



# The Birchgrove

THE BIRCHGROVE GROUP, P.O. BOX 9, ABERTILLERY, WALES NP13 1YD. TEL: 01222 520045

## Last will and Testament

Of Gareth Lewis ( never to be a Trustee )

In a personal Capacity

In accordance with the wishes of my Reverend Mentor, I, Registrant 1701 G Lewis, this day dated 14th November 1999, leave all my holdings within the Macfarlane Trust: to sit in some bank or trust fund accumulating interest. comforted by the thought that my flock of fellow registrants are dying in isolation and poverty. Still, the sheep are being watered, fed and kept warm at winter.

As instructed, I have made arrangements for this to continue for the next thirty years, by annual interest and careful management of the fund. The shepherds he leaves in charge have been taught in the Reverend way of Bullshit and finance and I will depart due to Aids, knowing my flock will be well looked after.

What more can I do? They have their monthly keep for food and water, They have money for drugs, they can have complementary therapy if they ask.

Their children are taken care of, by my congregation of workers and trustees. They can have new shoes once every four years and their clothes for school will still fit after five. Their bus fares and travel will be taken care of, but then, in my day we had to walk to school (Never mind that kids get killed and abducted walking to school-ed.)

Money for nutritional diets and a dignified, drug-sustained life is given with open hands, but only if you apply in triplicate to my single payment fund. OK, it will take a couple of months and if it's not supported by someone on my list of disciples, we may have to turn it down. Oh and if you're really ill, we can send you to a hospice. But hey, you have it easy, you haven't died yet..!

Recompense was only given for three years - don't blame me that you were unlucky enough to live! You all should be dead. No one said at the beginning that we had to spend it all. I thought it was for investment, to place an icon at Lent, to bring together my faithful trustees to worship.

My Reverend mentor always told me, "son don't pay the rent, let them fight to scrape a life, let them struggle to survive, let them die in ignorance, ( oh, happy memories ) you have done your bit in life. Who cares about reality who cares if you're not right, your legacy is written, your flock will be all right". But let me tell you Reverend, your ways of thinking are deeply flawed, your ways of understanding are shite. You hang on to a fortune thinking that it's yours, You go to government and accept 2 million pounds and sell our dignity and lives down the drain.

Your flock of trustees have been brainwashed in your holy crap and outmoded thoughts. You cannot see the picture of life with HIV/AIDS and you will never understand what it's like to be one of us. As we approach the Millennium with dread and fear in our hearts, the time has come to make a direct challenge to government. Self-help means taking responsibility for our own futures.

Where is your insight, or your understanding? I question that you even know the meaning of the terms. Compassion is not a four letter word - if you had been dealt the cards we are holding, then you might understand.

You have guided your trustees, and your staff, let them think for themselves, empower them to understand, you have given so much of your time and energy to the things we will never understand. The ones who need support are dying behind your back. We can only hope our children will not have to face a virus in the future. HIV/AIDS and HCV are killing us now.

Turn around and face your flock, listen to what they say, take time to understand them they will not go away. Our needs are getting greater, the longer that we live !

You may not understand this, the pressures are too big, but have you ever struggled? How many hands have you held belonging to someone dying from a virus? They ask your permission to die. I've been there many times. These are the

Continued from Front Page

situations your Trustees need to see. Without the contact and the pain, they will fail to accept or understand. Some will and some might have felt this pain on a personal level but for me this is and has been, much more. I've been to more funeral than years I have lived. If you do take onboard something from this piece, then meet us, talk to us, try and explain. The people who are dying do not need this crap - they need financial security, they need a life of dignity, they need to feel a part of life, they need to feel secure, they require a will to fight, a will to live. This trust fund that you protect so well, was given to secure some of the things I've mentioned. When will you open the door? Your kingdom is not sacred, your trustees can be brought down. Don't make us fight the way they did in France. We have not got the time, we are getting ill. The drugs to save us are killing us. For some people, it's already too late. If this must be last thing you do to us, why can't it be something kind? You know what's needed, you know what should be done. The government, who are responsible for infecting us with this disease, need to be told about the crap were having to take. I really hope you sleep at night. For me, I never can. The drugs, the shit that I take, the pressures just to survive, the thoughts of my children the day that daddy dies. My wife, my friends I leave behind. The memories of what we've had to put up with will remain with me till then. I urge all registrants to get up off your asses and do something before it's too late.

Gareth Lewis

Proud to sign this letter. I have nothing to hide.

### I HAVE THE RIGHT

To be treated with respect as an equal human being, regardless of my sex, gender, sexuality, faith, race, class, age, mental or physical ability.

To express my feelings. To say yes or no. To generate my own opinions and choices and to make my own decisions.

To make (and hopefully, but not necessarily learn from my) mistakes.

To change my mind. To ask for what I want. To deal with others without wanting or needing their approval. To have clear information about sex. To express my sexuality in any way that does not abuse or oppress other people. To sexual fulfilment and pleasure. To say 'no' to any sex or form of sex I do not want. To sexual health, well being and wellness.

## Birchgrove On Tour

During the year 2000, Members of Birchgrove will visit a centre near you. We are undertaking a study too try and highlight which and where services for those Haemophiliacs, Co-Infected with HIV/HCV, are good or if the case maybe not.

The tour will start in February at the Birmingham Haemophilia centre. Representative of Birchgrove committee are available to visit your centre and discuss services and treatment with centre directors or nursing staff. If you would like Birchgrove to advocate on your behalf then ring the Cardiff office 02920 520029

We hope to visit at least 20 centres across the UK. And once data as been collated we will publish a league table which hopefully we will update twice a year there after. We will be looking for volunteer to take part in this ongoing project on a regional level. We would prefer that people do not visit and access their own centres but travel to the nearest centre, this would enable a safe and honest accessment to be made and also protect the researcher from any feedback hassle that may arise if your centre ends up bottom of the league.

We ask Haemophilia consultants, Haemophilia nurses, don't be frightened we will not bite all were trying to do is highlight some of the differences of haemophilia care for those Co-Infected from centre to centre.

As pointed out by Mr Melson we are angry, but all were trying to do is help haemophiliacs get the care and services that they have the right to expect, they did not ask for co-infection, they had no choice. So please help us to help everyone, future generations will benefit from what we put in place now.

Birchgrove Tour Committee

MIKE O'DRISCOLL

*The Observer's Coverage of the Hepatitis C Campaign*

**I**t seems the Hepatitis C compensation campaign is back in the public eye. The Observer newspaper devoted an article and an editorial to the campaign in its issue of 7th November 1999. The article, headlined "Poisoned Blood Left Thousands to Suffer Unaided", and written by reporters Anthony Barnett and Tracy McVeigh, highlighted the story of Len Holmes, a mild haemophiliac infected with Hepatitis C following treatment with contaminated Factor 8 during surgery. Len died last year, aged 60, from liver cancer directly attributable to Hepatitis C.

The article pointed out that in 1995, as the Opposition, the Labour party supported a campaign for compensation for haemophiliacs who had been infected by Hepatitis C through the use of contaminated factor 8. In 1995, 233 MPs, including 16 current Labour MPs who are now Ministers, signed an early-day motion calling for compensation for hepatitis C victims. Among the signatories were Frank Dobson's successor as Health Secretary, Alan Milburn, Health Minister John Denham, and other Ministers including Kate Hoey, Helen Liddell, Kim Howells, Peter Hain and John Battle.

How different was the pathetic response of Frank Dobson when Labour came to power. Last year, he rejected the calls for compensation, stating that the circumstances were different for HIV+ haemophiliacs and Hepatitis C infected haemophiliacs, seeming to think that there was no proof that the NHS had acted negligently. But evidence uncovered by The Observer directly contradicts Dobson's ill-informed interpretation of the situation.

The newspaper cited a number of scientific papers in leading medical journals dating back to the early 70s, that warned of the dangers of transmitting 'Non A, Non B Hepatitis' - better known to all of us as Hepatitis C - through the use of Factor 8. An article in the Lancet in 1975 warned that 9 out of 18 haemophiliacs treated with factor 8 in a three month period in 1974, became infected with Non A Non B. According to the distinguished American professor Dr Frank Putnam, it was known 30 years ago that heating blood products would kill hepatitis.

and began heat treating all its blood products. But here in the UK, it seems that our health ministers and NHS officials had their heads buried up their own asses. Had they bothered to read the relevant papers, then we would surely not be faced with the current situation where more than 5000 haemophiliacs have been infected with Hepatitis C.

The solicitor, Graham Ross, who represented HIV+ haemophiliacs in the recompense campaign and who is now working with Hepatitis victims, has won a decision from the court of appeal to gain access to confidential government documents that indicate "severe neglect." However, surprise surprise, Ross has been prevented from making the contents of these documents public.

Why? Surely if, as Dobson claimed, there was no proof of NHS neglect, then these documents will vindicate him. Or is Dobson, in government speak, 'being circumspect with the truth'? That's 'telling porkies' to me and you.

Britain calls itself a 'civilised nation' but in practice its actions contradict this notion. Other civilised Governments in Ireland, Canada and Italy are now accepting their responsibilities and are compensating haemophiliacs infected with Hepatitis C through state owned blood laboratories. Now that Dobbo has moved on to try and screw Ken Livingstone and the people of London in the same way that he has screwed us, perhaps we can hope that Alan Milburn will have the courage of his earlier convictions and do the right thing. Or am I still living in that lovely place called Cloud Cuckoo Land?

Birchgrove is calling on all those co-infected haemophiliacs, their friends and families to write to their MPs, Welsh Assembly Members and Scottish MPs, as well as to Alan Milburn himself, urging them to reconsider their disgraceful treatment of the haemophilia community.

If you need help in finding out who to write to, or indeed in what your letter should say, then please contact us at the Birchgrove office. We will be only too happy to provide the relevant information.

Yours in Solidarity

Mike O'Driscoll

## "Fear and Loathing in Cardiff" or "Something for the Weekend"

PATRICK BATEMAN CONT PG4

This was my first experience of a Birchgrove conference weekend, and although I already knew a few people attending I still felt a little apprehensive and had a few butterflies on the journey down to Cardiff. Having been part of self-help groups for positive haemophiliacs in the past, I am very aware of the stark realities involved. You face your illness head on in these situations and confront your worst fears. The reminder of fate and illness and death. Talking about HIV, HCV and haemophilia related problems in depth are not always easy. I am also very aware that we are the experts regarding our own illnesses, we live them every day and who better to talk to and understand than those people in similar situations.

The meeting in the hotel bar seemed to go smoothly as everyone introduced themselves and people they already knew. We were easily identified as the majority of us limped or hobbled about. Once the drinks started flowing and people became more relaxed inhibitions seemed to disappear. There were six of us who had never been to an event like this before and some who had minimal or no contact at all with other positive haemophiliacs in the past. So once started it seemed there was no keeping anyone quiet. Conditions and illnesses were at first spoken about in discreet whispers and subtle codes but after a while, and a few more drinks, it really didn't seem to matter what we spoke about. We always seemed to have plenty of room in the hotel bar for some reason. For many this was a unique experience and it felt good.

After dinner a posse visited Cardiff for a change of scenery and some better tasting Guinness before returning to the hotel bar to join the rest of the group for some furious pool playing, drinking and mad conversations. By now we had all got to know each other a little better and we all had a story to tell. Conversations about our experiences, coping with life, relationships, families, hospital experiences, football, women, travelling the world, worries about our livers, whose

round was it, recreational drug use, life, death, how we blew our cash, coping with unemployment, motorbikes, tattoos, piles, living in secrecy, support networks, discrepancies in the services we receive, our tolerances and intolerances, complimentary therapies, combination therapy, balloon popping Bangkok strippers, coping with HIV whilst spending time in prison, drunken speeches and lots of sick jokes, tales from Amsterdam, comparing knees and the pros and cons of replacement operations, what's the best car you can get on motability, a lot of piss taking and whose round is it were only a small fraction of the topics covered into the early hours of the morning.

The hungover faces of those who made it to breakfast said it all. There were numerous visits to the toilets as the previous night's drinking took its toll. The swimming pool, Jacuzzi and sauna were perfect for waking up and feeling human again. These facilities were well used all weekend and they certainly helped the aching joints. One guy hadn't been in a swimming pool for a few years because he didn't feel comfortable with his disabilities so for him this was a real bonus.

The Saturday's presentation by Fiona the pharmacist and Zoe the dietician, both from University Hospital Wales, was informative and easy to understand. There was a lot of information that I had read about or heard about before but having it explained again was extremely valuable in its understanding. There was information about a lot of new drugs on the horizon and now available both for HIV and HCV which seemed to give most people a sense of hope. Zoe sent everyone into panic with her food and water safety talk. No soft cheese, boil water for teeth cleaning and don't buy meats with a furry green glaze from deli counters, all seemed to lean heavily on the side of caution. We all agreed to use our common sense and not worry too much. There was excellent advice on vitamins and nutritional support and overall I felt that we had all come away

## "Fear and Loathing in Cardiff " or "Something for the Weekend"

Cont from page 3

with more knowledge and understanding. It was also important to be able to talk to Fiona and Zoe on a one-to-one basis about our personal drug regimens and complications. Some people had never spoken to a pharmacist or dietician in all their years of infection, so for them this session was extremely enlightening.

The evening was a little steadier on the Saturday and it was pointed out that I was drinking half-pints on a number of occasions, conscious of my throbbing liver. The conversations continued at their frenzied pace, however.

Tim Hunt tried to inject the Sunday morning session with enthusiasm as he herded us into groups to talk about the changing goalposts. As we had done nothing but talk about our situations, this was an easy and lighthearted end to the weekend's programme. It seemed that most of us felt better now about our prospects and care than we did ten years ago. Ten years ago I kept being told that I didn't have long to live. I've stopped believing that.

After Sunday lunch we all made our journeys home in a trickle with lots of "see you next year", "It's been really good to meet you", "lets keep in touch" good-byes.

Personally I thought the weekend was a success and I gained a lot of knowledge, met some new friends and overall felt good about life. Although there was a low turnout of people over the weekend it gave us all a chance to get to know each other and get a lot of frustrations and anxieties off our chests in an empathic environment. It gave us an opportunity to have a laugh about life as well. I only hope these events will be continued to be financed in the future, as their value to our support is immense.

P Bateman

### TO WHOM IT MAY CONCERN, OR EVEN CARE TO READ.

CONT ON BACK PAGE

**I** read this week about compensation for Haemophiliacs with HIV and Hepatitis C,B and everything else that goes with blood products. I would like to express my feelings towards it, As being married to a Haemophiliacs,

I would like all those people out there, do you know what it's like, too be involved / married too a Haemophiliacs, whom I love so much, we are like soul mates. Everyday he's in chronic pain with his joints due, to his haemophilia and continual bleeds. Four to five days a week he's taking treatment for this, by injections, yes ! You may add just like a pin cushion, that just won't go away. But also an other issue that wont go away is, he's got to do it, or he'll haemorrhage and die. Because he has severe haemophilia status. I'm also wondering what he's pumping into himself, at the same time.

We rely fully on the government, our government too help us, keep us safe, we don't want any more viruses coming our way. But yet again, time after time they let us down. He works full time, because he doesn't want to be a (scrounger off society ) We can't live off benefits with two children to care for, He wants the best for them. Like any proud dad, Yes talking of children, I think I may be pregnant again. Just because we want to be really close, you know like normal people do. Because we feel like murderers combined with a life long sentence around our necks. We'll have to go through a number of test now for twelve months, too see if the baby and I are safe. Because of the endurance of it all , I'll most probably be on my tranquillisers again after the babies born.

I'm to scared to go to the doctors, and say I might be pregnant, because of the gruelling questions that I will be asked. The quilt I feel and my husband, as all this burden, just for one night of passion and just wanting too feel close. It doesn't only stop here it goes on and on, with my daughters they will be carriers of haemophilia, most of their son's will have it, it's like a curse it goes on and on.

The government gave us a measly

# Thought's from a Journey

ADRIAN MELSON

The Oxford Meeting.

Driving back from Oxford on Tuesday, suffering through what can only be described as a "something I ate" headache, I was filled with the thoughts that we are now about to embark on a fight whose outcome is still largely unknown.

My impression from the meeting is that the time is now right for an action by a separate group, particularly with what seems to be happening in Wales and Scotland, and the positive attitude they seem to have had from their respective Parliaments as HIV/HCV co infected haemophiliacs.

( This as come about with a united front of haemophiliacs from all sections of the community ) : ed

It is a shame that an organisation such as the Haemophilia Society the ones who are supposed to be looking after our needs, feel that we are co-infected first and Haemophiliacs second and perhaps we will just disappear ! The news is we won't! The government thought we would all be dead by now and I sometimes think the Society hoped that would happen too. On listening to some of the statements mentioned by the new health minister, it is obvious that the sooner these troublesome bunch of 400 odd haemophiliacs disappear, the better. I can only say once again, we won't, at least not until we are listened to and our case heard.

Before I joined the Birchgrove Group, the things I had heard were, in hindsight, amusing, such as angry young men, a very militant group and even to see the Birchgrove Group down in certain listings as a "special interest group". Well, if being angry

is wrong for the position we have been put in, and if special interest means that we want to keep what is left of our dignity and live as normal a life as possible, then I, along with a growing number of people, am happy to accept that description.

( Angry yes, but the letters of support that Birchgrove has received over the years would have sank the titanic ) : ed

It will also be interesting to see the results from the UK Centre Tour that has been planned. I wonder whether the phrase "continuity of care" will ever be used again, or is it too militant of me to suggest such a thing?

If it is then the phrase "Sod it" springs to mind.

Anyway enough of me harping on. I would like to thank the longer standing members of Birchgrove for inviting me to become a committee member and to be able to voice opinions from both Haemophiliacs and members of their families with whom I have contact. Partnership and joint working has gone on for to long, it's time for Co-infected people to take control once more. Only those living day to day can present a case to government for an enquiry into the injustice of the first recompense.

I call upon all those Co-infected to join Birchgrove in the fight for dignity and a right to sustain a life of control, the government took this away from us, don't let them or anyone else, tell you that the Co-infected Haemophiliacs are OK.

## A Burgess

**A**s discussed at the recent meeting of National Birchgrove, I am submitting this letter to be published in the next Newsletter.

It was back in 1994 at the Piccadilly Hotel, Manchester, that I first met with the Birchgrove Group. I had travelled on my own and had to admit to being a little nervous but also filled with anticipation. I had heard of the Birchgrove through Body Positive newsletters and I was hoping that Birchgrove would help the isolation I was experiencing. I was not disappointed.

The friendships formed at that weekend in Manchester 5 years ago are stronger than ever. Over the years it has been a roller coaster ride emotionally with the obvious downside of friends dying from AIDS, and others getting so ill you fear you will not see them again. But the highs have outweighed the lows, and the main highs are the friendships formed, these being the only good thing to come from being infected with HIV.

It was at the weekend in Manchester that I decided to get involved in the Birchgrove, and applied to go on the steering group and was accepted. At first I wondered what I had let myself in for as one or two of the committee did not think that having new members was the way forward. There seemed to be more "clear the air meetings" than business meetings, but everything has since settled down and the Birchgrove has gone from strength to strength, despite the inevitable sad deaths that happen from time to time.

The Birchgrove Group is respected and indeed feared in some quarters !! And that is down to one man, Gareth Lewis, one of the founders of the group who has brought it such a long way from the early meetings in a pub, to the smart offices in which the Birchgrove now reside. He will probably think I am arse licking when he reads this but I do have a point, and that is that Gareth has stepped down as chairman of the group and I have taken over from him. He will be a tough act to follow but I will give it my best shot.

I hope that the Birchgrove can go on to become a campaign and action group as

well as a self help group. I hope that the name Birchgrove will be around for years to come, to remind the government of the shameful incompetence that led to Haemophiliacs being infected and to remind them that we are still here. Having fought for everything we have achieved, we will carry on fighting until we get everything we deserve.

### Ex Chair's right of reply !!

Firstly, I would like to take this opportunity to thank Alan for his kind, arse licking comments, and extend my thanks to all those Birches who I have had the pleasure of meeting over the years. Due to covert activities and some crap to do with drugs, the time has come for me to let go. But as a parting shot which hopefully will bring a smile to some peoples faces, I would like to tell you a story, which will link in with the friendship and bonds that myself and Alan have built up over the years. It dates back a few years and was during, a trip to Suffolk. After a skinful of beer and a good meal the night before, Alan decided to show us some of the historic sites of Suffolk and our tour started with a visit to the industrial heartland of Ipswich, followed by a countryside walk and a few beers in local hostelrys. During the trip back to our base in Ipswich, we were brought to a sudden halt by what I can only describe as something from another planet! In a field were two of Suffolk's finest pigs indulging in oral sex! This was a sight to remember and has raised a laugh and a few eyebrows on many an occasion since. The memory of that trip and the sight of that rather strange, porcine blowjob, will stay with me for ever.

Yours G Lewis

Ex Chair National Birchgrove

# Relationships

Alfie

What is, who are, and why do we need them? Relationships.. Firstly we need to define what it actually means and how to quantify a relationship. In the world of haemophilia HIV & AIDS, one has many relationships to contend with. Your HIV being the first., a hepatitis virus or two coming a close second and you then chuck in haemophilia. Whilst we are trying to define this we also have major relationships with Factor VIII.

Combination therapies, and the odd dose of pain killers, either one of these could go to the top of the list at any stage depending on the present or current situation. But each one is clearly defined and completely separate from the other. And one must not forget the relationships outside of our haemophilia & HIV / HCV. A lot of us will be in long term relationships with partners, wives, children families and friends. How do we distinguish between these and how do we maintain a balance?

Do they all overlap or are they kept completely separate? Our relationship with our doctors or Haemophilia consultant will also play a major role in decisions on life, the universe and every thing else. Let's try and pull this together. Haemophilia will be a constant and will always play a major part in one's life. HIV & HCV The devastation that these viruses bring turns your whole life upside down and you're faced with a completely new set of goals and a new playing field on which to set out your stall. No one way can be right or wrong - each individual will deal with their situation in their own way.

If there is a right way, then you will find it yourself. I think if you accept the situation and learn to cope and set in place some rules to live by, then you're halfway to coping with another side of Haemophilia.. You must build a sound base with which to discuss treatment options with your consultant. The more you

understand the easier it will be to stick with a certain combination. The problems will arise when one is faced with side effects and you were unaware of the implications of a certain drugs or its contraindication with another treatment. Discovering something new can be frightening but if you're aware that there is a possibility of this happening then it's not such a shock and you're better able to deal with the problem. So good luck with that side of things and remember whatever choice you make, make it for yourself.

We also need to look at our relationships with others who may only float into our lives for a short period of time. This is one I struggle with - I really want to tell everyone I meet that I'm positive and proud.

But you need to look at those people within your immediate family and how your decision will affect them. So you become very good at distorting the truth to suit whatever scenario you may find yourself in.

But my point is that " it can't be good for you " to have to continually deny the virus, to carry on for long periods of your life essentially living a lie.

But I honestly don't think there is an answer to this one, either. So just get on with it. I have lived with the consequences of being out !! and sometimes that can be pretty scary, there are benefits. Putting a copy of the AIDS Control Act on a table whilst travelling on British Rail or National Bus will 9 times out of 10 guarantee a undisturbed journey, which I quite enjoy. I think there will need to be a part two as I'm thinking about so many relationships and partnership crap, I feel the need to do more justice to all aspects of relationships. But this will do for a starter.

## My Thoughts

MFT Partnership Meeting, 16th November 1999

Another meeting, another tray of sandwiches, well prepared and presented but sadly they are getting harder to swallow with each meeting I attend. How can the representatives (trustees) of the MFT implement the findings of a report I when government refuse to advance funding to address the recommendations highlighted I doubt?

This is the strategic review which the government asked for, paid for, and then decided not to like the look of because it involved spending more money on issues that they naively assumed would be dead and buried long before a decision was required. (my opinion only of course?)

This only highlights further the total inadequate and naive actions of the government when they tried to evaluate the recompense and costing involved for immediate and future needs of all registrants with the MFT.

The present Chief Executive (MFT) has unfortunately been put in a impossible position. To plan the (the long term needs with any confidence. I'm sure the Chief Executive could do without any more of the hollow flippant remarks quoted from the famous Baroness Hayman (Minister for state health) "We will of course continue the commitment to provide the finances, which you need for the trust. Only to be told a few months later that there is only sufficient monies available to increase the monthly allowance by 11% January 2000! Whilst totally ignoring the rest of the recommendations made in the report? My income now is less than in february 1995 when working as a self employed carpenter. I wonder if Mr Blair (PM) would be able to cope financially on the wage he was receiving in 1985? Of course he's had the opportunity to improve his standing in life and good luck to the man doing so!!

Choices and control over your future needs are so important to live your life with dignity and contentment.

With Regards H W LEWIS (A very Patient Patient)



## External Correspondent

### Letter to "The Observer" Newspaper

I would like to thank The Observer for highlighting the difficulties faced by haemophiliacs who have been infected with Hepatitis C through the use of contaminated blood products supplied for their treatment by the NHS. For many of us, this is our second time round. For Hepatitis C now, read HIV in the 80s.

I had been married only a short time when I was diagnosed with HIV. Instead of looking to the future with my wife and, as we had hoped, children, I had to come to terms with the fact that I had perhaps as little as three years to live. However, as with many others in the same situation, we carried on and tried to live as normal a life as possible. After 15 years, with increasing numbers of haemophiliacs dying from AIDS related illnesses, the strain grew too much for both of us and the marriage ended.

There are approximately 30% of HIV infected haemophiliacs still alive in the UK and 95% of those remaining have also been diagnosed with Hepatitis C. These people were infected with the Hepatitis C virus through exactly the same means of transmission as with HIV - that is through treatment with contaminated blood products supplied by the Health Service. To add to this viral pot pourri, we have also been warned about the possibility of infection with CJD.

Through no fault of our own, our ability to lead something resembling a normal life has been severely compromised. Due to ill health the majority of us still living are unable to work, and many of us have seen the collapse of long-term relationships due to the stress of worrying what comes next.

Many haemophiliacs are now taking large combinations of drugs to prevent the onset of HIV related infections, yet at the same time these drug combinations may be causing problems to our Hepatitis infected livers. In fact, already, more than 100 haemophiliacs have died as a direct result of Hepatitis C infection. The choice for many co-infected haemophiliacs is whether to stop HIV treatment so as to prevent further liver damage. Many of us feel

we are caught between a rock and a hard place.

So what of the future? Other governments across the worlds have dealt with this matter and talked to infected haemophiliacs to see how they can help. In fact, the Welsh Assembly and Scottish parliament are consulting haemophiliacs right now to discuss some form of recompense and to make sure that those who were lucky enough to have had children need not worry for their future. English co-infected haemophiliacs expect the same treatment from Westminster.

Whilst some of the problems that confronted us in the past, such as the stigma facing those who are HIV+, and the lack of effective treatments, are perhaps not as pressing, the fact is that with Hepatitis C, we find ourselves once more having to worry about the future for ourselves and our families.

**SHIT**  
**THE DEFINITIVE ANSWER**

**TAOISM**  
*Shit happens*

**BUDDHISM**  
*If shit happens it isn't really shit*

**HINDUISM**  
*This shit has happened before*

**ISLAM**  
*If shit happens it is the will of Allah*

**CATHOLICISM**  
*Shit happens because you deserve it*

**PROTESTANTISM**  
*Let shit happen to someone else*

**JUDAISM**  
*Why does shit always happen to us?*

**RASTAFARIANISM**  
*Let's smoke this shit*

**DISCLAIMER**

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

"BIRCHGROVE" is published by:  
The Birchgrove Group, P.O. Box 9, Aberillery  
Gwent NP3 1YD  
Tel: (0345) 697231 (Helpline)(01222) 520029  
**Editor:** Gareth Lewis  
**Sub Editor:** Mike O'Driscoll

## Young People on Tour

**T**his weekend was run as a pilot with two clear objectives. Firstly to create opportunities for peer support for young men with haemophilia and HIV (aged 18-25) and their partners. Secondly, it was to be an opportunity to begin to identify some of the key issues being faced by these individuals, and to begin clarifying how these could be met by both the Society and other agencies.

The weekend was run at a hotel in Hove, near Brighton. Twenty-two delegates attended, including four partners and one sister. The weekend was structured around four main sessions, with time for informal mixing and socialising [see attached programme]. The sessions were facilitated by professionals and/or people living with haemophilia and HIV.

Written feedback was obtained from evaluation forms, whilst a full written report was produced on the Saturday afternoon sessions by the external facilitators. Other feedback was gained by members of the organising team in talking with individuals and small groups in informal settings between sessions, and in a feedback meeting at the end of the weekend.

The ethos of the weekend was that people were under no obligation to attend any sessions (apart from the initial meeting on Friday night). As a result people attended the sessions they felt most directly useful to themselves, with some attending few, if any, and some attending all.

### **FEEDBACK FROM SESSIONS:**

Meeting People, Telling People, Relationships and Sex:

Every respondent but one (who did not attend) put this down as a useful session. Comments varied, but most felt that the couple who shared their experiences at the start of the session gave everyone the confidence to share their own feelings and experiences about disclosure of HIV status, developing relationships, negotiating sexual relationships, etc. Breaking down in two sessions, one with the men, the other with the women was also seen as a positive step. Comments included: "Very open and honest"; "This was probably the session I got the most out of"; "It was good because everyone was in the same boat, and we've all been there, having to tell someone you care about"; "It was a very good idea, but

quite exhausting and emotional"; "I'm glad we split into groups".

### **WHICH were the most Important Aspects of the Weekend?**

Every respondent highlighted that the most important aspect was meeting up with others in the same situation as themselves, whether they were HIV positive themselves or were partners. The main reason was that there was no air of secrecy – the issue of HIV (and even of haemophilia) which they had kept secret their whole lives was out in the open here, and safely so. Furthermore, with the majority of those attending being in the same situation health wise, HIV and haemophilia were normalised rather than being abnormal. This meant people felt that they could relax. People made the following comments about what they felt was the best aspect of the weekend:

"Meeting with other people in the same situation, allowing me to talk about things that I couldn't with other people not infected".

"The chance to talk to other women in my situation"

"Being relaxed and being able to talk freely"

"Being able to talk without worrying who is listening".

"Because we are such a small group, we need support from those in the same boat".

The session on "Meeting People, Telling People, Relationships and Sex" was also the one most cited as the most useful and relevant of the weekend.

However, there were many comments that suggested that more time needed to be given over to social events to allow people to interact informally, and perhaps to have better leisure facilities (especially a swimming pool, which can be beneficial for people with joint problems related to bleeding disorders).

The main criticism was that the venue had too many stairs for people with joint problems, the lift access was poor, and the rooms too cold. Another problem was hotel staff wandering through rooms where sessions were going on, potentially breaching confidentiality, and causing disruption to some potentially sensitive sessions. Any future events would need to ensure full accessibility, and a lack of disruption by hotel or other venue staff. It would also need to be more

From Steve Fouch Haemophilia Correspondent

accessible to public transport and other amenities.

**AREAS TO BE COVERED FOR FUTURE EVENTS**

*More sessions on HIV and HCV treatments*

*A weekend for partners only*

*Housing issues*

*Support for carers*

*Having children*

*Alternative therapies*

There was a mixture of wanting both more information and more opportunities to meet up with peers outside of an everyday setting.

All respondents said that they would attend a future meeting, and expressed a desire to see such events happen regularly. Travel was not an issue, only one person stipulating that the venue should be within five hours drive of where he lived. It is worth observing that the location was difficult for some further north to get to, and future events may be more beneficial in a more geographically central location.

**Results of Discussion Groups**

The Saturday afternoon session "Meeting People, Telling People. Relationships and Sex" ended with the men and women splitting into two small groups to discuss their needs and issues in more depth. The results of these discussions were recorded and feedback by the sessions' facilitators.

**1) RESULTS OF WOMENS' DISCUSSION GROUP**

The partners group also included one sibling. The main findings coming from the group were as follows:

Feeling that their needs were often regarded as secondary to the needs of their male partners and/or siblings. A strong sense of isolation and lack of support, and a lack of information, especially around issues of pregnancy and reducing transmission risks in conception. A need for clear, plain English information on treatments, pregnancy and other issues. The need for a separate event for partners was very strongly expressed.

**2) RESULTS OF THE MEN'S DISCUSSION GROUP**

Feelings of low self esteem and guilt were widely expressed. The guilt mainly centring on the risk of passing on the virus to sexual partners, creating a strong barrier to forming intimate relationships. Fear of disclosure was a strongly expressed feeling, even disclosure to close family members. Concerns were expressed about hepatitis C, its transmission risks, treatments, and how it could affect their health. Many expressed a lack of a sense of direction or goal in their lives – insecurities about education and employment (i.e. can they restart their education, and will they continue in good health long enough to find steady employment, etc.). This was another cause of low self-esteem, and an overall sense of failure.

Most were experiencing stress in their intimate and family relationships as a result of their diagnosis, and felt they had no one to talk to. Most felt a sense of confusion about the role of their Haemophilia Centres in providing them with support in these and other non-medical areas of need. Overall, there was a strong desire to see such events as this weekend replicated on a regular basis. They felt that the experience of sharing experiences and feelings with others in the same sort of situation was invaluable, and extremely supportive and helpful.

**Discussion: Future Direction of Youth HIV Project**

The rationale for the HIV & Haemophilia Youth Project was based on the relative invisibility of this group, and the lack of any clear research into their needs. The Macfarlane Trust (an organisation set up by the Government to provide financial assistance to all those infected with HIV through treatment with blood products) conducted an extensive review of the needs of its 460 surviving members in 1998. This represents the vast majority of those still living with haemophilia and HIV infection in the UK. Out of nearly two hundred responses to questionnaires, focus groups and one-to-one interviews, only two respondents were under twenty five, even though the Trust know from their own statistics that there are around 150 of their registrants in this age group.

The reasons for this under representation are unclear, but may stem from a dislike of such formal mechanisms of information gathering and a fear of breach of confidentiality. It may also stem from a sense of low self esteem and

## Young People on Tour

lack of hope for the future amongst this age group who have grown up with both an HIV diagnosis, and potentially disabling inherited condition.

Identifying and meeting the needs of this group were felt to be a priority by the Society, and in partnership with other organisations, we have set up this project to meet this aim, and begin to develop services in partnership with other organisations and groups to meet these needs.

### *Future Events*

The Young People's Weekend in Brighton was the first step in the HIV Youth Project. The second step is a similar event geared at the under eighteen age group. This is both a far smaller group (about twenty-five individuals nationally), and one with different needs due to different developmental stage. The youngest individual in this group is now about fourteen, so any event has to be geared around the needs of mid to late teenagers. We hope to gain an idea of what needs and issues are being felt by this age group in similar way to those identified by the Brighton weekend.

### *Self-Help and Support*

The main upshot from the Brighton event was that such events are of great value, not just to individuals living with clotting disorders and HIV infection, but also to their partners and siblings, who often share the burden, but whose needs are even less well addressed generally. Longer term aims of the project will be to focus on the facilitation and development of local support initiatives as well as regular events, geared up at infected individuals and their partners (including meeting exclusively for positive people and exclusively for their partners). A meeting for partners and carers is currently being planned for early 2000, and other events are being looked into for later on in that year. The programme of such events will be informed by this meeting and questionnaires sent out to people registering for the events.

## 1981 - THE FIRST CASES OF UNUSUAL ILLNESSES : NEVER FORGET

**T**he HIV amongst gay men in San Francisco and New York Pandemic are noticed by doctors and epidemiologists. Of particular note is the number of young men Transmission suffering from Kaposi's sarcoma, a condition previously seen amongst older men. The term

GRID - Gay Related Immune Deficiency - is used to describe the collection of illnesses with which young gay men are presenting to hospitals.

*1982 - Growing numbers of young gay men in the US are beginning to die from a growing range of immune deficiency-related illnesses, including PCP pneumonia and Kaposi's sarcoma.*

GRID is officially named Acquired Immune Deficiency Syndrome (AIDS) after epidemiologists notice that similar immune system disorders appear to be occurring amongst haemophiliacs, Haitians and injecting drug users. The first AIDS-related death occurs in the UK.

*1983 - The Human T Lymphotropic Virus III, known as HTLV III, is isolated from people with AIDS by researchers in France.*

The numbers of people dying from AIDS continue to grow in the United States and in Europe, and begin to cause mounting public concern. HTLV III begins to infect the national blood supply in the US and Europe.

*1984 - HTLV III is renamed as HIV.*

The first antibody test for HIV is developed and becomes commercially available in the US. The development of early HIV prevention initiatives begins to gather pace amongst gay men in the US and, a little later, in Europe. A growing number of self help groups begin to be established by people living with HIV.

*1985 - Screening for HIV in donated blood begins in the US and the UK. Rock Hudson dies*

from an AIDS-related condition in the United States, attracting considerable media attention. The HIV antibody test starts to become more widely available in the UK. The first international AIDS conference is held in the US in Atlanta. The World Health Organisation establishes its 'Global

*Programme' on AIDS.*

*1986 - A national public information campaign is launched in the US. American experts predict that HIV will become a major threat to heterosexuals in the US. The UK government announces funding for specific services for people*

## 1981 - THE FIRST CASES OF UNUSUAL ILLNESSES : NEVER FORGET

with HIV, and launches prevention initiatives aimed at injecting drug users. The first antiviral drug is licensed for use against HIV.

1987 - The UK government launches a nationwide public information campaign aimed

at educating the general public about HIV; it uses the slogan 'Don't die of ignorance'. The first needle exchange schemes for drug users are set up in the UK, and co-ordinated prevention work is initiated in cities with large drug-using populations. The World Health Organisation discovers patterns of HIV infection in the developing world which suggests significant levels of heterosexual transmission. The first specialist HIV services in the UK are established by the

*National Health Service in London.*

1988 - The numbers of people dying from AIDS continue to grow throughout the world. In

developed countries the number of treatments for some opportunistic infections begins to

grow slowly. The UK Department of Health is

sued for compensation by a number of haemophiliacs who had become infected from contaminated blood products. Major initiatives continue to reduce HIV transmission in some UK cities with high drug-injecting populations. The first World AIDS Day is held on 1 December.

1989 - AIDS dissidents in Europe and America question whether HIV is the cause of AIDS, provoking debate with HIV researchers and experts. Reports from Thailand suggest that the country may be facing a large growth in the numbers of people with HIV. The World Health Organisation reports growing numbers of people with HIV in a growing number of African countries.

1990 - Compensation is agreed by the UK government for haemophiliacs who had become infected with HIV through contaminated blood products. An official report published by the

UK government reduces the estimates of the number of people likely to become infected with HIV in the future. This provokes a debate about the extent to which HIV is likely to affect people outside the main risk groups in the UK.

1991 - The Red Ribbon is adopted in the US as a symbol of AIDS awareness as a protest about

the amount of money spent on the Gulf War. Rock singer Freddie Mercury dies of an AIDS-related illness.

The World Health Organisation estimates that 11 million people in Africa are infected with HIV.

Concerns begin to be raised in the UK about the continued numbers of gay men testing HIV positive.

This leads to a debate about whether more money

should be spent on HIV prevention work with gay men.

*1992 - The international AIDS conference is moved to Europe from America in protest at US*

border controls on people with HIV. The UK government announces extra funding for HIV/AIDS which leads to an expansion in the level of services in many UK cities. Some tabloid newspapers in the UK begin to campaign for HIV transmission to be made a criminal offense, after allegations that an HIV-positive man with haemophilia had infected a number of women.

1993 - The preliminary results from the Concorde trial are announced and cause considerable disappointment. The study showed that there appeared to be few benefits to starting early treatment with the anti-HIV drugs available at the time. A number of new HIV prevention initiatives aimed at gay men are launched in the UK after criticism that this area of work had been underfunded previously.

*1994 -*

American researchers announce the findings of work which shows that HIV replicates constantly in the body from the point of infection. It had previously been thought that HIV went through a latency period after infection. The finding is expected to have far-reaching implications for anti-HIV treatment research. Epidemiologists warn of the likelihood of a rapid growth in the numbers of people with HIV in India.

*1995 - Researchers announce the results of the European Delta study and the US ACTG 175*

study. These show that a combination of two anti-HIV drugs works better than taking the drugs singly as monotherapy. Other research studies are reported to be coming to similar conclusions. In the UK the Department of Health publishes a strategy for HIV prevention which advocates targeting resources on population groups at highest risk.

*1996 - The international AIDS Conference*

is held in Vancouver, Canada, and hears the results of a large number of research studies which show that combinations of anti-HIV drugs are effective at reducing levels of HIV in the body, and improving survival. A number of new anti-HIV drugs are licensed in Europe and America - more are reported to be in development. Reports begin to circulate of vastly reduced numbers of people using AIDS hospices and hospital wards in the US.

American researchers raise the possibility of eradicating HIV from the body using anti-HIV drugs.

"Who Cares or really believes this" cd

## Paul Hooper

**W**hen I look back over the years I've had since being diagnosed, I wonder what I really have achieved in all that time. So many others have done far more to educate, inform and reach others in times of need, that I feel like a waste of space at times. It's not the fact that I've hidden from my status - I've read loads of stuff, but I haven't allowed any of this to sink into the old brain box. If I had, then perhaps the one person I'd have to acknowledge I was HIV to is me - does that sound really odd? - Desperately trying to outdo others physically so that I could appear to be coping so well with being a Haemophiliac let alone HIV - so back to front!

Frustration is constant but who and what with, is something I'm trying so hard to pin down. Maybe it's just as simple as the fact that I'm still angry about being HIV although should I still be this way 15 years on? One way in which I've failed to cope, even though I've had loads of counselling (this hasn't offered me any solutions), is by drinking in the pub. Why I've still got any friends to call upon is a mystery but I'm glad of the ones that have stuck by me throughout my darkest pessimistic era.

A ten year relationship came to an end just over two years ago because I didn't cope with loads of things - most of my problems stem from being a Haemophiliac. Just a little while ago someone said that while I'm treating myself for a bleed I'm stopping those around me from seeing that I'm in pain - this has moved on to my interactive skills with people and life.

When experiencing problems everyday life can come up with as well as those of being in a relationship, I do exactly what I do when I have a bleed. There are times I just shut down - this is fantastic for coping with pain but not when it moves over into areas you don't want it to.

So, after finding myself single again I just went on a year long binge. No matter what organisation I approached no-one seemed able to help. Would you believe I even made out to people in Birchgrove that all was so bloody Rosy in my garden, thanks! Who'd really want to admit that he or she was feeling so low at heart that it hurt? In the end I just cut everyone off totally

without any hint that this was the way I felt inside. Some people feared the worst had happened.

Even my own mother, who still to this day blames herself for me being a Haemo. Then, when this HIV popped up, well, that was the icing on the cake for her. Her guilt was final! (Mom I love you and I wouldn't change a second of my life if offered another go around). The only way my mother knew anything of me was through the best neighbours anyone could have (that's you Phil & Tracey).

Trying to find me wasn't hard if you knew that my time was spent in the local pub. With all the bills out the way this is all I did each day. Sitting watching the world go by I imagined how a goldfish feels - bored beyond belief and wallowing in more self-pity than is good for anyone. All that I did think of was what am I going to do now? I'm still here, planning a new career move in the pub!!! Day in day out, on the endless pints of Guinness wasn't getting me anywhere much at all. Even before I'd managed to find a stool the bar staff started to pull the pint as soon as they saw me.

Days initially went by very quickly indeed although I'm not sure of this fact because my drinking was exceptionally high, eventually coming down in consumption to a more manageable 15 pints each day, (just Guinness, mind you - no shorts).

Towards the end I was able to drink that amount very easily because it was over a long period of time. Even so, this was no way to lead a life, but that's what I found easiest to do - just drink! Hardened boozers wondered what I was up to because drink wasn't the first thing I reached for in the mornings. So why did I spend so much time in the pub? You can, I'm sure, tell that I enjoy good conversation!

News does travel fast, especially when people find out your HIV status - this was by no means tricky to handle when you think about being in a pub in Walsall which is a real friendly place, even if you are a Brummie. You'd be surprised to know how many attitudes have changed and moved forward, then again some people just simply aren't able to see that because I don't have any outward physical

## Paul Hooper cont

signs of disability why I can't do some 'cash in hand' with them on a building site no matter how many times I'd try to explain Haemophilia to them (even sober the next day !!!). It's probably better just to limp now and then just to put this type off.

Debating in the local became second nature to me, even with the landlords, who had a friend with Haemophilia. The staff also chose to ask me many questions, the main point being, 'why the hell are you wasting so much time during the day when you could so easily be doing something else?' What that was I didn't know until I started to see a future.

Knowing that you can't carry on drinking the way I was didn't mean I saw sense - well I didn't, as I'm a man who goes from one extreme to another! One point was certain to me, I didn't want to live the rest of my life alone anymore, so, dating commenced with some excitement mixed in with 'what will a women say when I mention my status'? Not only that, but when do you bring it up? - The second date? Well I plumed for the bull at a gate approach by bringing it up on the first date! No one ran away screaming (I wish more than one had though!) about this new found information. Saying things had changed since I was single ten years ago is understating it just a little.

Sure, some didn't want that second date but I felt that it was far easier to find out how someone would react early on before I fell too deeply into a relationship of any kind. Discovering that you're not the 'one man walking leper colony' that you imagine some amongst society look upon you as (even though some won't openly say this) came as quite a relief to me!

Who had moved the goal posts while I was in my last relationship? Also, could someone tell me why independent women won't accept going dutch, some even take offense at being offered to share petrol costs. Out of most encounters though, the vast majority just wanted to mother me. This wasn't what I had imagined I'd find as the most common reaction.

Moving from the direct approach I thought about other mediums of contacting someone who might like to get to know me, not just some walking accident zone with an over developed

appetite for the Guinness!

Samantha and I first made contact on a chatline way back in January this year - the day before my 35th birthday to be precise. We swapped phone numbers so we could chat some more and little did I dare imagine that in less than six months time we would be living together! Having given up a well paid job along with moving from all she had ever known to come to Walsall, Samantha has made such a wonderful impact on my life.

We have had so much to come to terms with although we have found support through the many close friends and family I still, to my amazement, have around me. Learning to be a father to Samantha's 12 year old boy, Aaron, isn't easy, but then if things were, would they be worth doing? Uncle status didn't help much because I'm the type that always has loads of fun all day long then just hands the children back, so I wasn't prepared for one that's for keeps.

He has had more than enough to cope with moving home and changing schools at the start of year 7, so when it comes down to my health he's so very protective towards me and isn't quite sure yet as to how rough he can play with me but that's not stopping us having loads of fun finding out about each other. His pet name for me is the 'antique', and that's not because of my joints. It's simply because I'm 35!

Finally I'm looking into all the information that's at hand even though at the minute it's making my head spin. Loads of tests later my cd4 is 130 with a viral load of 724 which is just as much of a surprise to me as it is to the treatment centre, especially when you take into consideration the 15 pints of Guinness a day for more than a year. Options aren't something to be afraid of anymore and all opportunities should be grabbed by the throat. At long last I'm starting to live a life - yet I still feel guilty for still being here!

Paul Hooper.

We will awaite part two, someone who knows there is a lot more ?? ( ed )

## 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

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

### Birchgrove Newsletter Back Issues

- BIRCHGROVE newsletter Issue 6
- 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 newsletter Issue 15

### 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:

.....

Address:

.....

.....

Send to:

The Birchgrove Group,  
PO Box 9, Abertillery, NP3 1YD.  
or Phone 01222 520029 Helpline  
01222 520045 Fax

cont from Pg 4

£20,000 for our trouble. ( for Aids ) We had a little bit of help off a trust fund. Which offers hardly any help unless were really desperate. Why haven't the government found a cure for haemophilia, why are blood products still contaminated. Why does my husband have to go through regimes of injections and many pills a day too, keep his health problems stable, why do I have to lie too people constantly about my husbands health and poor limbs, why do we have to feel guilty for normal activities that we need ? why do we feel like murderers ? going through a life sentence ? why is life so cruel ? Why are insurance companies denying us of any insurance for dependents, we leave behind ?

( everyone dies at sometime everybody is a liability ) If you had a blood transfusion, who's to say you are not infected ? Well I'll finish my letter in saying, now the Welsh Assembly is in force. I hope they will help us, because no body else has. Even on a social level, my husband doesn't like to get too close to his mates, who also has Haemophilia and a virus or two. Because you don't know who's going to be NEXT down the line. He's afraid of being too attached. What a lovely life, ( but who cares ). I feel so let down by the government, nobody cares.

*Do you ? Anonymous Because that's my whole life Anonymous, to scared to tell the world.*

The last thing I may add it doesn't matter where these viruses came from. The fact is we want a cure and compensation for the hell were going through, yes hell and at the end of the day.

Are you safe, are your son's and daughters safe, " Who knows "

*Fidelity / Infidelity comes from anybody out there.*

*( come to the office, Phone. talk to us ) ed ;*