



Nice to see ?
The Birchgrove Tree

The Birchgrove

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Front Page / Lead Article ?? So Many, you Choose

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Haemophilia Society's
HCV
Campaign

National Birchgrove
The Future
Charitable Status or NOT

2² Campaign

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What's it all about ?

Macfarlane Trust
Strategic Review What's in Store ??

WORLD HAEMOPHILIA
FEDERATION CONGRESS
Montreal, Canada July 2000

Oh and not to Forget
The problems we all Face
Living with Haemophilia HIV / AIDS & Hepatitis C
And all Being Volunteers !!
No Paid workers for National Birchgrove

Birchgrove Quiz

Find the one you want inside, first one to do so wins a prize !

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HAEMOPHILIACS TAKE ACTION GOOD LUCK "FROM BIRCHGROVE COMMITTEE"

22 CAMPAIGN

CAMPAIGN OF COHESION NOT DIVISION, INCLUSION NOT EXCLUSION

MISSION STATEMENT.

To campaign for all haemophiliacs/persons with bleeding disorders, who have been virally infected through NHS contaminated blood products.

CAMPAIGN AIMS.

1. Parity and recognition with other European countries regarding haemophilia settlements for viral infections
2. To advocate, educate and empower infected and affected individuals and their families.
3. To press for a public inquiry into injustices in the haemophilia community including finance and treatment.

Dear Member of the European Parliament

We write to you as a members of a self-help voluntary support group who represent and advocate on behalf of haemophiliacs and people with bleeding disorders and their families who are living with and affected by viral infections through NHS contaminated blood products.

We have members from all over the UK.

Individual members from your constituency are willing to write to you on a personal level if the response to this initial campaign letter proves to be unsuccessful or you need to represent an individual. We are asking you to look into the unfair way that UK haemophiliacs within Europe are being treated with regard to recompense for viral infection from contaminated NHS blood products.

A brief breakdown of the issues follows below.

In the 1980s over 1200 haemophiliacs were informed that they had tested positive for HIV and that they had been infected through contaminated NHS blood products. There are two interesting points related to this settlement which was agreed in the early 90's.

The first is that the Government only settled after it lost its appeal to prevent copying to the solicitors of haemophiliacs documents for which it claimed public interest immunity.

WHY?

The settlement was agreed three months prior to a trial in which the government's handling of the blood service in the 1970's would have been subject to public scrutiny.

The second point is that in order to receive the pay-out in the HIV settlement, haemophiliacs had to sign a hepatitis waiver.

WHY?

We would also like to point out that we believe the original payments to be based on a 3 year life expectancy and though sadly many have since died, over 400 still struggle to survive.

WHY?

Our dignity has been taken away and our lives have been devastated by the double blow of being informed many years later that we were also infected with the hepatitis C virus. The Government still refuses to recognise its moral obligation to recompense all those infected with hepatitis C (HCV) through NHS contaminated blood products.

WHY?

The aims of our campaign are to fight for a legal ruling as to the validity of the hepatitis waiver and to fight for parity of compensation with regard to settlements made to haemophiliacs in other European countries. We have instructed solicitors to challenge the validity of the waiver on the basis of "unfair contract." A large number of MPs from all parties are aware of this and are in support of our campaign.

We are asking for survival grants to be made to all haemophiliacs still living a compromised life due to the affects of HIV/ AIDS, as the original ex-gratia payment was calculated on such a short life expectancy.

We include a quote from Leonard Levy (formerly of NHS Executive Headquarters) with regard to haemophiliacs with HIV: "Those infected were all expected to die very quickly."

Unfortunately those still living are now having to deal with the double injustice of HCV infection. 95% of hemophiliacs with HIV also have HCV.

We ask you to support our campaign in the UK to help us fight for recompense for ALL haemophiliacs living with HCV. The treatment options for those who have both HIV and HCV (co-infected) are severely compromised as the drugs used to combat one virus can be detrimental to the treatment of the other.

The overwhelming majority of deaths are in the co-infected group.

Thank-you for taking the time to read this and we welcome your replies.

We leave you with a quote from the Magna Carta,

"TO NO-ONE WILL WE DELAY RIGHT OR JUSTICE."

People who Care

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WHAT'S DYSFUNCTION ??

Whilst sexual dysfunction can be a problem for anyone, people living with HIV may be particularly affected.

Loss of sexual drive or desire (libido) can have a significant impact on quality of life and feelings of self-worth, and may even contribute to emotional problems such as anxiety and depression.

Sexual problems are common during times of stress, such as when one receives an HIV-positive diagnosis or experiences work or relationship difficulties. Excessive intake of alcohol or recreational drugs can also diminish both the desire and ability to have sex.

Many of the drugs commonly used to treat depression, e.g. fluoxetine (Prozac) or paroxetine (Seroxat) can also affect sexual function. Additionally, megestrol acetate (Megace), an appetite stimulant, has been shown to cause loss of libido.

Issues for men

Sexual dysfunction among men can often be a result of decreased testosterone levels (hypogonadism), which can also lead to fatigue. Lower than normal testosterone levels have been found in people with advanced HIV infection, and can be caused both by the direct effects of HIV or chronic ill health itself. Many males receive testosterone treatment to alleviate these problems. Men who use testosterone replacement therapy usually gain muscle mass, experience an emotional 'lift', and an increase in their libido.

Strategies for impotence

Impotence, or the inability to get or maintain an erection, can be caused by HIV damaging the nerves in the penis which control an erection (autonomic neuropathy). Similarly, anti-HIV drugs that cause neuropathy such as ddC, ddI and d4T may cause numbness in the genital area, which can make it difficult to sustain an erection. Protease inhibitors have also been reported to cause impotence, though no mechanism to explain this has been identified yet.

Traditional interventions for impotence include the injection of alprostadil, a hormone produced by the prostate gland that alters the flow of blood in the penis. This can be done using Coverject, a tiny needle used to inject the penis with the hormone. This works very quickly, and the effects can last for hours, though some men may find the process unappealing.

The long-term effects are unknown and there is a limit of three injections a week, otherwise you run the risk of priapism, or persistent painful erection of the penis. Alternatively, alprostadil comes as a pellet which you insert into the urethra using an applicator. This is known as Muse.

A range of different implants are also available, but these will need replacing as time passes. A semi-solid

silicone implant can make the penis firmer, though not hard. Alternatively, a pocket can be created within the penis, into which a silicone rod is inserted to form an erection. Vacuum pumps, including the Rapport pump, are also available on the NHS.

Sildenafil, better known as Viagra, is a tablet used to treat impotence which works by increasing blood flow to the penis, making it more sensitive to touch. Viagra should be taken with care by people using protease inhibitors, NNRTIs, ketoconazole, itraconazole or erythromycin. A reduced dose of 25mg is advised in these cases, and no more than two doses should be taken in any 48 hour period. However, for people taking ritanavir, it is recommended that Viagra should not be used at all given the potential health risks. Similarly, the recreational drug poppers must not be used with Viagra under any circumstances.

Issues for women

It is not uncommon for HIV-positive women to experience early menopause as a result of abnormal production of the female hormones progesterone and oestrogen. Sexual dysfunction among women can also be caused by physical symptoms such as vaginal dryness or thrush, pain or severe pre-menstrual syndrome (PMS). Women can be offered hormone replacement therapy, though this should be carefully monitored for signs of masculinisation. Viagra has not been studied in women.

Psychological help

If you have concerns about any aspect of sexual dysfunction, consider talking it through with your doctor at your next hospital visit. He or she may be able to refer you to a specialist within the hospital, such as a psychologist or psychotherapist. If the underlying causes of the problem are emotional, then you may find that medications provide only partial benefit. A short course of sessions with a psychologist or counsellor may provide additional help.

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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BLOOD TRAILS

THE SMALL PRINT

Can I recommend a book for you to read which my mum put me on to. It is called "Blood." An epic history of medicine and commerce. Written by Douglas Starr. Published 1998 Hardback £20. E-mail Norman for details of paperback available from Amazon books USA for around 16 dollars US. I have hardback copy from British Lending Library. It makes fascinating reading and will make your blood boil! A large part of the book looks at the diabolical practices of American blood companies such as Armour, Cutter, Hyland division of Baxter and Travenol, recognise any names? The legacy of HIV and hepatitis C is a direct result of these practices and re-enforces the need here for a public inquiry. The British Government knew of the problems way back in 1975. Our Government repeatedly failed to meet deadlines to modernise and expand Elstree so that this country could be self sufficient in blood which would have prevented many people from becoming infected with American products. Across the border the Scottish National Blood Transfusion Service ran a clean, modern plant with excess capacity. The argument is that England could have collected plasma from its own donors (small blood lots with well-screened donors) and sent it for processing in Scotland. However this would have meant putting the facility on round the clock shifts, negotiating overtime pay with unions which was out of the question under the Conservative Thatcher Govt. The irony is a relatively small financial outlay at the time could have prevented many HIV and hepatitis infections and arguably saved the Govt millions of financial outlay now in HIV and hepatitis C treatment. As you read the book it is no wonder the Govt refuses to hold a public inquiry! I feel the book is a "MUST READ." The last point regarding the book is that it strikes me how complacent the haemophilic community has been in Britain compared to other countries, isn't it about time we changed that? Is there now a test for CJD in living victims, does it combine a brain scan and a test of tonsil tissue. We have written to the Society to ask for their views on this (it will keep them on their toes.) Although no one knows at present whether it can be transmitted in blood we know it has been found in plasma hence the recalls. I would like to know whether haemophiliacs who have died more recently from HIV and hepatitis C and had autopsies have had their tonsil tissue tested as part of the autopsy. We want to know whether this new CJD test will eventually be offered to what may be considered high-risk groups. The Society needs to get information on this quickly instead of lagging behind as it usually does.

CJD

This is about people who have received notices that the blood products that they, or their children, received, or that were used in the In Vitro Fertilization (IVF) cultures that produced their children, were recalled/withdrawn from the market because a member of the donor pool was diagnosed with Creutzfeldt-Jakob Disease (CJD) or was at risk for the disease. CJD is an infectious rapidly progressive fatal brain-deteriorating disease for which there is no treatment or cure. It is a member of the class of diseases called Transmissible Spongiform Encephalopathies (TSEs). Another TSE is Bovine Spongiform Encephalopathy (i.e. Mad Cow Disease) which is found in UK. The jury is still not in on whether CJD is transmitted through blood. The risk is said to be theoretical. There have been no documented cases of such transmission in humans. However, the CJD infectious agent has been found in blood. The United States Congress has mandated the Centers for Disease Control to determine if CJD is transmitted through blood products. People who have received blood recall/withdrawal notifications can still donate blood. One thing that is certain: RECEIVING A RECALL/WITHDRAWAL NOTICE CREATES GREAT ANXIETY. Therefore, the creation of the Blood-CJD support/discussion group. The goals are to provide support and disseminate research findings on blood transmission, preclinical tests, treatments and cures. At the present time there are no preclinical tests, treatments or cures for CJD. Hopefully, with the research going on in these areas this will change.

HIV/AIDS, Law, and Ethics (1) by Ralf Jürgens

Our eyes should be bright with the resolve to do practical things to slow the spread of HIV infection. In the little part which the law has to play in the great drama, we should be protectors of basic rights. They matter most when they are most at risk.(2) The approach of the law in responding to AIDS should encourage the cooperation, confidence and trust of those infected and at risk by protecting their dignity and integrity.(3)

I Introduction

The decisions made in court will be almost as interesting as the findings made in labs.(4) AIDS is more than just a disease, and spreading out from its medical effects, and the widespread fear they have produced, are social, economic and legal ramifications that pose challenges of their own.(5) One of the responses to HIV/AIDS has been an "epidemic" of laws and policies. As early as May 1991, the World Health Organisation listed 583 laws and regulations concerning HIV infection and AIDS from different countries. To this, more than 170 laws from the United States had to be added. The effectiveness of this legal response has been called in question. In the words of Justice Kirby, this "juridical outburst," while it may have solved some problems, has caused the appearance of "a new virus, HUL, for highly useless laws" (Justice Kirby, at the Symposium international de réflexion sur le SIDA, Paris 22-23 October 1987; see also Kirby M. The New AIDS Virus - Ineffective and Unjust Laws. Journal of Acquired Immune Deficiency Syndromes 1988; 1: 304-312). It is generally agreed that many of the legal or policy responses to HIV/AIDS are useless and often can be harmful and counterproductive because, instead of being based on an understanding of the medical issues, they are driven more by fear and the resulting public demand

for action than by medical research and its findings. Generally, a tension exists between "responsible legislators and jurists, who continually insist that statutes, regulations, and judicial opinions reflect the best understanding provided by medical and scientific authorities, and those who show a willingness to practice demagoguery by placating or stimulating false and irrational fears through proposed enactments or decisions that ignore established medical evidence" (see Hermann DHJ, AIDS and the Law. In: Reamer FG (ed).

AIDS & Ethics. New York: Columbia University Press, 1991, 277-309

The "Ten Commandments"

According to Justice Michael Kirby,(10) the following "ten commandments" for legal measures in the area of HIV/AIDS need to be taken into account: respect the cultural and legal diversity of every jurisdiction; ensure that the guiding criterion is containment of the spread of the virus; ensure that the law is based on sound scientific data; review old laws on public health and reform them; face up to making unpopular and unpopular decisions: So urgent is the challenge posed to society, public health and indeed global health by HIV/AIDS that law and policy makers must be willing to take bold action and to make unpopular decisions directed to the containment of the virus. Examples include the adoption of rigorous policies for sex education even in primary schools, the facilitation of the availability of condoms - including to young persons - consideration of review of drug laws and policy, the provision of sterile needle exchanges, and to cleaning bleach to cut down the spread of the virus amongst intravenous drug users, respect the human rights of all persons; resist simplistic solutions: There will be calls for "law and order" and a "war on AIDS". Beware of those who cry out for simple solutions, for combating HIV/AIDS there are none. In particular, do not put faith in the enlargement of criminal law, ensure that coercive measures are proportional to the needs for action; do not put too much faith in law: Laws and public policies on HIV/AIDS will have only a minor part to play in the reduction of the spread of the virus. Do not put too much faith in coercive laws as a means of stopping the spread. Law and the risk of punishment are usually the last things on the minds of people in the critical moment of pleasure (whether in sexual gratification or gratification from drug abuse). acknowledge the paradox of AIDS law: The most effective laws to stop the spread will include laws which help with the confidence and attention of people at risk. If we can change their behaviour - and keep it changed - we will reduce the risk of the spread of HIV/AIDS. By winning their confidence we protect them - and by protecting them, we protect ourselves and our world.

Thank you for your letter of 4th of April enclosing a mission statement from members of the 2-2 campaign group calling for compensation for people with haemophilia who contracted viral infections through NHS treatment with blood products. We have great sympathy for everyone who has suffered harm as a result of NHS treatment. It remains our policy, however, that compensation or other financial help to patients is only given when the NHS has been at fault. We do not believe that we should make an exception to that general rule in the case of people with haemophilia infected with hepatitis C. As the group say, some countries in Europe and elsewhere have compensation arrangements in respect of hepatitis C and blood or blood products, and that is a matter for them individually, according to their own circumstances. Ministers gave a great deal of careful thought to the position in this country but concluded that the introduction of the special payment scheme for people with haemophilia infected with HIV in the 1980s was unique. They faced the prospect of developing Aids and, as the Mission Statement acknowledges, a consequent short life expectancy at that time. This is not the case with hepatitis C. We all welcome the developments in HIV treatment which have taken place.

Although many of the 1200 haemophiliacs infected with HIV have sadly died, nearly 500 remain alive. We hope that there will be similar advances in therapies for hepatitis C, and we have asked the National Institute for Clinical Excellence to consider the most recently licenced combination therapy for hepatitis C as a matter of urgency.

The "2nd campaign, 2nd Injustice" Group's Statement outlines its experience of the origins of the HIV special payments scheme, and question the thinking behind the waiver which recipients of the payments signed and which, I understand, excludes them from bringing proceedings involving any allegations about the spread of either HIV or hepatitis through blood products. As you know, this was a matter for the Government at that time and I cannot offer insight into the reasons for the waiver. We remain very much aware of the needs of people with haemophilia and we are determined to provide support in a number of constructive ways. Following discussions with the Haemophilia Society we are funding an HIV/hepatitis C co-infection seminar to take place this year. This will address a number of problems for those with HIV/hepatitis C, in particular those of treatment and care. I am also pleased that the project we funded on support and information for young people with hepatitis C has produced very helpful booklets. These will be widely disseminated and will be of use to young people with hepatitis C and members of their families. We are committed to further work on similar projects with the Haemophilia Society. We have also welcomed the development of the Haemophilia Alliance, where professional and voluntary groups, including the Haemophilia Society, are working together on improving the quality of care for people with haemophilia. The Alliance has begun its work, which I understand will take the views of patients fully on board.

THE TALE OF A DIVIDED CAMPAIGN.

As the long standing partner of an HIV+ haemophiliac I was delighted to pick up the first issue of +ve magazine and read an article about haemophiliacs entitled "The Forgotten H". It was not the content of the article however that stood out in my mind but the realisation that once again a very important issue in the lives of many haemophiliacs had been omitted.

Steve Fouch the author of "The Forgotten H" and HIV worker for the Haemophilia Society went to some length to describe the problems of living with haemophilia (a disorder where the blood does not clot properly) and the added complication of also being HIV+ Steve sadly failed to mention one very important issue which is the cause of much anger and debate amongst haemophiliacs and that is HEPATITIS C, (one of several hepatitis viruses which affects the liver? and how it functions.) To explain why this should be such an emotive issue I need to explain first a little about the history of haemophiliacs and HIV.

In the 1980s, 1200 haemophiliacs were informed that they had tested positive for HIV and that they had been infected through contaminated NHS blood products. As part of their haemophilia treatment haemophiliacs have to inject themselves with plasma concentrates which helps the blood to clot, exposure to the HIV virus was through this-- plasma. After several years of fighting a campaign for recompense HIV+ haemophiliacs were eventually awarded an ex-gratia payment from the Conservative Government in the early 1990s and a trust set up to administer monies from the government. Haemophiliacs were supported in their campaign by medical staff, MPs and the Haemophilia Society.

There were two interesting points related to the settlement. The first was that the Government's Department Of Health did not accept liability. The Government only settled after it lost its appeal to prevent copying to the solicitors of haemophiliacs documents for which they claimed public interest immunity. In simple terms the Government's blood files were about to be opened up for the world to see. The settlement was agreed three months prior to a trial in which their handling of the blood service in the 1970s would have been subject to public scrutiny. The second point is that in order to receive the payout in the HIV settlement haemophiliacs had to sign a hepatitis waiver which stated that haemophiliacs could not instigate any legal proceedings if infected with hepatitis viruses before 13th December 1990.

Haemophiliacs were puzzled by this waiver but the following explanation was given to them. It was a known fact that some haemophiliacs had been exposed to hepatitis B through blood concentrates. Haemophiliacs could make an informed decision

regarding hepatitis B as they would know through previous hepatitis B testing if they had been exposed and if any liver damage had occurred. They were told that hepatitis A was not a problem to be concerned with. They were also informed that non-A, non-B hepatitis, as hepatitis C was then known, was "less of a problem than hepatitis A or B" and "nothing to worry about". Haemophiliacs were reassured and signed the waiver.

There was a test for hepatitis C in 1989 but our Government decided not to use this test on the grounds that it was not totally accurate. Other European countries however decided to use the test on blood donor supplies and err on the side of caution destroying any blood that tested positive rather than allow contaminated blood into the system. Widescale testing for hepatitis C was introduced in this country in 1991.

Around 1993 and 1994 many haemophiliacs were tested for hepatitis C some without their knowledge and without pre-test and post-test counselling. This wasn't difficult to do as haemophiliacs often give blood as part of their routine tests for example to check clotting levels. Haemophiliacs began testing positive for hepatitis C. There is evidence that some haemophiliacs were tested much earlier than this and decisions were taken not to tell haemophiliacs of their hepatitis C infection. 95% of haemophiliacs who were infected with the HIV virus were to find out several years later that they had been infected with a second virus hepatitis C; for those who had also been exposed to hepatitis B, it was virus number 3. There were now over four thousand haemophiliacs in total with hepatitis C as many who had escaped HIV now found themselves to be hepatitis C+.

Haemophiliacs began ringing the Haemophilia Society asking the Society to set up a further campaign for recompense because as more and more facts were emerging it was clear that hepatitis C was not the harmless little virus haemophiliacs had been led to believe. There was also written evidence showing that the Government knew at the time of the HIV settlement that non-A non-B, as hepatitis C was then known, could lead to serious liver disease and some deaths had occurred in UK haemophilia patients.

The Government has its own medical advisors who research health issues and as far back as 1985 an article appeared in the Lancet medical journal entitled "Progressive liver disease in Haemophilia: An understated problem?" This 8 year study looked at 79 unselected patients with haemophilia who had received factor concentrates. It looked at liver disease in these patients and concluded that histological evidence suggested that non-A non-B hepatitis was mainly

Cont : From Pg 4

responsible although the influence of other viruses could not be excluded. At that time few reports of death attributable to liver disease in haemophiliacs had occurred. However the study anticipated that liver disease in haemophiliacs would become an increasing clinical problem. The writing was on the wall!

I began campaigning myself for all infected haemophiliacs in 1994, and contacted my MP who took up the issue immediately. At first the Society refused to take up the campaign but were concerned enough by 1995 to launch a hepatitis C campaign and announced this in their magazine "The Bulletin". The campaign however has had a devastating effect on the haemophilia community, splitting it apart.

The Haemophilia Society took the unwise decision to campaign for financial recompense for hepatitis C infection on behalf of the mono-infected, (those haemophiliacs with hepatitis C only) and exclude the co-infected (those who have both HIV and hepatitis C). They enlisted the support of MPs, many of whom until recently did not realise that there was a group of haemophiliacs with both viruses. Co-infected haemophiliacs found out by accident that meetings had been arranged with MPs and Government ministers to discuss hepatitis C to which only the mono-infected had been invited. Haemophiliacs were turned down for recompense but only the mono-infected had been given an opportunity to present their case. Some people believe that because of the particular problems related to co-infection which are presented later on in this article that there is a far stronger case on health grounds and suffering to provide recompense for haemophiliacs with two life threatening viruses.

The biggest irony for co-infected haemophiliacs was watching on the national news as the Haemophilia Society, MPs and mono-infected haemophiliacs laid 113 white lilies for those haemophiliacs who had died from hepatitis C without explaining that the overwhelming majority of those deaths from hepatitis C were from the co-infected group. There are now at least 7 more lilies to add to the 113 as 7 co-infected haemophiliacs have died from liver problems in the months since Christmas. I do not wish to cause any distress to the mono-infected as I fully acknowledge that deaths have occurred in that group and some mono-infected haemophiliacs are very ill, I simply wish to state facts and for the deaths of the co-infected to be recognised. It is still my wish that all haemophiliacs unite and fight together for justice.

My campaign aims have as stated earlier always supported the fight for recompense for all hepatitis C+ haemophiliacs whether mono-infected or co-infected. I feel from many conversations with

Haemophilia Society staff that the Society is afraid that because the Government awarded a payout for HIV, which is a distinct and separate virus from hepatitis C, that the Government would not consider a second claim. The Society seems to think a campaign is easier to win without the co-infected, but what about 'Dignity and Justice'? To be fair there are some individuals within the Society who do still support these principles and I applaud those individuals for helping where others wouldn't.

I ask the reader to consider the following scenario. A man is knocked down on a zebra crossing by a driver who fails to stop, his back is injured and he receives compensation for his injuries. He is not asked to sign a piece of paper to waiver his rights for compensation should he be knocked down again. Several years later he is hit by a drunk driver who mounts the pavement and the man receives another pay-out for leg injuries he has received. He is not deliberately penalised for being injured previously in an incident where he was not at fault.

We can look further at the Consumer Protection Act. If a woman buys a pie from a shop and becomes ill with food poisoning which is proven to be related to the pie she can take some form of legal action. It seems that recipients of contaminated blood products (are they not consumers of a kind?), have few legal rights yet they pay taxes which go toward funding their health care. How many times have haemophiliacs heard the immoral argument that they needed plasma for their condition and that this fact makes it acceptable to put them at risk of death from contaminated products? Previous Governments had choices, they refused to put the necessary money into the manufacture of blood products in this country until it was too late for many people and instead concentrated on importing American products that were known to be less safe. There is medical evidence going back to the Korean War that soldiers who were treated with blood products from huge pools of donated blood (that is blood from many donors) were at high risk of contracting hepatitis and there have been campaigns in the past to reduce the size of these blood pools. Now haemophiliacs do have the possibility of using recombinant treatment which is produced from genetically modified animal cells.

This treatment is safer but whether you receive this depends on your age and where you live. Some health authorities will only fund recombinant for under 16s. There is pressure to obtain recombinant for all bearing in mind that recently British made plasma was withdrawn because of a theoretical risk of CJD.

After a number of years trying to get the Society to support all hepatitis C + haemophiliacs in their fight for recompense the co-infected have launched their

THE TALE OF A DIVIDED CAMPAIGN.

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own campaign we are fighting for a second pay-out because there has been a second injustice. Haemophiliacs are setting about legally challenging the hepatitis waiver and also looking towards the European courts. (Ireland has already paid out to haemophiliacs infected with hepatitis C through blood products.) Co-infected haemophiliacs and their families are often asked if their campaign is just about money. It is hard not to get angry when asked this but most would have answered that its primarily about justice for those who are infected and for those who have families. It is about not allowing ourselves to be conned by people whom I suspect did not anticipate that HIV+ haemophiliacs would be left alive to fight a second fight. There are about 443 of the original 1200 infected still living and even if only a handful were left their families would fight on in their name. Winning the fight for justice would also bring added financial security for those who are too ill to work and help family members who may themselves have given up their own careers to become full time carers. There are of course the myths which fly around that the co-infected and their families are rich and live in the lap of luxury. I make several points here.

One is that the money awarded for the HIV settlement was based on a very short life expectancy and without being so sick as to quote figures I will say that the total lump sum award granted for example, to a young haemophiliac, who should have had a long healthy life to look forward to, was similar to a nursing sister's salary for one year. It's hardly the high life! We must not of course forget those who are no longer with us including my partner's brother who died (aged 20) long before any recompense was awarded.

What are the particular problems of the co-infected? In a sentence, the two viruses do not get on well together!

Higher levels of hepatitis C virus are generally found in HIV+ persons as opposed to HIV negative persons. The higher the serum level of hepatitis C virus, the less chance of a response to Interferon -a treatment. A higher rate of liver failure is seen in HIV+ haemophiliacs. The majority of liver disease in patients with haemophilia and HIV is caused by hepatitis C, but other opportunistic infections can go unrecognised,

Birchgrove Hepatitis C Pamphlet

Drug combinations taken to help combat HIV can cause problems to the liver of someone with hepatitis C and may affect liver function. Treatment discontinuation due to liver toxicity is also more likely in people co-infected with hepatitis C. Interferon I Ribavirin used to treat hepatitis C is often considered

an unsuitable treatment for HIV+ - haemophiliacs with damaged immune systems. Even if this were not the case some hospitals are at present being turned down in their bids for funding this type of treatment.

HIV+ haemophiliacs are usually at the bottom of the list for liver transplants as the risks are generally considered too great. On a positive note there is a co-infected haemophiliac who has had a liver transplant and seems to be doing well 6 months after his operation. It appears that part of the reason is that unlike the majority of co-infected haemophiliacs his HIV was stable and he had no detectable viral load. There is of course a waiting list for transplants and those who are deemed to have the best chance of being successful are the ones to go ahead. Co - infected, for the reasons stated, would rarely make this category.

Drugs such as AZT (taken as part of an HIV treatment regime) combined with Interferon can lead to a significant risk of anaemia. There is evidence that some people who go onto Interferon I Ribavirin combination therapy are more likely to see a significant rise in their viral load. This is a strong indicator that the HIV combination therapy is beginning to fail.

Even routine operations on elbows, ankles, knee joints etc that are common in treating haemophilia related conditions become a risk as anaesthetic can be dangerous to people with liver problems. There is some evidence that co-infected haemophiliacs may be more likely to transmit hepatitis C virus through sex perhaps because they may have higher levels of the hepatitis C virus in their genital fluids than those who are HIV negative.

Finally, to return to the title of this article, "The Forgotten C". It is my hope for the new millennium that the issue of hepatitis C is not swept under the carpet by this Government. I would say to Mr Blair and Mr Milburn please listen to what we are saying, we want a full Public Inquiry into how people with haemophilia and related bleeding disorders were infected with hepatitis C and HIV. We have still not had answers to our questions.

As the Haemophilia Society approaches its 50th year celebrations. I would suggest that before it looks forward the Society needs to reflect on why it was set up in the first place.

I can not forget that haemophiliac friends of mine went to their graves feeling angry and let down by the Society. I urge people reading this who are infected or affected by hepatitis C to do their bit in educating others and to those haemophiliacs who have taken a bit of a back seat to write to your MPs.

This campaign needs you!

THANKS TO NAM

For most people with HIV who don't take anti-HIV treatments, the longer they are infected, the more damage the virus does to the immune system. After this reaches a certain point you can become ill from infections that your body could have easily fought off before. These are called opportunistic infections.

Doctors can predict when you are at risk from opportunistic infections by counting the number of cells which help fight such infections, called CD4 cells (or T-helper cells), in your blood. For adults, your risk of developing most serious infections is low if your CD4 count is above 200-250. But the number of infections that you may develop rises the further your CD4 count falls below 200-250.

If your CD4 count falls below certain levels, your doctor may recommend that you take medication to prevent particular infections.

This is called primary prophylaxis - preventing an illness before it occurs. If you do develop an infection, once you have recovered you may need drugs to prevent it from recurring. This is called secondary prophylaxis or maintenance therapy.

Better drugs to prevent or treat opportunistic infections have increased the life expectancy of people with HIV. For some infections there are very effective drugs. PCP, a pneumonia which used to be the main cause of death for people with AIDS, can now be largely prevented.

However, not all infections can be prevented, and clinics may have different views on which drugs they recommend.

Deciding whether to take prophylaxis means weighing up the benefits of preventing the infection against the inconvenience of taking medication and the risk of side-effects. For some infections such as PCP the balance is clearly in favour of prophylaxis. For others such as CMV and MAI, the balance is less clear. It's important to consider the following issues when deciding.

First you should consider whether you are at risk of a particular infection. Partly this depends on your CD4 count, but your doctor can also offer blood tests to see if you are infected with certain organisms, such as toxoplasmosis and CMV.

If you are not yet infected, you may be able to take steps to avoid exposure, rather than taking drugs.

If you are at risk, find out how effective the medication is likely to be, and what side-effects it may cause. There is no way to tell whether you will develop a particular side-effect. Most side-effects from preventive drugs will go away if you stop taking them. Some drugs must be taken with special foods or no food at all, or at particular times of day.

This may require changes in your routine that could affect your quality of life. There may be several possible drugs, so you can choose one that suits you best.

Some people may not be able to find an acceptable prophylaxis treatment. Others may not like the idea of taking any medication whilst they still feel well. An alternative is for your doctor to monitor you for the earliest signs of each opportunistic infection. When caught early on, most infections respond well to treatment.

However, opportunistic infections are serious - they are the main cause of death among people with AIDS. People who develop opportunistic infections nearly always lose weight, which may be difficult to regain and increases the risk of further illness.

Preventing infections in the age of HAART

The use of Highly Active Antiretroviral Therapies (HAART) has dramatically reduced the incidence of most HIV-related illnesses. In fact starting HAART may be the most effective way of protecting yourself from them. Nevertheless, even if you are taking effective HAART, your doctor will still advise additional prophylactic medicines for opportunistic infections if your CD4 count is below 200.

Stopping prophylaxis

Evidence now suggests that people whose CD4 count on HAART is maintained above 200 for several months can safely stop any prophylaxis to prevent PCP which they may have been taking. Whether preventative medicines for other illnesses can be stopped is less clear, so discuss the possible risks and benefits with your doctor.

P Bateman

Many of us already use complimentary medicine or therapies alongside our treatment regimens or as an alternative to conventional medicine. The type of treatments or therapies available are quiet widespread and can be used to help a variety of problems caused by suppressed immune systems. The MFT also give an introductory grant to anyone who wants to try alternative or complimentary therapists as an incentive to its registrants to improve their well-being.

So how do you decide what kind of therapy to use and also where to get in touch with someone who is experienced in treating people who are immune suppressed ?

I did a bit of research into this and was surprised that there is no national database of such therapists that I could find.

If you live in London congratulations, there are numerous clinics around the capital that have experienced therapists giving free treatments throughout the daytime and evenings and in most kinds of therapies available.

Free treatments are available at ACE Project 0208 646 0646, CARA 02077271623, FACT5 0208 3489195, Globe Centre 0207 7912855, Immune Development Trust 0207 7041777, The Link 0207 2671100, London Lighthouse 0207 7921200 and Positive Place 0208 6949988. Body and Soul 0207 833 4828 offer treatments to straight only (non-gay) HIV+ people and if you live outside London you can still access their services. There were a few other places that gave free treatments but seemingly to gay only, black only or positive women only. If you fit into any of these categories you will have more avenues open to you.

Outside of London there are a variety of free complementary therapies at random venues but certainly not accessible to everyone. Solas in Edinburgh 0131 661 0982, BP Strathclyde 0141 3325010 and BP Tayside 01382 461555 are the only providers of free complimentary therapies in Scotland that I could find. In Wales, SWISH BP at Swansea 01792 461848 is the only option. The rest of England is served by Newcastle BP 0191 2322855, Wear BP in Sunderland 0191 5483144, THT in Leeds 0113 2951920, Pennine Aids Link in Bradford 01274 734354, N.Yorkshire Aids Action in York 01904 640024, BP North West in Manchester 0161 8738100, Merseyside BP in Liverpool 0151 7070606, LASS in Leicester 0116 2559995, Shropshire Buddies in Shrewsbury 01743 350075, The Foundation in Worcester 01905 611602, Freshwinds in Birmingham 0121 3508423, FBT in Suffolk 01502 531300, The Crescent at St. Albans Herts. 01727 842532, Open Road in Essex 01206 766096, Aled Richards Trust in Bristol 0117 9551000 and in Bath 01225 444347, Devon HIV and Aids Association 01392 494 441, WPTT in Maidstone 01622 755207, Positive Action in Hampshire

01252 511980, Bournemouth BP 01202 297386 and Open Door in Brighton 01273 605706. Brighton BP 01273 693266 offers therapies at a reduced rate.

All of these offer Aromatherapy, Reflexology and Massage and many offer Shiatsu, Acupuncture, Craniosacral therapy, Hypnotherapy, Reiki, Homeopathy, Traditional Chinese and Herbal medicine, Iridology and Tai Chi. Some of these centers also offer home visits.

The best starting point I think would be at Body Positive who have a wealth of experience and a large database of other agencies. The Immune Development Trust were also extremely helpful and gave me a list of contacts. The Internet is also invaluable for information on this subject. www.aidsmap.com gives a lot of advice about choosing a therapist, what questions to ask, what each therapy is actually about and how it might help. It doesn't however give help on how to find one. The Immune Development Trust www.idt.org.uk and Body positive www.bodypositive.org.uk have details of all the Associations and Governing bodies that have accredited practitioners on their books. The MFT may also be able to give you advice. If you know what kind of therapist you want the easiest way to find a practitioner is to consult the relevant association, which can refer you to a qualified practitioner in your area. All you have to do then is call and make an appointment. Having a home visit, by a reflexologist or aromatherapist for example, I personally find more beneficial, as the relaxed state you are in after the treatment is not conducive to having to drive home.

However this can be more expensive than visiting a practitioner. I feel that a range of complimentary or alternative therapies should be available to all of us via our centers but either lack of funding or doctors reluctances to accept them seem to get in the way.

As treatment options start running out due to resistance to anti-HIV therapy or just as an alternative to taking anti-HIV treatments or to work in line with existing treatments as an immune system booster and general stress relief complementary therapies have an important role.

If you have never applied for a complimentary therapies "taster" grant of £200 from the MFT just pick up the phone and ask. There is no need to write a letter for this grant and it is also available for your partner / carer as the MFT recognize that carers need some relaxation and stress relief too. If you are already receiving complimentary therapies and know of any other avenues for receiving free treatments either at places not mentioned in this article or through your own center or G.P. please inform The MFT or The National Birchgrove group so this information can be passed on to other members.

ONCE A SMOKER, NOT ALWAYS A SMOKER

BY BABS EVANS

I had my first cigarette when I was about 10 years old. We had a shop and it was easy for me to nick the odd packet from the store cupboard under the stairs. With my constant supply I had much 'street-cred' with the other kids on the estate.

By the age of 14 I was a regular smoker and was often in trouble at school for feeding my nicotine habit in the toilets, at the end of the playing field or behind the out buildings. I envied the sixth-formers because they had their own common room and could smoke in comfort at breaks or during free periods.

If you were asked to get a teacher from the staff room the nicotine rush hit you as soon as the door was opened. My furtive smoking however, meant I was often waiting to see the headmistress for the obligatory lecture, during which I had perfected the art of slouching, chewing imaginary gum, skyward expression and look of extreme disinterest.

The final straw for my parents came when they were summoned to the school after a rapidly discarded fag-end in the loos ignited the paper towels in the bin, resulting in mass evacuation and an emergency visit from the Fire Brigade. Nothing to do with me of course!

Following this Mum and Dad allowed me to smoke at home in the hope that I would no longer need to do it at school. Unfortunately they hadn't realised that there was a social element involved and I continued to meet up with my fellow smokers at break time. As I was supposed to go home for lunch I took great delight in lighting up one step beyond the school gates knowing that I was beyond punishment.

When I left school at 16 I went to Art College which was quite a culture shock compared to my all girls Grammar school. We could come and go as we pleased and smoked to our hearts content - not only tobacco - after all it was our duty as Art students to get high in the name of creativity! My Graphics Tutor tried hard to be trendy, smoked 'More' cigarettes and drank Whisky in his office. It seems odd in these no-smoking times to think of us sitting at our drawing boards filling up the ashtrays as we did the Guardian crossword and pretended to work whilst discussing last night's *Brideshead Revisited*.

After college I embarked on my career in advertising and design. Nearly everyone smoked in the studios I worked in, and people who didn't smoke cigarettes smoked dope anyway so didn't object. It was 'normal' to smoke and over the years my daily intake increased to 40 a day.

I could never imagine myself as a non-smoker and was critical of the increasing number of people who objected. Although I heard the messages that smoking was bad for me I didn't listen and felt I had a right to smoke. On trips home I filled my parents house with

clouds of smoke from morning to night. I refused to enter no-smoking cafes and theatres, cinemas and aeroplanes were all an ordeal.

When I was diagnosed HIV positive I had even less reason to stop smoking, after all I was going to die anyway so it didn't matter. I embarked on a trail of over-indulgence, over-eating, over-drinking, over-working, over-playing, over-spending and over-smoking. A couple of years later I was ill with suspected PCP and could barely breathe. It was one of the few occasions that I couldn't smoke, but after a day or two I managed to light up again.

I had lots of chest infections, ear infections, a raspy voice, breathlessness and a terrible complexion but I used HIV to explain away these symptoms.

There wasn't one particular thing that spurred me to stop smoking, more like a variety of influences. My new job was in a non-smoking zone and standing outside in the rain at 3 o'clock in the morning on a night shift was irritating me. I was trying to get fitter but swimming one length of the pool left me breathless and coughing. The white paintwork in my living room was yellow and sometimes if I had smoked a lot the night before I could smell the stale tobacco next morning. One evening I mentioned to my lover that his breath smelt of garlic, "Well, it's better than cigarettes" he responded. During this time I was trying to cope with the nausea resulting from my drug combination and sometimes I would be retching and still trying to smoke.

One of my work colleagues had stopped smoking and he told me about a book called 'The Easy Way to Stop Smoking' by Alan Carr. I bought the book but didn't open it for 3 months. I knew that once I read it I would have to take action and was putting off the inevitable.

In the end the timing seemed to work itself out. My friend had offered to redecorate my living room and so I planned to stop when the work was done. I spent the weekend reading the Alan Carr book and put out my last cigarette on the Sunday night. I was going to go straight to bed but felt that would be cheating so I stayed up another couple of hours and it wasn't too bad.

The first day was hard but I found myself on a bit of a high. I felt really good that I'd managed not to have a cigarette and rewarded myself with a takeaway in the evening. The next couple of days were harder though and I found myself getting emotional and tearful.

I had deliberately avoided going out during the first few days but at the weekend I went to the pub with friends. It was previously inconceivable to think that I could sit in a pub with other smokers, drink and not have a cigarette, but I did it.

During the following couple of weeks I allowed myself a certain amount of comfort eating and bought little treats to nibble on during the evenings. However I was

ONCE A SMOKER, NOT ALWAYS A SMOKER

very worried about putting on weight so after three weeks I became strict with myself and made sure I didn't substitute the craving for a cigarette with food. As a result I didn't put on any weight and have actually lost some.

When my next pay day came I withdrew £200 (the amount I would have spent on cigarettes) and bought myself some clothes. Then I set up a monthly Standing Order of £200 and 7 months later I bought myself a computer, with money I would have set fire to!

The difference in my health has been amazing. My skin looks fantastic and no longer has the yellow tinge that I didn't even realise it had until afterwards. My level of fitness has improved drastically and I swim 3 times a week. People tell me I sound different on the phone, my

breathing is not as shallow and I don't clear my throat all the time.

It is a year now since I stopped smoking - from 40 a day to zero and I'm really proud of myself. I had one relapse last November when I was very drunk and smoked but I felt dreadful the next day - as if I'd failed - and it hasn't happened since. I am trying hard not to be hypocritical and I tell people I don't mind if they smoke, but it stinks!

Finally, I was in Manchester last weekend and saw my old Graphics Tutor. It was like a time warp, he was still trying to be trendy and still had a 'More' cigarette in his hand. I'm glad I've moved on.

LONDON BODY POSITIVE

CLOSURE

In a devastating blow to the capital's HIV services, Body Positive has been forced to close after nearly 15 years and will cease operation on 31st May 2000. Despite continued support from particular funders such as Kensington & Chelsea and Westminster Health Authority, The Monument Trust and The Elton John AIDS Foundation, the balance of funding needed was not forthcoming resulting in BP trustees closing the doors forever.

"This was a tough and very sad decision to make" says BP's chair of trustees Martin Skipworth. "Although our closest funders had agreed to continue their support for BP, it was simply not at the level we need to continue operating. It's a crushing blow to the staff and volunteers - but especially hard for service-users who depend on BP for treatment information, counselling, therapies and training at a time when demand for our services is increasing."

BP managers have spent months trying to streamline the organisation to a sustainable level resulting in cuts being made in staff, services and facilities. "That's what is so disappointing," says Skipworth. "We have made every effort to adapt BP, and all to no avail. We did not require money for expansion - just enough to enable us to keep going and to underpin our plans for the forthcoming year. Our business plan was realistic and we were extremely confident of some exciting new funding that would have sustained our services for many years to come. And now there's a great gaping hole at the heart of London's HIV services."

Ironically, the closure of BP comes at a time when its services are more popular than ever. The ever-growing demand for services placed a heavy burden on BP's already tight budget. Efforts to maintain the high quality services on offer had forced the organisation into a deficit situation to the tune of approximately £120,000. "We had hoped that, by working with our main funders - the Health Authority, Monument Trust, Crusaid and EJAF - we could

negotiate a package to ensure BP's survival," adds Skipworth. "Although most have expressed their willingness to work with us, it simply wasn't unanimous, and my fellow trustees and I have no choice but to close down."

The closure will hit service-users hardest and BP managers are working to ensure services can be transferred to other agencies. "BP has always been at the forefront of providing services that put HIV+ people first," says Skipworth. "Most of the services we provide have a direct effect on the quality of people's lives. Our Skills for Success programme is one of our most popular - and all of those taking the courses will now be interrupted mid-stream. It is important that these services are continued with minimum disruption - even though, in many cases, that will mean continuing to access services through other HIV agencies."

Other organisations within the sector have been extremely supportive to BP at a time of great sadness and disappointment. "The National AIDS Trust played an important role leading to the Department of Health's decision to forward funds to help the transition of our closure," adds Skipworth. "We are currently working closely with the KCW Health Authority and other agencies to ensure that by the end of the month alternative arrangements are in place to ensure services can continue to be offered to service users - something we wouldn't have been able to do were we forced to shut the doors today".

Although every effort has been made to ensure the least inconvenience to service-users some have understandably reacted angrily to the news. "It's outrageous," says one. "It seems that no one understands the importance of BP's services to people with HIV. "Why are some organisations constantly campaigning for money when that money doesn't filter down to the charities who need it? Have they stopped to think about the effect this is going to have on ordinary people like me?"

Relationships

I LOVE ' WE LOVE ???

I am a fairly new reader of the Birchgrove Newsletter and generally find it thought provoking although often challenging and more than a little depressing at times but nonetheless I am quite addicted to reading it even though at the end I know it is unlikely I am going to be leaping for joy. One of the ongoing issues seems (understandably) to be about relationships - both getting one and keeping one. So I thought I'd add my own comments and experiences in to the pot.

It is a fact of life that relationships can be difficult even in the most ideal circumstances so with the added complications of Haemophilia, HIV and HCV - a challenge is a gross understatement. Now, I have worked in HIV for a long time. I spend my days counselling people pre and post test. I also counsel the partners, carers and significant others of positive people and do huge amounts of prevention and general sexual health training. So I think without being too self-promoting that I know a fair bit about HIV.

So, if my career is a plus point then relationships are definitely a minus. My brother, in the way that brothers can be unkind, tells everyone that I am to good relationships what Danny Le Rue is to Rugby Union. So I guess you get the picture my relationship history has not been a great success story. The term serial - monogamy (and sometimes more serial than monogamy) was coined with me in mind. None the less I do have a qualification that says I can counsel people around their relationship issues, the irony of which is not lost on me - or my past partners!

One thing I have learned, through a series of quite disastrous relationships and from my clients, is that when you meet someone you have loads in common with you agree on everything and enjoy the same activities. But give it a few years, months or even weeks, and you sit down and say those words - usually to someone else not to each other - "we have nothing in common". Now will someone please explain this to me, do we all lie blatantly when we meet someone we fancy? Do we smile sweetly and say yes I love fishing, golf and Kylie Minogue - and no I've never done hang gliding but I have always wanted to? Do we at that moment, totally blinded with lust, really believe that we like all those things? Are we convinced that we will like them as long as we are doing them with the gift from heaven that is sat before us, or are we secretly plotting to turn them off trainspotting and on to knitting at the first opportunity. Of course, eventually, all is revealed and we either grin and bear it or we leave (or are left). I confess to be a leaver and a left rather than a stick with it person. Hence I arrived in my late thirties convinced (once again) that I am better off on my own.

But fate has a nasty way of poking me in the eye and the best time to find a new relationship (apparently) is when you don't want one. I met my current (I think that

might be another temporary status acknowledgement?) partner through my work. I am ashamed to say he was not only the first positive haemophiliac I had ever met but also the first haemophiliac (which may suggest that I have had a more sheltered life than I thought). Most of my work, as you would probably expect, is with gay men, so heterosexual positive men are still a novelty in more ways than one. We both had issues to confront around that!

During our early discussions, the subject of relationships and their associated problems cropped up and obviously I do know enough to acknowledge how difficult it can be to find a partner when you are HIV positive, most obviously, at what point do you tell them your status? First date? Telling too early will probably elicit the response that sex was not on the cards anyway. But wait a few dates until it is on the cards and then it's probably too late, both of you may get hurt if your new partner can't handle it and there is the risk that if your status is not known it soon will be - not good! You don't have to tell but way down the line your partner may be angry you have not trusted them enough to confide and accuse you (hopefully unjustly) that you have put them at risk.

Of course that was not an issue for us as I knew his status before I knew him. S from day one everything for him was out in the open - in fact I felt like I had more to confess than he did. So is it easier for us? - Well, I think the jury's still out on that one...

I have had sex with people I know to be positive and I have had sex with people that probably are and I have had lots of unsafe sex and I should know better. But life is not a text book or a training session and I do get cavalier from time to time so the fact that currently I am negative is probably more by luck than judgment. However, I have never, up till now, knowingly had a positive partner, which is more than just having sex with someone who is positive, you have to buy into the whole caring and sharing routine. Even though I know all about 'it' ,rather than making it easier, in many ways it is harder. I did not want to feel like I was always at work and I did not want my personal life to impact on my job. Well, I had to forget both of those ideals very quickly - there is no way I can keep things completely separate. There are probably loads of reasons why this relationship is not a good idea and only one that it is - and that is that I really like him and that's good enough for me just now.

I have read and heard much from the Birchgrove wives that they chose to marry a haemophiliac they did not choose someone who was HIV and HCV positive. I of course 'chose' to be involved with all three things so does that mean I have forfeited my right to complain, to be angry or to seek sympathy. The problems of having a positive partner are well documented but because

Relationships

we(I) do not get the chance to wallow very often I will labour them again. I have no right to be sick or have problems, as no matter how bad I am, his will be worse. I must listen and comfort when he is depressed and concerned about the future but I cannot talk to him when I'm worried as this may bring him down. He can choose to tell no one his status because it is his secret and I am tied into that secret with the associated problems it gives me. I do hold my breath every time he gets a cough, or a pain. I respect his right to take risks with his medication, his health and his life even though this may shorten the time we have and I can never ever say "what if the condom splits". Of course this is all nonsense and all in my head, my partner is the angel of understanding and this is my stuff, my rules, my issues and my problems

This is also of course exacerbated by my daily work. I talk to people whose therapy is failing and then I go home and talk to my partner. Yes I get to know all the good news but I get to know all the bad news too and when I go home how can I say 'how it was for me at the office today darling'. Lots of undealt with emotions and never the right time. I was also stunned at the lack of support I got from my friends who know what I do and have always supported me 100%. I was told "don't get involved", "don't have sex", "don't kiss him" (what??). The most encouraging comment was "I guess you know what your doing but I'd rather you didn't". Just for the record I have no clue what I am doing but I am happy and I don't care (much). Not one person seemed to be able to say they were happy that I had found someone who made me smile again.

So is it all gloom and doom? Absolutely not, the good stuff far out weighs the bad and most of our life is not spent talking about 'that!' In the beginning I read a lot and learned a lot about haemophilia and I can't say what is because of his situation and what is because of him, the person, but he is honest and straight forward and nothing phases him and he is wildly optimistic and the glass is always half full and never half empty. He is blissfully uncomplicated and blissfully unlike me. He puts up with the fact I am always at work, have demanding friends, and am selfish and stropky. He is probably one of the most together people I have ever met in my life, one of the few people who does not need counselling and should we ever need to stop being lovers, I do hope he will always be my friend.

And finally to sex. Try as we might most of us just can't avoid it. Sex with my positive partner is very different to sex with a positive person and an untested/unknown status person. If I know I am having sex with a positive person I am usually more careful (obvious?) but if it is probably a 'one off situation then it is easier to be clinical and unemotional. If my partner's status is unknown it is easier to take risks (they are probably negative?). When I suddenly had a positive partner I

didn't want sex to be clinical where being safe became the major factor. I made decisions about which risks were OK risks for me and admitted to myself that I could not cope with a physical relationship that did not include total intimacy and shared bodies. So in detail, for me/us mutual masturbation is OK, oral sex is OK (actually that should have said great not just OK- but you get the gist), and we use condoms for and only for, penetrative sex and we delay the moment for as long as possible. I hate condoms with passion. I can name them, all and their colours, flavours and uses; I can demonstrate them using every available penis substitute, but I still hate using them for sex, and using condoms because you want to or think you should is very different to using them because you have to. To think this is it, condoms forever, depresses the hell out of me. Rather than spending all that money on a vaccine programme how about finding a spermicide that kills the virus in the sperm (OK that was a joke - after the vaccine will do).

So yes I am a sexual health adviser and I take more risks than most health professionals suggest I should but as I said earlier I live in the world not in the textbook.

So, if you are embarking, or thinking of embarking or thinking you will never ever be able to embark on a new relationship then be optimistic. There are people out there who are going to be OK about your status (and not just those that work in the field - in fact avoid those if you can). When to tell people about your status obviously depends on a million factors. Most of all it should be when you are ready and never let any one bully you into telling any one before you have sex if you do not want to. This is your secret and when we embark on a new relationship we slowly build up trust and bit by bit share more and more of our life experiences (aka skeletons in our cupboard). If you imagine your life as a chest of (three) drawers. The top drawer is the trivial stuff you share at the drop of a hat with any one, the middle stuff is shared only with people you know and trust and have a much deeper relationship with and the bottom drawer stuff is shared with probably only a handful of people in your entire life. Now which drawer your status is in will vary but I guess for most people it is the middle or the bottom. We have to take risks in life and loving someone involves the huge risk of opening us up to the possibility of getting hurt. So sharing our darkest secrets can be just as hard as disclosing our HIV status and all carry a risk of betrayal but the alternative is a safe and secure nothingness. So being brave carries a risk but also a potentially huge reward - or is it easy for me to say that?

And by the way in case you were wondering, my partner and I have nothing in common, absolutely nothing. We disagree about almost everything, so maybe that is why it works - at least for the moment!

Who or what are we. “Defining the term Haemophilia”

LETS GO DISCO LETS GO !!

The term ‘haemophiliac’ is a sign of being lazy and comes from not thinking about language. I choose to use haemophiliac about myself after having thought about it. I will try and explain why below.

I wholeheartedly agree with you that we should think about the language we use and what effect that has on people, that the definition of words and roles are important and do affect how people view us. However by asking for a blanket imposition of a phrase (people with haemophilia) you are allowing, indeed I would go so far as to say promoting, a system which allows people to get away without thinking about the language they use and so in practice prevents your objective. Any compulsory word use would do the same and so I prefer a system where people are required to justify the use of each word in its context.

I reject this notion of being a person with haemophilia because I am a person first and haemophilia is a secondary trait. There is no first and second to immutable aspects of me. I am a white, straight man. I am not a white person first and a man second or vice versa. I am all of these things at the same time and all of the time. I also reject the "color-blind" approach of pretending to ignore someone's attributes such as skin colour or disability. Black people are treated differently to white people in society and I think that should be recognised and acknowledged. Logically, as I see disabled people as being treated differently to non-disabled people in our society, sometimes generically and sometimes according to their specific disability. I think the specific disability should be openly recognised and acknowledged.

Groups when they have chosen to define themselves in Europe have all followed the same linguistic pattern. Hence where self-definitions have come they have been for example, black, gay, deaf, disabled. Please take particular note of disabled rather than people with disabilities. I also call myself disabled rather saying I am a person with a disability. I will say that I have a disability if I feel the context is appropriate much as I use the adjective ‘disabled’ when I feel the context is appropriate. These words / labels are used as way of describing ones own immutable characteristics and not as bonus qualities that one has. I am not a person with male genitalia or a person with heterosexual tendencies nor is my lover a ‘woman with enhanced melanin.’ I am straight and male, and she is black.

I cannot conceive of myself without haemophilia having had it all of my life; it has shaped my schooling, my attitudes toward life, my relationships toward other individuals and my type of work. This does not mean it is the most important thing in my

life merely that I would have been radically different without it. Society may have played a large part in the shaping which followed from my diagnosis of haemophilia, such as whether I had to go to a special school or not.

(It led me to look for white collar work, prevented my freedom of physical movement, left me in pain each winter and made lying in bed having a cuddle with my girlfriend a careful adjustment of which of my limbs can comfortably go where.)

That this diagnosis leads to negative social consequences does not mean I feel I should not have been given the label of disabled. I wish to challenge the perception of disabled people as stupid, not challenge the recognition of their disability.

Haemophiliac/person with haemophilia is a role, albeit not an explicitly defined one in life. Roles people choose and are assigned take the verb ‘to be’, not the verb ‘to have’. I do not have ‘information work’, I am an ‘information worker’, I do not ‘have parenthood’, I ‘am a father’, etc.

These roles are not the whole of my being and I take on other roles at other times. I am a patient at times, a commuter at others and a tourist at other times. I expect other people to recognise and be aware of this. I view people who can only view me in one particular role as wilfully or unthinkingly simple minded.

Whether that is a client of mine who wants me to continue my role at weekends when I am not working, or people who denigrate visitors to their home town does not matter. I am only that role some of the time. If a person has a perception of the role of a haemophiliac and can only conceive of me in that role, then they are wrong, not the word itself.

Some of my roles are more than transitory or not self defined. These ones include ‘son’ which will persist until both of my parents are dead; ‘worker’, until I retire; and ‘haemophiliac’ which will be ‘til death or liver transplant. I have not chosen to take on these roles - they were determined by society before I arrived. I can choose to ignore them and pretend I am not someone's son if I really want to but I cannot biologically stop being those peoples' son any more than I can biologically stop being a haemophiliac. I have parents and I am their son. I have haemophilia and I am a haemophiliac.

(Editor's comment: I imagine this will create at least one letter of response. It's a subject that has concerned me for many years. I see myself as Gareth Lewis, a loudmouth from Wales, the Bastard from Birchgrove. The one who has dedicated his life to fighting for dignity and justice for all those infected with whatever virus).

Moat House Oxford

Well I'll do my best to give you all an insight to this event. As expected the AGM was nothing but predictable with any questions that contradicted London remits and policy, eliciting the standard long term responses. I was not elected onto the board of trustees but after some of the canvassing that went on prior to final votes, that was to be expected. North Wales Adventure Holidays funding withdrawal questions were answered with the biggest load of - what's that stuff bulls produce lots of? starts with s ends with t? Finance and future - nice presentation, nothing else to say on that one from me.

Seminars

Dr Peter Jones summed up this first session for me in a sentence "It's good to see the society haven't changed to much in fifty years and still book a seminar room with a flight of stair as the only access." He went on to explain the history of haemophilia treatments, but I've heard it all before nothing new, nothing mind-blowing.

The next hour was a total waste of my time - 50 years of the haemophilia society!!!

Dr David Evans - a trustee - tried to instill some humour into this, but on reflection the last fifty years have been wasted. We then had a history of Oxford Haemophilia centre. Brilliant though it has been, for me the best bits were looking at old pictures of my present doctor and friend, Has Dasani, in his youthful prime. By this time it had all become too much and with the effects of some serious alcohol abuse the night before I missed bits (no, lets be honest, all of this session) in a haze of sleep and tiredness.

Lunch, amazingly, was brilliant. I sat with workers from London and had the normal flow of banter between myself and members of staff old and new, who for whatever reasons, still don't know how to react to my dry, off the wall sense of humour.

After lunch was for me the highlight, not only of this weekend, but of the whole of my dealings with people from the world of haemophilia. Lauren Kelly from the big old USA, gave a performance and a show about haemophilia in the third world that will have a lasting effect on future decision I make regarding who, why, and what needs to be done. The contrasting images that were displayed made me think, and also brought many others to tears. I will be contacting this woman again and hopefully will set in place a way for us in the UK to help make a difference for somebody in the world.

Workshops. Nothing took my fancy. Carriers and Women with bleeding disorders / HCV Physiotherapy / Orthopaedics Parents and School.

So I created my own "Football in Haemophilia" and went and saw the second half of FA Cup final

Looking forward to the next one !!!!!

Helping Ourselves By Helping Others

Recently I attended a workshop led by Rick Griggs of "Griggs Achievement". The focus was on achieving balance in one's life. Griggs performed an in-depth analysis of successful people who lead balanced lives. He noticed that people who maintain balanced lifestyles have several characteristics in common. These include regular social engagements with friends, taking vacations, and regular involvement in annual activities, such as fishing trips, sporting events, conferences, and retreats. Also on the list is participation in volunteer or committee activities. This last activity shows up on number of lists of recommendations to promote a balanced life-style. Picking up a health magazine or "volunteering" are suggestions for psychological well being. Recent articles tout the benefits of volunteer work, reporting that the simple act of giving of one's self can boost longevity as well as overall health. The reasons for this are not known. There is some speculation that the act of doing for others serves to distract us from our own worries and concerns. This may positively impact our immune system. There is also a social aspect to involvement in community activities, which provides support, stimulation, and good feelings about one's self.

There are no shortages of volunteer opportunities. For those with chronic hepatitis C, consider participating in an area that focuses on an issue related to HCV infection. What are your strengths and interests? Do you have a passion for the political arena or the health field? Do you prefer the tasks of envelope stuffing or office duties? Do you like to chat on the phone? Are you a public speaker? A fund-raiser? Do you write? Do you like the camaraderie that support groups provide?

Consider contributing your time and talents, whether it is an hour a month or an hour a week. No martyrs are needed. Consider starting out with short-term, realistic goals. The rewards will be far greater than you can imagine.

Motivation

The following was sent to me by Marnie Fehrer in response to my request for readers to share their strengths and hope. In spite of being in treatment, Marnie sent me the following: "Over time, I've learned to look at what psychospiritual lessons I can learn from having hepatitis C. For me, that involves viewing it as an opportunity to slow down and be more present, learning to accept and love myself just as I am, remembering to nurture myself and also allowing myself to ask for and accept support.

To help me during the year's treatment with Rebetrone, I do a lot of reframing. When the part of me that dreads taking the interferon comes up, often I am able to reframe it so the fatigue is my body's way of allowing my energy to be put into healing. I am then able to thank the medicine for its powerful healing. Noticing that I feel better when I haven't had interferon for three days reminds me that this is all temporary and I feel very thankful for that. Starting each day by writing out five things that I'm grateful for helps me to focus on the positive. To help keep me positive and also to help pull me out of a negative mood, I have an affirmation tape that I made. It is custom-made with uplifting reminders and easy to just pop into the tape deck in the car or at home. I also have one that has positive statements about my health: "There is no more hepatitis C in my body. My liver is strong, the virus is gone." Saying it in sync with the rhythm of my breath helps to keep the message alive (anchor it) with each breath. Sharing with close friends has helped me develop a support system that is invaluable. I have people I can socialize with who understand if I just want to be quiet and rest. At times when I'm moving too far into negativity to pull myself out, they are there with a positive comment and support. I've also reached out to various prayer groups as a way to feel support that is both universal and spiritual."

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

Available from the Birchgrove Group, free of charge to those directly affected by Haemophilia/HIV or registrants, are the following information leaflets and back issues of the Birchgrove Newsletter.

Birchgrove Newsletter Back Issues

- BIRCHGROVE newsletter *Issue 6*
- BIRCHGROVE newsletter *Issue 7*
- BIRCHGROVE newsletter *Issue 8*
- BIRCHGROVE newsletter *Issue 9*
- BIRCHGROVE newsletter *Issue 10*
- BIRCHGROVE newsletter *Issue 11*
- BIRCHGROVE newsletter *Issue 12*
- BIRCHGROVE newsletter *Issue 13*
- BIRCHGROVE newsletter *Issue 14*

Birchgrove Information Leaflets

- Hepatitis C – Special Edition

We can also supply the following items.

- Red Ribbons (Cloth) £0.50
- Red Ribbon Badges (Enamel) £2.50
- Birchgrove Red Ribbons (Enamel) £2.50

Name:

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Address:

.....

.....

Send to:

The Birchgrove Group,
PO Box 9, Abertillery, NP3 1YD.
or Phone 029 20520029 office
029 20520045 Fax



Thanks to Bayer for their kind donation of £600 to help with production of this issue of the newsletter..

STOP PRESS

AT A MEETING HELD ON MONDAY 22ND MAY AT ALLIANCE HOUSE LONDON.

The partnership group ! I was utterly amazed and disbelieving, that after all the promises, it seems we are still to be denied a measure of dignity and choice; we will have to continue to beg, crawl and plead for support to give us a level of financial security which we have lost through our viral infections.

In essence, this is what came out of the Macfarlane Trust Strategic Review and Partnership group!!!

The regular monthly payments are to be increased by £100 across the board. But what exactly will people gain? After over a year of interviews, meeting, and personal accounts, we will be £100 better off per month, but what is that when set against inflation over the last two years?

Compare this monthly increase to the curtailment of the single payments -cut, in my view, to try and claw back some of the monthly increase. For example, the automatic Motability grant of £1000 will no longer apply unless you can make a case on medical grounds with a letter of support from your consultant. On top of which we've already lost the £500 holiday grant !! For some people, that is £1500 gone out of £3600 3 year increase, without any other problems. We await a full listing of new guidelines telling us what we can and cannot apply for.

Hopefully the trust will produce a full information sheet explaining all the changes. Lets hope it's before they're implemented so registrants can have the opportunity to comment and send in feedback.

We will try and keep you up to date with development but finance and volunteers are limited. (Ed)



A Picture springs to mind

