



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

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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

It 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"

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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.

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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.