophiliacs will die horrible deaths without compensation or even assistance from the industry responsible.

This year, the blood industry will collect about 2.5 billion dollars. Since the military developed the technology to remove hepatitis from albumin in 1950, the blood industry has taken in something like 100 billion dollars. Where has that money gone? It has gone into the pockets of the government blood regulators, into Haemophilia Federation pockets, into the pockets of lobbyists and lawyers. It has gone into the pockets of the most disease riddled segments of society in exchange for their blood. It has gone into the pockets of enormous multi-national corporations who collectively make many times 2.5 billion per year.

If you believe that the tens of thousands of victims of the blood industry should receive justice, demand that a real, "follow the money," investigation of the entire industry be instigated. This is the only way that the full story will ever be revealed. I said recently that another medical disaster was imminent; I now believe that another medical disaster has already occurred.

*"You can't patent marijuana, it's a plant. They can't make any money. No way."*

*"You know, these are the cards you got dealt, you've just got to play 'em or fold."*

BY LARK LANDS, PH.D.

Many people with HIV/AIDS use vitamins, minerals and other nutritional supplements to try to improve or maintain their health. This article discusses many nutrients and suggested doses. Supplements can interact with each other and should be taken carefully.

As with all therapeutic interventions, it is important to discuss supplementation with a knowledgeable clinician or with any other doctor that you see. Vitamins and minerals cannot work alone. A good, healthy diet is essential. Don't spend limited funds on nutrients at the expense of quality food.

The following list includes the nutrients that should probably be taken by virtually all those living with HIV infection, regardless of disease stage. The list is based on the nutrients that have most often been found to be deficient, even in early stages when CD4 counts are still high. It is believed that deficiencies of these nutrients may create significant immune dysfunction, contributing greatly to the overall immune system decline.

Dozens of studies presented at the 7th, 8th and 9th International Conferences on AIDS emphasised the importance of nutrients for people living with HIV. A number of those studies reported that many deficiencies begin when CD4 counts are still high and result in significant immune dysfunction. Multiple nutritional abnormalities occur relatively early in the course of HIV infection and appear to facilitate disease progression. Researchers also reported that to reach adequate blood levels of the nutrients required consumption of 6-25 times (!!!) of the RDA (recommended daily allowance) for the nutrients most often found to be deficient (B2, B6, B12, A, C, and E), and even at these levels some people still fell short! This obviously makes the recommendations made by some dieticians and physicians for only consuming RDA levels utterly, hopelessly, dangerously inadequate. Research has also clearly showed that even at these dosage levels there was absolutely no evidence of toxicity, a clear contradiction to the absurd warnings of toxicity so often issued by those same badly informed dieticians.

Following the core list is a listing, by symptom, of the nutrient deficiencies that may be at least a partial cause of certain symptoms commonly seen in those living with HIV. Replenishment of these nutrients can often eliminate symptoms.

Two cautions are in order. First, it is critical to remember that many of these symptoms can also be caused by infection or drug side effects. All symptoms should be discussed with your doctor and careful consideration should be given to other causes; only when they have been ruled out should you consider particular nutrient deficiencies as a possible cause of a given symptom. Second, please remember that any supplementation aimed at specific symptoms must be

in the context of a complete nutritional approach that provides resupply of all missing nutrients for the best effect. Nutrients seldom work singly in the body. Rather, they work as a package that only in whole affects total body changes such as immunological improvement and symptom elimination.

## CORE LIST OF NUTRIENTS

**Multiple vitamin/mineral:** a bioavailable, hypoallergenic multiple using advanced forms of minerals (citrates, picolinates, ascorbates, etc.) and B vitamins (e.g. B6 in the form of pyridoxal phosphate rather than pyridoxine) for the best absorption/metabolism; take with 3 meals/day.

**Antioxidant formula:** one with multiple antioxidants such as beta carotene, selenium, tocopherol (vitamin E), glutathione, etc.; one with each meal; HIV infection yields high levels of free radicals and oxidative damage which antioxidants counter; critical to address autoimmune component of HIV infection. *(therapeutic range for selenium is 400-800 mcg/day; more than 1000 mcg from all sources can be toxic; check totals).*

**Acidophilus:** ½-½ teaspoon or 2-4 capsules before each meal. Naturally occurring intestinal microorganisms aid digestion in persons with HIV, particularly those on antibiotics, or those with candida problems. Supplements containing acidophilus can help to prevent candida overgrowth, digestive tract damage and malfunction, and diarrhoea. The good bacteria directly attack yeast and produce chemicals such as lactic acid which suppress its growth; it may also help to prevent infections like MAC, cryptosporidiosis or CMV from taking hold in the intestines.

**Ascorbic acid/Vitamin C:** 6-20g (6000-20,000 mg) /day with meals; very important as antioxidant, antiviral, antibacterial, antifungal, anti-inflammatory. It is generally non-toxic; amounts beyond tissue saturation level can cause diarrhoea. *(Can cause urinary oxalate stone formation in a very small percentage of people; no other toxicities are known although myths - either disproven or unfounded - abound).*

**Beta Carotene:** 50,000-200,000 IU/ day; powerful antioxidant; critical to thymus; research has shown CD4 increases at 100,000 IU/ day. It is non-toxic even in large amounts. *(Vitamin A, however, can be toxic at more than 25,000 IU/day, long-term.)*

**Coenzyme Q10:** 30-300 mg/day; critical for immune function/heart muscle/periodontal health; levels decline as HIV progresses.

**Vitamin E:** 200-400 IU/day; critical antioxidant; important if on AZT to prevent bone marrow suppression (multiple and antioxidant formula will contain E; check totals). (*Doses above 400 IU/day of vitamin E can interfere with clotting. Haemophiliacs should discuss the use of this vitamin with their doctor.*)

**Essential fatty acids/EFAs:** omega-6 fatty acids such as gamma linoleic acid (GLA is found in evening primrose/borage/black currant/grape seed oil; 240-1440 mg/day) and omega-3 fatty acids such as EPA & DHA (Max EPA: 300-600 mg/day); can cause skin problems/fatigue/immune dysfunction.

**NAC** (1800-9600 mg/day) and **glutathione** (450-1500 mg): powerful antioxidant; critical to immune function; levels decline as HIV progresses.

**Zinc:** 25-50 mg/day in bioavailable form such as citrate or picolinate; deficiency common and can cause skin problems, taste/smell disorders. (*multiple vitamin may have enough zinc; toxicity is possible at more than 100 mg/day long term but only likely at very high levels; long-term use should be balanced with copper 2-4 mg/day taken at different meal than zinc.*)

#### SYMPTOM RELIEF

Nutrient supplementation can significantly affect symptomatology, often eliminating many symptoms such as the following (nutrients that may help eliminate that symptom are listed in italics).

**FATIGUE** *B12, EFAs, C, E, magnesium, chromium, coenzyme Q10.*

**SKIN PROBLEMS** *Zinc, EFAs, vitamin A, beta carotene, B6.*

**WEIGHT LOSS** *enteral and parenteral formulas, multiple nutrients.*

**LOSS OF SMELL OR TASTE** *Zinc, EFAs, potassium.*

**LOSS OF APPETITE** *Zinc, multiple nutrients.*

**COGNITIVE DYSFUNCTION** - memory loss or loss of ability to concentrate *B12.*

**SOME NERVE PAIN** *biotin, B12, choline, inositol, thiamine, B6.*

**DEPRESSION/ANXIETY** *B12, B6, zinc.*

**MUSCLE CRAMPS** *Magnesium, calcium, Vitamin E.*

All additions to your program should be made in consultation with a licensed health care practitioner qualified to monitor your progress.

#### DUESBERG'S TEN QUESTIONS

1. Why is immunodeficiency in haemophiliacs directly proportional to their lifetime dosage of commercial factor VIII (over 99% foreign proteins) received - irrespective of their antibodies against HIV?
2. Why are only antibodies against HIV, rather than HIV itself, found in haemophiliac AIDS patients?
3. Why should a virus that, like HIV, replicates so prolifically take up to 10 years to cause AIDS?
4. Why have so few wives of HIV-positive haemophiliacs contracted sexually transmitted, viral AIDS in over 10 years?
5. Why has the median life expectancy of American haemophiliacs increased from 11 years in 1972 to 27 years in 1987, a period during which 75% of them became infected by HIV?
6. Why has mortality in American and now British HIV positive haemophiliacs started to increase ten-fold right after cytotoxic DNA chain terminators such as zidovudine and other toxic anti-HIV drugs became standard treatment in the USA and the UK, in 1987?
7. Why is the mortality of zidovudine-treated, HIV-positive haemophiliacs 2-4 times higher and their risk of AIDS 4-5 times higher than that of untreated HIV-positive controls, according to a Lancet report?
8. Why is the mortality of Darby's UK HIV-positive haemophiliacs only 0.8% before 1987 - the equivalent of a biblical lifetime of 125 (100/0.8) years?
9. Why do haemophiliacs almost only develop pneumonia and candidosis from a virus said to cause Kaposi's sarcoma and dementia in homosexuals?
10. Why do the T-cells of HIV-positive haemophiliacs increase up to 30% in 2-3 years, if they are treated with purified factor VIII, and not with zidovudine - despite the presence of the hypothetical T-cell killer HIV?

BY OUR DRUGGED CORRESPONDENT

So you've got HIV and HCV, and you want to make a choice about which drugs to take bearing in mind how they might affect your immune system and your liver. Well, to start with, even Paracetamol is a problem for your liver to break down, and the problems (or side effects) of AZT, Septrin, Pentamidine etc. have resulted in whole rainforests being used up to write newsletters, manuals and books. But what about proper drugs? The ones that may not do you any good, but are much more fun to take.

Alcohol is considered a real bad thing for the liver, and not so good for the immune system either. But bearing in mind how many haemophiliacs are not dead yet, but drink far more than is wise, it surely can't be that fatal. There is actually tons of stuff on how bad alcohol is for you and a few articles saying that it is good for you - preventing furry arteries, etc. As usual the recommendations are geared up for a boring life, no binges, and two alcohol free days a week. So restrict binges to only five days a week!!

Smoking has also filled books and magazines with descriptions of how it kills you, along with a few glossy brochures from tobacco companies saying it is totally non-addictive and completely harmless. Caffeine I refuse to look at as I'm an obsessive coffee drinker and chocolate eater!

Some recreational drugs have had surprisingly few studies done on how they affect your system. No one, it seems, has looked to see how acid or angel dust affects the immune system. What an appalling oversight! Most of the studies have looked at heroin and methadone and a few at amphetamines. Many of them are conducted by researchers or doctors and consequently are badly run, unscientific and with the most obvious reason for the results ignored or not thought of. Often the lifestyle of participants is ignored. If you have to get up at 3am to go burgling and then spend a couple of hours trying to find some heroin at the right price it can be a bit stressful.

Also, its not a widely known fact that most heroin in Britain is crap. There can be less than 2% of pure heroin in an ounce and a variety of other substances like bleach are used to pad it out. In some places its so bad you can't even smoke it. Sometimes it's cut with strychnine to help those suffering from drink problems. Another problem, is that the users studied take methadone and tend to be in touch with hospitals or doctors and so may have easier access to other medical services when they get an abscess or an alien trying to burst out of their stomach.

There appears to be no conclusive proof about whether heroin adversely affects the immune system and some studies I have read seem to suggest that it boosted some parts of the immune system. In other words taken in moderation, its probably less harmful

to you than Septrin. The side effects are a lot better too, although both make you vomit the first time.

And with amphetamines, again no clear picture emerges of how good or bad it is for your immune system and no study seemed to find it boosting immune responses, shame eh. However, staying up all weekend, dancing for hours and hours, and running up hills at 4am as a friend of mine used to do, it probably does knacker your system, regardless whether you've taken some speed. Generally, it makes your heart beat faster and makes you feel energetic and if you don't kill yourself being athletic, the actual drug is unlikely to lower your T-4 count! Purity is much more variable for speed because you can make it at home with a chemistry set. Warning: Do not contact a chemical company and buy all the ingredients as they will inform the police, after you've paid for them of course.

Cannabis also has little proof either way. One study looked at a group that used it in a weekly religious ceremony and found few reported health problems, although that just might be because they were to stoned to bother going to the doctors. There are some suggestions that it may increase your risk of throat cancer even when smoked without tobacco. Other studies have suggested it may be good for multiple sclerosis, HIV and even arthritis. Bound to be better for you than non-steroidal painkillers, and it encourages you to eat as a bonus. If anyone is conducting a trial on its effects on arthritis I am more than willing to risk a marginal increase in my risk of throat cancer to get stoned every day. I mean, of course, to enjoy the benefits of pain free winters.

Sleeping pills obviously have no problems for HIV positive people or doctors wouldn't hand them out like smarties, or would they...

As for sniffing Butane, glue, petrol, "Pledge", etc.; remember not to smoke while your doing it and if you are over 15, grow up and start doing something more adult, like drinking babysham.

In short, everything in moderation and remember that, after a good time comes a bad time, or a hangover. Most drugs give hangovers and if you get pissed three nights in a row the resulting hangovers can feel three times as bad. So it is with most drugs. Have fun and remember this article in no way encourages you to take drugs or risk life and limb sniffing marker pens.

*Our anonymous contributor is currently a drugs worker who has haemophilia and all the usual viruses.*

## THE MILITARY MODEL continues

*"Homeopathy defines health as the ability to constantly adjust to changes within ourselves and our environment"*

evolution and credits the constitution with intelligence and knowledge far exceeding our own modish scientific trends and fashions. It considers symptoms - which by definition imply a prior cause - to be an intelligent statement indicating where that individual has become dis-eased or 'stuck'. Homeopathy defines health as the ability to constantly adjust to changes within ourselves and our environment. Chronic disease is defined as the inability to adjust to such changes and thus symptoms are considered to be expressions of resistance to change.

In contrast to the orthodox medical interpretation, homeopathy believes symptoms of an acute disease (as opposed to chronic) to be a unified effort made by the constitution to return to a state of health and well-being. It is a running joke among teachers that they always get 'flu at the end of term as a delayed reaction to the stresses of the profession. Influenza makes us lie down and stop; we lose our appetites and taste, we kick out mucous and catarrh and often have diarrhoea as part of the purging process.

After the dis-ease has resolved, the constitution returns to a state of well-being. In other words, homeopathy views acute disease as an attempt at cure. In this model, microbes are actively employed by the constitution in an attempt to re-adjust and recover. So, rather than viewing microbes as the true 'cause' of acute disease, homeopathy suggests that microbes only 'effect' symptoms when the organism is already dis-eased at some level.

In this sense we prompt a change in reality. If chronic illness is a resistance to change and acute disease is an effort to get better with microbes being part and parcel of this phenomenon, then they cease to be the enemy. The need to stamp the intruders out with chemical warfare is lost, and all the military metaphors fall away and become redundant misconceptions.

*"we have not only severely disrupted the natural ecology of the body, but we have mutated microbes to the point where they have become totally drug resistant"*

From primordial soup to the end product of the human being, we have evolved hand in hand with disease. Disease has been an integral part of our evolutionary process. Over the last 200 years we have profoundly interfered with this partnership to extremes never previously witnessed in our evolutionary history. The discovery of microbes and the medical manipulation of the military model have qualified the extensive use of vaccinations, antibiotics, antivirals and other antimicrobial drugs. As a consequence, we have not only severely disrupted the natural ecology of the body, owing to the toxicity of these pesticides, but we have mutated microbes to the point where they have become totally drug resistant.

we have seen an explosion in the incidence of cancer, auto-immune illnesses, mental and emotional disorders and in more recent times AIDS. Homeopathic philosophy would argue that suppressing symptoms with chemicals in the name of 'curing' disease may well have been a trade off. We may have swapped the more superficial expressions of dis-ease for chronic, morbid, internal pathologies.

Our current AIDS research and treatment surely epitomises the ultimate application of the militarist medical model. A recent interview with a top London consultant revealed that his ideal prescription for asymptomatic HIV-positive people would now contain no less than seven different drugs in combination. If the billions of dollars spent on research mean we still have no reasonable explanation for AIDS in terms of HIV and more importantly no therapeutic resolution or cure for AIDS - despite our most aggressive chemical weaponry - then surely something more fundamental is amiss. It is certainly a paradoxical delusion to imagine that piling ever-increasing amounts of toxic medical drugs into our bodies will eventually produce a state of health. It may well be the case that modern medicine's unswerving search for that elusive 'magic bullet' has actually back-fired.

Not only do the huge amounts of data on HIV stand testimony to the most redundant research efforts ever mounted but our singular 'viral agent' pursuit may have inadvertently revealed some of the greatest flaws in our contemporary medical thinking. For example, there is still no clearly identified mechanism as to how HIV destroys CD4 cells; no-one develops AIDS at the same rate; different illnesses develop in differing risk groups; the same illnesses have completely different symptomatology; there is no accounting for the AIDS illnesses that are not associated with immune deficiency or microbes; the 'latent-period' has been constantly adjusted, the AIDS defining illnesses require constant expansion in order to incorporate HIV theory; we make no allowance for the psychological and physiological consequences of programming everyone to get sick and die, and we can no longer clearly differentiate long-term medical drug use toxicities from genuinely presenting symptoms.

With our current model of HIV and AIDS we stand defeated. The militarist medical model does not work anymore. Perhaps the real problem stems from the militarist perspective itself. We are on the brink of another medical revolution. AIDS, more than any other illness, is hastening the approach of a change in our medical models. Maybe it is time to change 'reality' again.



### BIRCHGROVE IS A FORUM FOR:

- The treatments 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 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 feelings and confronting the issues directly
- Have needs that are best understood by drawing on the experiences of those in the same situation
- 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

Available from the Birchgrove Group, free of charge are the following information leaflets and back issues of the Birchgrove Newsletter.

#### Birchgrove Newsletter Back Issues

- BIRCHGROVE newsletter Issue 3
- BIRCHGROVE newsletter Issue 4
- BIRCHGROVE newsletter Issue 5
- BIRCHGROVE newsletter Issue 6
- BIRCHGROVE newsletter Issue 7

#### Birchgrove Information Leaflets

- HIV and Itchy skin
- An ABC of Hepatitis
- Liver Disease and HIV
- HIV and Vitamins & Minerals
- Glossary of terms

We can also supply the following items.

- "Living with Haemophilia and HIV" £2.00
- "Keeping it in the Family (report)" £2.00
- Red Ribbon Badges (Enamel) £2.50
- Birchgrove Red Ribbons (Enamel) £2.50

Name:

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Address:

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Send to: The Birchgrove Group,  
PO Box 313, Canterbury Kent CT1 1 GL.  
or phone Lo-Call 0345 697231

### GONE TO POT

People that know me are well aware of my illegal tendency to smoke cannabis regardless of the current legal position. My first thoughts on the topic are that cannabis should be no different to any other drug. It should be available from your doctor or from your pharmacist. I believe that if it was taken as prescribed and in moderation, it could be very beneficial to the person who is taking it.

The problem is that doctors without the benefit of concrete research data on the positive or negative effects would find it very difficult to prescribe correctly. They could hardly send me home with a prescription reading smoke two to three joints a day, to be taken before eating the entire contents of the fridge.

As for the question of addiction, or the temptation to try other stronger or more dangerous drugs, cocaine, crack, speed or heroin for example, I have never felt the need or desire to further my education with these. Nor do I see why those who drink lager, will automatically go on to drinking spirits, or those who drink spirits, who will go on to drinking pure alcohol!

Over the years of living with haemophilia I have used cannabis both for pleasure and to relieve pain. Instead of continually taking Paracetamol, DF118 or Pethidine to relieve my pain, I would roll up some relief and quietly smoke the problem away. I have always thought that painkillers are far more addictive and far more harmful to my system than any dope I might smoke. I realise that any form of smoking can harm your lungs, and one cannabis joint has the equivalent effect in nicotine and tar intake as smoking ten normal cigarettes. But, by smoking cannabis neat in a pipe and not mixing it with tobacco into a rolled cigarette, you can reduce the nicotine and tar intake considerably.

Since being told of my HIV result in 1985, it took a few years to come to terms with the news and a few more years to work out what I needed to do about it. Despite all the concerns that I have had to face, my escape has always been to roll up a joint, collapse into a hot bath, and let the worries of the world wash away.

Finally, I have come up with my own personal game plan.

1. Reduce stress, its very bad for you, HIV feeds on it!
2. Keep a fit and active body, infections hate them!
3. Eat well and enjoy yourself!
4. Everything in moderation!

A peaceful mind is a healing mind, so I will keep taking my medicine until the medical profession comes up with something better.



# The Birchgrove

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## Due South

A Canadian Adventure

A Melson

quire, yes a gospel quire, and I must say other than the religious aspect of it they were very good, this however only went on till about 9.30, and as I had found out in the previous week this city does not wake up until midnight.

This was my first international Haemophilia event, and I didn't quite know what to expect. I had been wandering the streets of Montreal on my own for a few days waiting for other UK members to arrive. On the Saturday I booked out of my hotel and got a taxi to where I was supposed to meet Gareth. Unusual I know but we had arranged to meet in the Hotel bar!!!!

Well, roughly 3 hours late due to customs, delays etc, we were at last ensconced in the bar, along with maps and tourist brochures, not to mention our list of relevant seminars that we were attending.

We decided to wander along to the Palais de congress and register, unfortunately Gareth's information (and I lay no blame anywhere in particular) was not on file, whilst I found myself being registered as Dr Melson, a title which we have now adopted

For the main reason being that if some of the people who we met claimed to be Doctors then I am sure I qualify.

After registration we headed off back to the hotel to formulate a plan of action, we earmarked the seminars to attend, and sorted out what we wanted to see in this great city.

I must say I have never seen so many people with a limp gathered in one place for a long time. A relief actually because sometimes I do get a bit self-conscious of my own limp. Anyway back to the bar, we met others from the UK delegation, one in particular whom I cannot mention, mainly because I think any links with Birchgrove may endanger his future career as president of the Haemo Soc, but he knows who he is (don't you Andrew).

Well we sat in the hotel bar getting to know the barman and the majority of the staff all by first name terms (not that we were there that long) and decided we would have an early night to recharge for the following day, this was roughly 1.30am.

I am leaving Gareth to fill you in on the medical aspects of the seminars, I am dealing with the social side, however I must say that the Doctors, nurses health professionals call them what you will, definitely divide in to two categories, those who care, and those who care about corporate hospitality.... I think you all know what I mean.

I think if Birchgrove did have a paramilitary wing then we certainly found a few targets to practice on, in fact I think we would have to expand.

On saying that I did meet a lot of people who do genuinely care and have not forgotten the issues of the past or present which to me was very refreshing.

Let's get back to the social side then. Well, we had tickets to see a gospel

So Gareth and I and One other, (who must remain nameless) decided to go for a wander. I had found a quiet little club not far away and proposed we went there, yes was the reply. However without blaming myself too much I was somewhat confused by where we were at the time, needless to say we walked quite a distance before it was pointed out to me that the building we had to keep in front of us was now some distance behind...(a minor glitch). Any way I new a shortcut.

We crossed the street (a somewhat dimly lit one) and proceeded to walk past what can only be described as a semi derelict block, with some very choice furniture strewn around the derelict cars, (well you can't stick to the tourist route all the time can you), there was very loud music coming from above, but no one seemed to want to go in?

We crossed over and found an information board, apparently we were 12 blocks astray somehow!!!

On orders given to me in quite a stern voice we hailed a taxi, I must say it did take us about 10 minutes to get there, but on getting there thankfully the owner remembered me and we took a table. We sat there until the early hours putting the world to rights and discussing what was wrong with just about everything.

The next day, or at least a few hours later, we proceeded to the seminars, as I said this subject is being dealt with so I won't go on....sod it yes I will, the HIV seminar we attended that day was I thought quite informative, and dare I say fairly hopeful, as long as we can hang around for about another year or so for the new treatments to come on line.

The next few nights were taken up by much of the same, the odd restaurant and bar and generally seeing the sights, I must however at this point thank Gareth for turning down a free meal with one of the drug companies because I could not attend, cheers.

On the final night of the congress we all had invites to attend the "last supper" as we called it, this was quite a formal event, ball gowns etc, and that's only for us (This relates to a subject that no doubt will be broached in the magazine inferring that most positive Haemophiliacs want to be women,) anyway we attended, the evening went well and finished, albeit quite early on a high note with everyone looking forward to Seville.

The next day we had arranged to hire a car and drive the short distance (yeah rite) up the road to Quebec, it amazes me how anything in North America is "just up the road". We had arranged to collect the car that morning and strolled in to Budget to collect said vehicle, first problem, since my early retirement I don't use credit cards but on travelling on

CONTINUED FROM FRONT PG

my own I thought it was necessary to get one, only thing being I had forgotten to authorise it before leaving blightly...the ultimate embarrassment, it was refused, "not yet valid" was this how the day was going to go.

Luckily one of our number had both credit card and driving license on there person but defiantly did not want to drive, so car paid for keys in hand we bundled into the car like the anthill mob, I slipped it into drive and we screeched out onto the highway, still not quite convinced we had taken the correct car, still no one ran after us so what the hell.

Now we had two navigators sat in the back, and I was suddenly taken back to when my estranged wife and I used to drive abroad, there is something inherent in the female of the species (sorry not trying to be sexist) when giving directions that they tell you to turn when you are doing about 70 and you have to cross 5 lanes of traffic to get to the junction which is about 10yards ahead!!!!

Needless to say we missed the junction, we ended up taking the scenic route, still it's only "up the road". We decided to keep the St Lawrence River on our right and we couldn't go far wrong. We went through quite a few picturesque little towns and decided to stop at a truck stop for breakfast. Here we took a look on the map, this short trip up the road suddenly looked something reminiscent of the Paris -Dakar, still we've got 24 hours to get the car back.

We eventually got on the interstate, heading in roughly the rite direction, I set the cruise control and we were of.

I think it was about 4 hours later we arrived in Quebec, all I new was I had seen a picture of a castle that looked nice so lets find it. Bad move really, I think Quebec must have more castles than Disneyland. We did find some interesting places however, and luckily found a car park in the middle of town, which was as it turned out quite convenient seeing as though Quebec to a Haemophilic with a dodgy knee was a cross between San Francisco and Mount killamanjaro (yes it was very hilly).

We must have been down every street ally road lane and anywhere else you could think of, but it's a beautiful city and well worth it. By the time we got back to the car I required at least one knee replacement, 2 ankle joints and a bottle of neat oxygen, and don't ask me why, but I suggested going further on to see the water fall rumoured to be 30 meters higher than Niagara.

I was taken up on the suggestion (aghhh), we hit the interstate once again, luckily by this time one of the navigators sitting behind had sussed out that you don't cross the red traffic lights....many thanks that's obviously were I have been going wrong all these years!!!!.

We drove for about 30 minutes (whilst I contemplated how long a UK citizen would get for manslaughter of one of his passengers, and how deep the St Lawrence was) when we reached the falls. They were impressive, with a cable car climbing the cliff face to restaurant on top. We decided to eat, probably a bad move in hindsight, there was a wedding going on at the same time, and the restaurant was basically dress for

dinner type...we hadn't.

Now we got there at about 7.30 I think, and the cable car (the only method of getting home) closed at 9.00 sharp, to say that this restaurant was not the speediest of eating establishments was at least an understatement, it got to around 8.30 and we had just been given the main course. By this time I was contemplating the trip home and wondering when my "second wind" of energy would start, (it had to be soon).

Any way I decided to leave and grab the cable car and skip the goats cheesecake, after all these goats are quick on there feet and it could have been at least another two or three hours before they were milked!!!!

All safely at the car park and the cable car now closing for the night we wandered towards the car, now when we picked it up, the very nice lady said take the RED one, well this was about as close to red as, the pope is a rabbi, still the keys fit and we've got to get home, sod it to late now anyway.

Rite everybody in "doors to manual" as they say, and we are off again, now I was honest and did mention that I wear glasses at night because I have poor night vision, this was greeted with laughter from the rest of the explorers, well I warned them.

Headlights on, in fact all the lights I could find to switch on (every little helps), we set of back on to the interstate towards Quebec.... into Quebec.... out of Quebec. around Quebec....you get the picture, yes the navigators were in fine harmony telling me this time on a six lane carriageway (and I am in the sixth lane), yes this is the junction coming up, yep there it goes, now I did suggest that although the vehicle we were in did have approximately 12 airbags I thought it was prudent not to use them just because they were fitted (perhaps that's just me, I am old fashioned).

After seeing Quebec and the surrounding wilderness several times on the way home

The interstate for about 2 hours, when I herd a noise, now this is were I have to be very careful because it's not like me to offend!!!! But the noise turned out to be one of our navigators snoring. Now it was suggested to me that we did an emergency stop, but people who know me, and know that I am a kind humanitarian wouldn't do such a thing, and anyway this person had there seat belt on so it would have been a waste of time.

Now I don't know what time it was when we reached Montreal, I think it was about 2.00am or something...and by this time I wanted something to eat. I had my second wind, and I was now on a mission....it was to hunt for junk food, it was easy really, we swerved into the "golden arches" restaurant, (I was told this description of McDonalds by a fellow passenger and found it amusing, thanks E.R) were I pulled up at the microphone and tried to order, for some reason we all started crying with laughter, which I think somewhat annoyed the attendant, especially when I told him I didn't want the drink that comes free with the meal.

Well we are off on the final leg, I've eaten and full of energy

From day one we have had a 'tempestuous' relationship as Paul likes to put it. We did however hit crisis point around Christmas and had to really decide whether to work at it or call it a day. Well, here we are....very happy most of the time, and a great little family unit. We have learned to laugh at our differences and most importantly to walk away.

Anyway, back to the weekend, so therefore thinking I'd resolved most issues, come to terms with almost everything, I arrived in Coventry.

*Wow!...I thought...nice hotel!*

We, the eight partners who attended were given a run down of the proposed agenda for the weekend and introduced to all the 'professionals' present and the facilitator, Fran.

At this very early point I was surprised to find myself feeling anger....about how the whole situation with HIV and hepc, etc had occurred ...and feeling this anger directed to those 'professionals' present.

So, we all introduced ourselves and had to say what if any were our reservations over the weekend. Well, I decided to say how I felt and that whereas I wouldn't physically attack anyone, they could be in line for some 'constructive' criticism....ha!

What pleased me the most was that I could see the other partners nodding in agreement when I said how angry I felt about everything and how let down we all had been by the system, including the Trust, the Society and the medical profession.

*All that off my chest, I felt much better....*

Lots of issues did indeed come up in discussion groups, such as lack of information/honesty from healthcare professionals. This was quite a 'biggy' for most of us and due to an 'oversight' on the part of the facilitators inviting three members of one partners health authority, we kicked them out for that discussion.!

We said how we were sick of being lied to and treated by many as if we were idiots with no understanding of our partner's health issues. All of us shared at least one story of a bad experience with such professionals, there were also a few positive stories but unfortunately they were thinner on the ground!

Isolation was a huge issue for nearly all, as most families affected by hiv seem to live double lives with few if any others knowing the situation outside of their immediate relations. For myself, this is not an issue but it deeply saddened me to see the problems such couples/families face, such as having to invent cover stories for illness and hospital appointments,etc. More importantly though is the fact that such people often have no-one to talk to or share things with.

The group of us decided that we would all like to keep in touch for this reason....even for those of us who don't lead a double life it was such a relief to meet others who know what its all about and share many of the same worries, fears,etc. We also decided that we wanted to have a voice! As partners we often feel that our needs are overlooked. For example, we do not get 'our own' allowance from the trust. Many of us are stuck in the benefits trap and cant afford to go back to work, even part-time. We get a grant for a taster session of alternative therapies, but then having decided that we like it and it has helped us, we can't afford to carry on with it!

(I subsequently found out on my return to Walsall that we do indeed have representation on the Partnership Group from three partners! For some reason, this wasn't mentioned, but the more of us the better!)

Needless to say this became a very emotional discussion with many tears and tissues.

Another discussion took place about 'preparing for death'. I didn't attend this one so cant really say much about it other than those present said it was very good covering many of the practical issues such as, wills, property,etc that are sometimes difficult to discuss objectively at home.

As a group of strangers(mostly), we all got on really well. I don't think that there was anybody that didn't gel. There was a wonderful atmosphere of warmth and support which was probably the best thing about the whole weekend. The opportunity to discuss and share so many feelings that are for the main part kept bottled up whilst at home so as not to upset our partners or give the game away to others was the best medicine we could have been given.

I don't think we all realised how stressed we were or how much pressure we are at times living under until we had this chance to let it all out.

I know that for myself, I didn't expect to cry or feel so emotional so much of the time. It was an unexpected reaction, and my god...did I ever need it! All that combined with the alternative therapies we had, aromatherapy and spiritual/reiki healing left me feeling very physically relaxed but so emotionally drained that I could have spent at least the next two days asleep!

*Fran and Babs were great fun to be around and I have to say....nice people, despite who they work for!*

*The other professionals present were also very affable.*

The only criticism I have about the hotel was that the food was bloody awful!!! I'll never eat fish again!

I do not feel that I have covered even half of what happened, but before I sign off I would like to appeal to other partners out there to try and attend the next one. If the only thing you take from it is the knowledge that you are no longer alone then it's worth it!

So, having got much off my chest, made some friends and recharged my batteries I went home. As great as the weekend was in many ways it was wonderful to see my son and the man I love.....even though I had only been away for such a short time. How sad am I?

**AN OTHER PARTNER**

## DISCLAIMER

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

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## TO USE IT OR NOT, THAT IS THE QUESTION

# FACTOR VIII

Over the last year or so I have been meeting many people with haemophilia and HIV/HCV, discussing shared challenges and problems. Whilst this has been of much benefit to me I have found one aspect of our lives that is very different. I was surprised that most of the guys (and they all are) that I chat to have taken the decision to use as little blood clotting treatment as possible. I say surprised because I use factor on a prophylactic basis and made the assumption that many other people did the same. Although I don't stick a needle in my veins for fun I am determined to never again experience the pain and frustration that comes with a bleed. Therefore I inject myself every other day in order to live a bleed free life. I would like to state at this point that I recognise each individual's choice around their treatment options and am not saying my way is right and others wrong, it just interests me.

Ironically I was just coming to terms with haemophilia when I was diagnosed HIV+ at 29 years of age. Yes it took me a long time and it was a struggle but I had finally realised that I did not have to put up with the pain of a bleed and had begun to treat myself and talk to other people about my condition. I used to live with bleeds as I had done all through my childhood and refused to use factor until it was too late and the pain had begun. Learning to treat myself on a prophylactic basis took most of that pain and uncertainty away and I probably went too far the other way, treating myself more than I needed to, it became almost an addiction.

When I was told I had tested positive for HIV I don't remember treating myself less although that doesn't mean I didn't worry about what was in the syringes at the time, I did. With the lack of knowledge and support from my centre at that time I just assumed it was too late to do anything, the bad blood had got into me and what harm could I do to myself now. The centre staff stuck to the mantra of the benefits outweighing the possible dangers, no mention of HCV of course, they just let history repeat itself. I do remember being given heat-treated product when it became available and feeling relieved as I assumed this was totally safe. Well I say assumed, I was told it was. And now I am battling to get recombinant factor as everyone says it is better. If you look at the issues closely though recombinant still uses human cells or it would not work properly. So, what's the difference? A new recombinant product is due out soon so those of you fighting for this product beware when you get it; it could well be the old one that nobody wants!

As I said earlier many of the men I talk to have made the decision not to treat themselves for many reasons. They reason that their livers have to put up with enough abuse already from the anti HIV/HCV combinations and I can understand that. Also the risk of further infection with varying strains of HIV and CJD are constant worries although our Doctors say its safe to use nowadays. Well, will we ever believe them again? It is not very nice injecting yourself with crap as we all know and it is a constant reminder of what has happened and may happen in the future, I wonder what it is like for those of you with inhibitors, if I think I use a lot of factor Christ knows how you all feel.

I know that my centres policy with newly diagnosed children is to encourage treatment and most parents accept this, I sincerely hope that kids born with haemophilia don't have to go through the pain I experienced as a child but wonder if those parents would still want their children treated with factor if they had half an hours chat with one of us. Some women carriers still have terminations if a scan shows they are pregnant with a male child. How does that make you feel? So, I would be interested in other peoples feelings about this, how often do you use factor, how safe do you feel about your product, do you still get bleeds, is recombinant the saviour, write in and let me know.

In closing I would like to say that although I still stick that needle in me I feel weird every time I do it, and always wonder what they will find in me next.

*Please send all comments to*

*Richard Oakley@birchgrovegroup.org.uk*

### Partnership Meeting

Thursday 10th Aug 2000

Being very new to actually meeting face to face with the MFT, as for so many yrs you only had access to anyone via the phone, my excitement at the prospect of actually being able to have a proper voice for the first time was initially exciting. This excitement didn't last. It was as if the ghost of John Williams still pervaded over all, a favourite line he frequently spouted "If registrants find out about something they can claim for they will claim regardless of need" Peter Stevens is without doubt a very well educated man although I'm unsure as to who's best interests he has in mind.

Mr Stevens was granted a meeting with Lord Hunt to explain the MFT was going to have to spend more money quicker in the very near future, Lord Hunt was concerned that this may cause problems although he would look into providing the money. WHY oh WHY is Lord Hunt so overly concerned that registrants are asking for some form of help from the MFT when there maybe a local authority, or even another charity we could seek assistance from first? Should we really have to do this I wonder. Approaching the MFT even now is hard enough without the thought of having to go elsewhere. Wont some one please protect our anonymity from organisations we shouldn't need to contact and disclose our status, thus saving any unneeded stress and worry, PLEASE

Each and every registrants circumstances are going to be different, we are after all individuals with many and varied changing needs. If Lord Hunt feels the Govt dept hasn't kept a closer eye on the way the MFT has spent monies, so much so he is thinking of putting in a civil servant to look into this as soon as possible.

Perhaps Lord Hunt feels we shouldn't still be here, let alone asking or even pleading for our voice and needs to be met. I'm sure more registrant would gladly meet with the MFT Trustee's to talk given an opportunity. So many issues are being discussed, sadly to hear Peter Stevens comment upon how we need to streamline the amount of registrants for further meetings due to the expense was disappointing. The lights maybe on at the MFT, but is anyone really paying any attention, or are they just working hand in glove with Govt Dept's to cut back as much as they can. Thus making life more complicated and frustrating than actually needs be.

## WHEN OPTIONS RUN OUT

### Last Chance Saloon

After a drugs holiday of some months, The experts, The doctors, The one's who hold the key, it's time to start another regime. your getting weak and ill. Seems quite strange this, as I've had AIDS for over 7 years and HIV+ for what seems like a lifetime. This where the fun starts, What drugs, how many times a day, what are the side affects, do we eat now, after, before, during, or what. Lets call a multi disciplinary meeting we could invite the dietitian and pharmacist and really discuss the shit that comes with combination therapy. Oh and we can have a tasting session first. Great another day a the great UHW Haemophilia Unit, but sounds interesting never been to a drug sampling session before, plenty of wine, whisky, beer tasting events bet never one to see if I will like what's going to save my life. " or not "

After many discussions and a reluctance on my part I decide on a last chance combination, I won't go into names and doses of drugs as some of you might be offered this down the line and I believe everyone reacts differently to drugs and I would not want to put you off talking something by writing about my experience. All I will say is, boy it was a shit full of various big ones, little ones, ones that make cry, and one I've called Lucy because of stories, I've heard about side affects. Offered a week at A7 penthouse suite UHW bed and breakfast, Hospital to start new regime, this would enable closer monitoring and help with the initial weeks of side effects. I agree, drugs are ordered, Ones in liquid form taste like something from an elephants backside and not sure if I can take these over a period of time, but anything for a laugh, big mistake. Taste just lingers for about five hours and sickness is horrendous.

Dates set, bed booked, spent hours and days keeping mentally prepared to start this new all singing all dancing combination, when it's cancelled for a week, You will not believe the problems this caused me, having prepared, my life and that of work and family members for my week in hospital and it's all put on hold, I was close to telling the hospital to stuff their treatment up the same elephants backside " think about it " But agree to wait, reason for delay not important, but made sense to someone. So on a bank holiday Monday book in to my suite ready to start my cocktail at 8.00am Tuesday morning, but what happens drugs not on ward, first cockup and it's only the first dose. So much for they must be taken on time and you must adhere or they won't work and the hospital can't even deliver on time, British Rail or what !

Oh shit, perhaps I should outline the history and how this last option came about. Those of you who know me or who might have been at the conference in Bath 1993 will remember I was not at my best and many thought Oh well that's the last we will see of him ! After driving home from weekend I was rushed into hospital with PCP and started treatment for this and my first combination therapy, reluctantly. Since that time I've tried and become resistant to all

current class of Anti-HIV drug combinations, dealing with rejection and side effects of numerous different regimes only to be told they had failed. The effects on owns mind / pressures failures bring not just for you but for every one around mood swings, anger, death, what happened now, how long do I have, but I've been through this before and I'm still here. All this became to much and for my wellbeing and after nearly 7 years, of hell I decided to have a drugs holiday, which brings me quickly back to the present. The side effects and complications during this time were horrendous with the shits, constipation, itching, bleeding, stomach cramps, stones in kidneys, peeing claret red blood, losing white cell and needing to take another cocktail of drugs just to deal with the problems of supposedly being made better

( load of crap that one I was always better before and after starting and stopping drug treatments ) only to be told on every occasion that the drugs don't work. Lets try a different lot. By this time I was living out of sets of different size clothes due to weight loss and gains which happens rapidly, and I found myself with what I called three different sets of clothes, My well set, My Oh shit I'm losing weight set, and my death set. funny I know but this was a fact of life. I even had a room at home called the death room which some people found really hard to deal with. But still fighting and have now changed death room into treatment room, and thats another story.

Also noone told my about the enormous amount of extra money that would be needed during these periods, Your use of toilets rolls increase six fold, your clothes are ruined by blood and steroid creams, sheets and bedding needs to be washed daily and replaced weekly due to excessive bleeding, would you take the risk of asking your partner to sleep on blood infected sheets and bedding. Your food and diet and the times you can eat are all thrown into disarray and family life just come to an end. Your ability to cope with day to day problems is gone your mood swings and tolerance of others is taken away. You take out your anger on those you love, you become a recluse because vanity stops you living a open and honest life, people look and stay and your conscious of spots and scabs all over your body, your next door neighbours child of 7 asks if you have chicken pox, The pox yes that how it feels but I don't think chickens has anything to do with it.

Lets get back to day one, drugs arrive at about 11.00am and first doses taken straight away sickness and the taste of liquids make everything feel like iron your tastebuds are gone and this last for about 4 hrs. So the first dose done, sit and contemplate the next round of drugs and wonder when, if, how, will this regime effect my quality of life. Try to eat some hospital food but that another story. This goes on for 8 weeks and what the F... happens I fail this regime. So no options until the mad scientist come up with new class of drugs.



## INSIDE THE CLOSED SHOP

# Partners weekend

I recently took part in a Partners weekend promoted by the Macfarlane Trust. It wasn't an easy thing to do, especially as the introductory letters advertising the weekend were only sent out to married partners! Fortunately, through my partner's contacts I did hear about it and the MFT consequently followed with letters to ALL partners irrespective of their marital status!!

I was surprised to discover that only 9 partners had subscribed. Why was that? Did you know about it? Were you not grabbed by the way it was promoted? Do you not feel like 'talking about things'? Would it all be too 'touchy feely' and emotional?

*Had you been there, done that?*

Some of these thoughts I had but I had not talked about HIV and how it affects my life with very many people for a long time. With all things considered I decided to go for it.

"I must be mad," I thought as I headed off down the motorway straight after work on this particular Friday. "I am spending my first weekend off in ages with a load of strangers!"

What kept me going was the flip side to all this. I knew I was about to meet some people who had at least one thing in common - Our partners all lived with Haemophilia, HIV and/or Hepatitis C and all our lives were affected by that fact.

*I hoped that something good would come out of this.*

I was fortunate to meet people who could empathise with my feelings and who experienced similar problems with coping as I do sometimes. I also met people who dealt with things very differently. I received lots of positive support and felt a release of tension as I was able to discuss for the first time in public issues such as: HIV, night sweats, combination therapy, telling friends (or not), isolation, families, having children (or not), safe sex, the list was endless and this was just the first evening at dinner.

Representatives were there from the MFT, Haemophilia Society, Newcastle Haemophilia Centre and St Thomas' Hospital. They made us feel at ease and helped the conversation flow

*(This process was also admittedly helped by the complimentary wine).*

During the weekend various sessions were held where we would be able to discuss, share and explore various factors affecting our lives.

Some of the sessions were pretty heavy and I cried, as did others - but it was a safe environment to do so. Most of the sessions were facilitated well and lots of support was available. I also learned a lot about treatments and felt very much more informed about lots of issues.

We also had the chance to discuss financial matters confidentially with the MFT's financial advisor, Susan Daniels - this I found extremely useful and she was able to advise me with all my financial queries from pensions to mortgages. Susan is available to registrants and partners and will advise you on an individual basis. You do need to get authorisation from the MFT first.

We all received free complimentary therapies on the Saturday. We commented on how happy, revived and relaxed we all looked when we came out of the treatment rooms following our sessions. We were also able to use the hotel's leisure facilities for free. These included a swimming pool, Jacuzzi and sauna. There was also a well-equipped gym for our use.

That evening the wine flowed again and we chatted all evening. I realised that I was relaxed and felt like I was with a group of old friends. I was very glad to have attended.

We looked to the future on the Sunday morning and we had the opportunity to put forward recommendations to the organisations involved. MORE OF THESE EVENTS! Was on the top of the list.

The weekend was such a positive experience for me. I now feel less isolated, more informed and more supported. I also feel like I can contact individuals from the MFT and Haemophilia Society with much more confidence now that I have spent a weekend getting to know them. I also came away with a list of e-mail addresses from the other partners. It is a less obtrusive way to contact someone. I have been in touch with a couple of people since - it feels good but it is not interfering with my day-to-day life. There is also talk of partners meeting up without the attendance of professionals. I shall definitely be there.

### A PARTNER

#### PARTNER'S WEEKEND ( 2ND ARTICLE )

I was quite excited at the prospect of going on the Partner's weekend. Hee hee, I thought...another excuse to go away for the weekend! This is not meant as a slight against my son or Paul, but I just love going to places on my own. It's a different experience and you can really just be yourself without wearing the mantle of wife, mother or carer.

This particular weekend would not be quite the same however, as by it's nature I was going as a partner.(why do I keep hearing the music to the twilight zone?)

No problem I thought to myself, I can handle this! Before I continue, a brief history is needed I think.

Paul and I have only been together just under two years. I moved very quickly to be with him, bringing with me my son Aaron, who was twelve at the time and my cat...oops...and all my worldly goods of course.



## DUE SOUTH CONT

again, so lets go (I'm still wondering about the "red car" situation) we drive past the Olympic stadium, only twice I think, then down some familiar looking streets, not that that's a good thing after all they could be familiar for the wrong reason, oh well the wheels are turning and we are off again, when there is a voice from the back, someone is stirring, they are awake !!!! I have another flight plan passed to me, we stop for petrol, and not a bad idea I suppose we are nearly empty. I pull the limo up at the pumps and ponder whether its like the good old USA were you pay first, well that and rigger-mortis had firmly set in so getting out was a bit of a struggle.

Now this is when I was suddenly thrust into the "wide awake club" as one of the navigators who by now was wide awake had grabbed the petrol pump in their hand, was opening the flap with the right and whilst stuffing the petrol pump nozzle up my nostril with the left, fingers poised on the trigger...a scary moment for someone who smokes I tell you, needless to say the other members of the crew had wound the windows up and were involved in nothing less than hysterics...at this stage the thought of manslaughter came flooding back..(Would it be worth it?? YES).

We managed to refuel without leaving a small crater in the Montreal suburbs and we were of on our final leg, the crew still tittering in the car.

If any one has ever seen "Mrs Bucket" telling her husband not to hit that women...yes you guessed it, the women going in that shop 500 yards up the road, well this is what was happening to me, now I like to think I kept my cool, I think I did, I just kept convincing myself that they still had the death penalty for murder over here, especially for tourists.

You may by now be fairly bored of this story; well bare with it the hotel is not far off.

We hit the main street of downtown Montreal, its most definitely a party city, and unusually safe too, god knows what time it was, it was very late,

## BIRCHGROVE CENTRAL PART ONE

**O**ver the past year or so (it seems longer) my self and Paul (Hooper) have been trying to resurrect Birchgrove in the Midlands, it seems lately that more than ever there is a need for such organisations who can offer support and advice to those in need.

We have identified several concerns recently, one of which is something that may offend some but I know not others and that is the level of care from outside the Haemophilia centres i.e. drop in centres where other alternative treatments and counselling may be on offer. Recently I was invited to a meeting at the Birmingham Health authority, where I was astounded to meet a group of social workers that were asking me as a Haemophilic HIV positive person what I thought of helping to set up a new group. Now this is where I may offend, but frankly "I don't give a damn"(Gone with the wind). The background on why this group is being set up is basically from the concern over HIV positive heterosexuals, yes I said heterosexuals, now there is a large number of these people living and dying in the Midlands who because of one reason or another do not, will not seek treatment and any form of proper counselling, this intern has lead to a rise in the suicide rate amongst these individuals, and for those others isolation. The meeting I attended was to seek some format to establish a positive heterosexual group, which hopefully will grow in size over the next year. Now there are several issues around this subject that you have to deal with. Firstly it will be thought that you are some form of homophobic group, but any one who says this I would ask them to contact HIV heterosexual people living in rural areas, and not somewhere like London or

or quite early whichever, the streets were alive, traffic jams night clubs roadside bars and cafes, the atmosphere is quite overwhelming really, anyway I am drifting of the subject, the hotel is on the right...yep there it was, this time my mistake, I reverse up to the entrance, and pull in to the budget car park, yes you guessed it I park next to the RED hire car, oops, well no one said any thing.

We all disembark, Gareth by this time is fumbling for the mini bar key (bloody good idea), we all fall silently into the lift which takes us to the hotel foyer, we then get separate lifts to our rooms (a complicated system).

We hit the minibar with a vengeance, as what can only be described as the first rays of the morning come through the curtains. We sit pondering the day, or two days, or however long its been, then the phone rings, there is what can only be described as an hysterical person on the other end of it, who I think if they had laughed any more we would have required an ambulance for them. This person, who cannot be name for legal reasons (chuckle chuckle) was just polishing of a bottle of gin, which was quite obvious as you could hear it clattering against the telephone and spilling on the sheets.

Well that is it my story is at an end, this one anyway, but there are others so keep watching.

On reflection of the Canadian trip, personally I think that it was very fruitful, not only in a medical awareness sort of thing but I feel that I have made new friends within this "Global Family", I think that it can only be of benefit to all of us to use the internet or whatever is at our disposal to keep in touch with others throughout the world, it does help, and although I have bored you with what I hope is one of a few amusing stories, there was and is a serious side to what we do at Birchgrove, at the end of the day we all have to laugh sometimes don't we ?.

Manchester before they comment.

The idea of this group is over the next few weeks to extend to the positive woman's groups in the Midlands which are also due to their history woman only groups, and who have expressed concern over why only single sex, why not mixed, indeed if both sexes suffer from HIV then why can they not talk as a mixed group, (what an amazing concept). Now there has also been identified to me (not by name before someone shouts confidentiality) that there are positive Haemophiliacs out there, a few of whom I have spoken to and who have related some quite horrific stories to me over the same types of issues that I've mentioned.

Now call me what you will, but if there is any way that we as Birchgrove Central can help set this group up and at the same time help these Haemophiliacs their partners, widows or dependents then WE WILL.

The first meeting is being held in Stourbridge on the 25th of this month if anyone is interested then drop me a line and I will give you the details. Now I have advertised this I do expect some negative feed back, but can we please remember one thing, that there are two definite sexualities, homosexuality of which yes I am fully aware has had a hard time being recognised, but the other is heterosexuality, which I am afraid if you are both heterosexual and positive is in some areas an even greater struggle.

comments to :

a.melson@birchgrovegroup.org.uk

#### BIRCHGROVE IS A FORUM FOR:

- The treatments of haemophilia and HIV
- Taking care of ourselves, through informed debate and argument
- Staying healthy with Haemophilia HIV & AIDS and HEP C
- Ways in which HIV affects love and sexuality
- The social and psychological aspects of haemophilia and HIV

#### 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 feelings 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

Her Royal Highness

Queen Elizabeth II

Buckingham Palace

London

SW1 1AA

14. August 00

Your Royal Highness.

I feel there is a matter which should be commented on by yourself as head of state.

This involves not only myself but a forgotten community of which your family were apart, I talk of course about the Haemophilia community of this country.

As you are no doubt aware over the past twenty or so years a large number of us within this community have become infected with not only the HIV virus but also Hepatitis C, both of which has been passed to us by contaminated blood products.

I do not have to quote letters from your own family in recent history to tell you what Haemophilia means in itself to the sufferer and the immediate family.

A number of years ago over 1200 Haemophiliacs were infected with HIV, there are at present only 412 of that group left, of which I am one, but we have now all but a few been re-infected with Hepatitis C which means that having a combination of the two viruses leaves us with little or no treatment options.

We have many times approached your Government to seek a public enquiry but with no avail, all we ask is for the evidence to be heard and that the mistakes of the past do not happen in the future.

We have also been told that the enquiry and police action taken in Canada recently was authorised by, and I quote, "Queen Elizabeth II Head of State", if this is true then why can this not happen in this country, we are after all still your subjects and although The House of Windsor may now be free from Haemophilia please consider for one moment if it was not, if for example your grandson was a sufferer how would this make you feel when you know that the life giving treatment given to him has actually shortened his life drastically.

We have as a community embarked on a long struggle over these remaining years for the truth to be heard, I like many have had my chance to be a father and carry on a career taken away from me, we all now live in near isolation thanks to the way we have been treated.

As time goes on there are fewer and fewer of us, but we will make sure that the denial of the past will not be re-enacted in the future, but we do need help, and we need someone such as yourself to recognise the wrong that has

been done.

With the evidence that has now been lodged with our legal representation it is quite obvious what happened in the past, and it will sooner or later be made more public than it already is.

What I am asking is that lessons from other countries be learned and I quote Canada because of its ties to our own United Kingdom, but the same events are actually taking place now in Southern Ireland. There should not be a need to put extremely sick and dying people through a long and traumatic court case when the conclusion is an obvious one.

I am writing this letter to you as our Head of State and as our Sovereign and hope that you may feel either as a member of a family which suffered from Haemophilia in the past, or indeed as our Queen and mother of her own family, that you may be able to pass comment in some way on this subject.

Many thanks for your time and I look forward to a response.

Yours Sincerely

*A Melson*

Mr Adrian Melson

British Subject

(Ed)

*Come on all you people out there lets get similar letters sent too all members of parliament and even as our friend Adrian Melson has done send HRH( Haemophilia Related Highness ) a letter aswell.*

*We are making people look over their shoulders and many MP's and members of organisations who covered up this scandal need to take stock and come clean before we cite them in legal cases that are just around the corner.*

*We at Birchgrove would like to congratulate all our friends in the North for the articles and personal stories that we have all had the pleasure of reading over the past week.*

*Hopefully it will kick off in Wales soon with similar bits going into local press as we try and finish this newsletter update.*

*Oh shit I'm sat here trying to fill this space I'm tired, Married, have two children, It's raining and Melson and Hooper are sat on their Arses and drinking my Lager. If they start to smoke my fags I will kill them. and thats another story.*

*Gareth Lewis*