



Birchgrove

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the aids hypothesis

Although the following article is contentious and may cause some people concern, we feel that the ideas which are expressed should be available for debate. Birchgrove is a forum for discussion, and provides opportunities for people with haemophilia and HIV to debate ideas and opinions about HIV&AIDS. We would encourage anyone who may have strong views regarding this article to write to the Editor. We are keen to publish any thoughts or views which help to promote a healthy debate.

"Above all, do no harm." - attributed to Hippocrates

For a decade and a half we have been subjected to AIDS propaganda. We have been indoctrinated into ever-changing and ever-more-elaborate AIDS mythologies. Over 100,000 papers have been written on "AIDS". The jargon, the technobabble must run to hundreds of words by now. It all seems hopelessly complicated - far beyond the comprehension of a mere layman, a non-specialist. And yet, at bottom, "AIDS" is really rather simple. My goal is to cut through the trappings and mystifications of "AIDS", to lay bare and articulate its fundamental assumptions and contradictions. I want to bring us back to the Reality Principle: to see things as they really are.

My entire message can be expressed in three brief points:

- There is no such thing as "AIDS"
- HIV is not harmful
- People with "AIDS" diagnoses became sick in the ways that they did because of health risks in their lives.

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THERE IS NO SUCH THING AS "AIDS"

The so-called Acquired Immunodeficiency Syndrome or "AIDS" is not a coherent, single disease entity. It has neither symptoms nor diagnostic criteria of its own. Other diseases, such as mumps, measles, polio, chicken pox, rabies, gonorrhoea, malaria, salmonella, the common cold, or bubonic plague, can readily be described and diagnosed. Not "AIDS", which is defined entirely in terms of other, older diseases, in conjunction with dubious test results and even more dubious assumptions. Although people are undeniably sick, "AIDS" itself does not really exist; it is a phoney construct. The core definition of "AIDS" can be expressed by the following formula (I am indebted to Peter Duesberg): INDICATOR DISEASE & HIV = AIDS

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First, the good news: the weapons deployed will be strictly conventional. The bad news is that it isn't just sticks and stones that can hurt you. I'm referring to an apparent state of war between some Haemophilia Centre Directors, and some of their patients. Some of you may be saying, "What war?" Others might be asking, "How did it come about?" or "Who threw the first stone?"

The truth is, it doesn't matter. What matters is that doctors begin listening to their patients and respecting their wishes, and that HIV positive haemophiliacs give credit to those whose attitude and approaches have changed. Attitudes on both sides have remained entrenched. But over the last few years, many positive haemophiliacs have begun to question the paternalism which pervades all aspects of their treatment. They have sought out and gained access to information that was denied them, for whatever reasons, by the medical profession.

Such illicit information includes doubts about the efficacy of certain drugs, and the toxicity of others; the fact that arthritic conditions among haemophiliacs may be more related to HIV and HCV infection than to bleeding disorders; a questioning of the value of liver biopsies; knowledge of the possible benefits to be derived from large dosages of Vitamin C; the therapeutic effect of practices such as Acupuncture and Aromatherapy; the sense of empowerment many positive people experience through involvement with self-help groups.

It isn't hard to see why many Centre Directors were so afraid of us throwing open the lid of this Pandora's box. Where once their word was sacrosanct, now patients are beginning to question the approach of Haemophilia Centre staff to treating HIV/AIDS related illnesses. The perception seems to be that we are biting the hand that feeds us. As a result, there seems to be a growing paranoia among some Centre staff that has more to do with a fear of a diminishing power base, than it has to do with concern for their patients.

The way to resolve this conflict is not difficult. All that is required is an acknowledgment of past mistakes, and an acceptance by Centre staff that patients have a right to be informed of new developments, and a right to have their wishes regarding treatment respected.

Is that really too much to ask?

HEPATITIS C SUPPORT GROUP

The Mainliners Hepatitis C Support Group meets every 4 weeks on Tuesday nights at 7.00pm (No entry after 7.30 pm).

The meetings schedule for 1995 is:

7 March, 4 April, 2 May, 30 May, 27 June, 25 July, 22 Aug, 19 Sept, 17 October, 14 Nov, 12 Dec. Please call to confirm.

The meetings are held at Mainliners, 205 Stockwell Road, London SW9. Entry is by entryphone system at number 205. The meeting is held in safe, comfortable surroundings and is facilitated by a peer group member. Attendance is limited to those who are HCV positive.

The aims of the support group will include:

- To share information and experience
- To provide support
- To provide a forum for discussion of related issues.
- To create a pressure group for action on Hepatitis C.

If you would like further information please ring Christine at Mainliners. on 0171 738 4656. If you cannot attend but would like updates please write and ask for details of the Hep C newsletter.

The views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group. The Birchgrove is a forum for discussion and seeks to encourage debate on the issues that affect people with haemophilia and HIV. We would encourage anyone who may have strong views regarding any of the items published in this newsletter to write to the Editor. We are keen to publish any thoughts or views which help promote a healthy debate. No assumptions should be made regarding the health status of any individual whose name appears in this publication.

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THE AIDS HYPOTHESIS: continued

In conjunction with HIV, an "AIDS-indicator disease" becomes "AIDS". In the absence of HIV, the "AIDS-indicator disease is called by its old name. Let's try a couple of examples: TB & HIV = AIDS, TB - HIV = TB or, Dementia & HIV = Aids, Dementia - HIV = Crazy. At last count there are 29 "AIDS-indicator diseases", not one of which is new. All of them have causes other than HIV. Both components of the AIDS-defining formula are absurd. The AIDS-indicator disease part is absurd because the diseases have nothing in common. Although the central idea of "AIDS" is immune deficiency, some of the AIDS-indicator diseases, like the cancers, wasting, and dementia, have nothing whatever to do with immune deficiency. The HIV part of the formula is also absurd, because it is almost always based on unvalidated and unreliable antibody tests; because it is sometimes based on "presumptive" diagnoses (in other words, on guesses); and above all, because HIV is not pathogenic. Since the very definition of "AIDS" is absurd, it necessarily follows: "There is no such thing as 'AIDS'".

"Since the very definition of 'AIDS' is absurd, it necessarily follows: 'There is no such thing as 'AIDS'"

HIV IS NOT HARMFUL

Molecular biologist Peter Duesberg has argued that it is not in the nature of retroviruses to cause serious illness, and HIV is a completely typical retrovirus. HIV's consistent lack of biochemical activity is a salient reason for rejecting the HIV-AIDS hypothesis. There are different ways of evaluating the activity of a microbe, just as there are different ways of evaluating the activity of a human being (such things as motion, heartbeat, breathing, body temperature, etc.). If I were running the 100 meter race, I would be much more active; if I were asleep, I would be much less active; and so on. HIV is consistently inactive, even in patients who are dying from so-called "AIDS". It therefore cannot cause disease, any more than a human being could rob a bank at the same time he was lying in a coma.

PEOPLE WITH "AIDS" DIAGNOSES

became sick in the ways that they did because of health risks in their lives.

The basic idea here is that different "risk groups" and different individuals are getting sick in different ways and for different reasons. We need to find out what factors have affected their health in ways that caused them to develop one or more of the 29 old illnesses that qualify for a

diagnosis of "AIDS". With regard to any specific risk group, the question is not, "Why have these people developed AIDS?", but rather, "Why are these people sick?"

Why Are Intravenous Drug Users Getting Sick?

- No study has ever been done to determine if all, or even most, IVDUs with "AIDS" diagnoses ever did share needles (most IVDUs, in fact, do not share needles),

- The hypothesis ignores the harmful consequences of putting chemicals into the body, and,
- HIV is not pathogenic.

The clinical profile of an IVDU with "AIDS" is emaciation (wasting) and one or more lung diseases. And yet, for a hundred years, the classic profile of a chronic heroin user has been emaciation and lung disease. Heroin is bad for the health and bad for the immune system; on top of that, it suppresses the respiratory system. The consequences are tuberculosis or one or another form of pneumonia: emaciation and lung disease.

In his paper, "AIDS Acquired by Drug Consumption and Other Noncontagious Risk Factors", Peter Duesberg cites many medical references that indicate: "From as early as 1909 evidence has accumulated that addiction to psychoactive drugs leads to immune suppression and clinical abnormalities similar to AIDS."

So then, IVDUs are getting sick in 1995 in the same ways and for the same reasons they were getting sick 86 years ago. The only difference is that now their illnesses are called "AIDS".

Why Are Gay Men Getting Sick?

It is only a very small, particular subset of gay men who are getting sick, and they are getting sick for reasons that are all too obvious once the right questions are asked.

- "Recreational drugs" (drugs used for intoxication, rather than for medical purposes)
- Venereal diseases & antibiotics
- Psychological factors
- AZT and other nucleotide analogues

I have devoted thirteen pages of my book, *The AIDS War*, to describing the health risks in the lives of those particular gay men who became sick with AIDS-illnesses. Some of the drugs they used, like the nitrite inhalants (or "poppers"), were hardly used at all by anyone who was not

"HIV is consistently inactive, even in patients who are dying from so-called 'AIDS' It therefore cannot cause disease"

THE AIDS HYPOTHESIS: continued

a gay man. Certain "designer drugs" that were popular in the gay disco scene were virtually unknown outside the gay scene.

It would appear that this subset of gay men became sick primarily because of drugs, both medical and "recreational". At any rate, there were abundant health risks in their lives, and it would have been surprising if any of them had remained healthy.

Iatrogenic AIDS

We must also take note of "Iatrogenic AIDS", which is "AIDS" caused by medical practice. This mainly consists of treatment with AZT or other nucleotide analogues. Most of the victims are given these drugs on the basis of an HIV-antibody-positive diagnosis.

RECOVERY FROM "AIDS"

When it comes to treatment, the prevailing AIDS-paradigm, including the HIV-AIDS hypothesis, has led nowhere. The mood among AIDS researchers is one of pessimism, gloom, and confusion. In contrast, we who advocate the Risk-AIDS hypothesis have a very optimistic outlook. We believe that there is no reason why individuals who are HIV-antibody-positive should not remain perfectly healthy, provided they take care of themselves. And we believe that most people with "AIDS" diagnoses ought to be able to recover fully, if they take the right steps.

The one thing people with "AIDS" diagnoses must not do, if they want to get better, is to take toxic drugs that they don't need. At the top of the list is AZT, about which I have written a great deal since 1987. AZT is the greatest iatrogenic disaster in medical history:

- The theory behind AZT therapy is wrong: HIV is not the cause of "AIDS". Even when HIV can be detected, it is not replicating.
- AZT's toxicities are severe: AZT is the most toxic drug ever prescribed for long-term use. AZT causes severe anaemia, headaches, nausea, muscular pain, and cachexia. It damages the nerves and every organ in the body. It is a known carcinogen.
- AZT was approved by the FDA on the basis of fraudulent research: I have examined hundreds of pages of documents that the U.S. Food and Drug Administration (FDA) was forced to release under the Freedom of Information Act.

WHOSE FAULT IS IT ANYWAY?

Ten years into this fight and we're still hearing the same old stories; "I just can't cope when it comes to telling others?"

How will the members of my family react?

Who should I tell and what should I say?"

The list is endless, and even though I'm open about my own status, everyone has a different way of coping with the stigma related to HIV.

Stop and think for a moment, why should you worry, "whose fault is it anyway?"

"Certainly not yours", but then who can we blame? The government, who wouldn't pay for self-sufficiency in factor eight? The drug companies, who manufactured it?

The doctors who injected it? I know, it must be all those gay men out there, they must be responsible? "What a load of crap!"

Surely haemophiliacs can only blame themselves. In the early days of HIV, we should have been out there in the big world, fighting for our rights, educating people about our problems and dealing with the isolation and stigma of HIV infection. If we had done this, then perhaps the public would have a better understanding of our particular problems.

The routes of infection may be different, but when you think about it, the people who are really at fault are those who say "it's nothing to do with me. I'm not in one of the high risk groups, so why should I worry?" Or, if the Haemophilia Society had accepted it's HIV+ members with open arms and not tried to hide them away and wait for them to disappear, people may just have had a better understanding of this virus.

Those of us living with this virus, should have spent more time in "raising awareness" and less playing "innocent victims". We should have been open about our situation from the start. Only by doing this would people have gained a better picture of the life of positive haemophiliacs. Perhaps, we wouldn't have to hide away and keep our anger and frustration to ourselves. Maybe we could start living life again to the full.

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"Those of us living with this virus, should have spent more time in raising awareness and less playing innocent victims"

"There is no scientifically credible evidence that AZT has benefits of any kind"

It is clear from these documents that the Phase II AZT trials were fraudulent: that all kinds of cheating took place, and that the investigators deliberately used data which they knew were false. (The Phase II AZT trials, conducted in 1986, formed the basis of AZT's approval in the U.S. and 31 other countries.)

- There is no scientifically credible evidence that AZT has benefits of any kind: The studies that have been used to claim benefits for AZT were all paid for and controlled by Wellcome, the manufacturer of AZT. They are therefore unworthy of credence, in light of the fraud that was committed in the Phase II AZT trials.

Peter Duesberg has claimed that AZT is now the single greatest cause of "AIDS", and I agree. Since AZT can cause several of the AIDS-indicator diseases, and since patients given AZT are already HIV-positive, it's clear that AZT can cause "AIDS", according to the formula: AIDS-Indicator Disease and HIV = AIDS.

"I hope that when the "AIDS epidemic" is behind us, and the lessons have been drawn, it will be seen as a vindication of the holistic view of health"

What people with "AIDS" should do is identify the health risks that made them sick in the first place, and then eliminate those health risks from their lives. It's as simple as that. In most cases these health risks are toxins: medical as well as "recreational" drugs. But psychological factors, infectious diseases (and the concomitant treatments with antibiotics), and genetic factors undoubtedly also play a role in causing particular AIDS-indicator illnesses.

In simple outline form, a program of recovery may look something like this:

- Take charge of your own recovery.
- Break away from the AIDS death messages.
- Adopt a holistic concept of health: a sound mind in a sound body.
- Identify and eliminate all health risks.
- Detoxify both mind and body:
- no "recreational" drugs.
- no cigarettes.
- no toxic medical drugs (like AZT).
- Observe good nutrition: avoid sugar.
- Exercise.
- Reduce stress.
- Get enough rest.
- Have faith that good health will return.

If this looks like a program for healthy living, that's what it is. Illness is usually multifactorial in origin, and good health is "always" multifactorial. Good health doesn't depend on any one panacea, but on a number of elements: freedom from toxins; nutritious food (in moderation); vigorous, balanced exercise; pure water; pure air; freedom from hostile stress, including noise; satisfying friendships; satisfying sex; satisfying work; an intellectual life; and enough sleep and rest.

CONCLUSION:

The AIDS organisations, including such pseudo-radical groups as Act Up, are always demanding a "cure" for AIDS. By "cure" they mean a new, high-tech drug that will attack HIV. This is all wrong. What people living with an HIV or an "AIDS" diagnosis need, is not a new drug, but a counsellor with a clear mind and a warm heart. They need someone who will treat them as a whole person, not as a patient labelled with particular diagnoses. They need a friend, who will help them put their lives in order, and who will guide them back to the path of good health. I hope that when the "AIDS epidemic" is behind us, and the lessons have been drawn, it will be seen as a vindication of the holistic view of health.

John Lauritsen

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COLUMB WHELAN

1953 -1995

When I saw Columb walking through the room, it was like meeting an old friend anew. It was the first Birchgrove Conference, held in London 1993. What I saw was a man who had matured and had a seriousness in his face. I had first met him when he was 13, whilst we were at Lord Mayor Treloar College. Would he remember me 20 years later? I have always been amazed how many of us had passed through its elementary walls. We were both entering a time in the sixties of Bob Dylan, radical politics, articulating joints (the ones that talk when you're stoned), and the ultimate meaning of life and death. One thing was sure, Columb never stopped questioning everything and everybody around him.

In the interim period, we took our separate journeys into our twenties and thirties. We both developed similar interests in the wonders of diverse cultures, in esoteric beliefs, in philosophy, in astrology, the wonders of nature, and shared a knowledge of counselling, pain and HIV. I knew Columb near the beginning and close to the end of his life. I saw, that like myself, he had retained the awareness and interests that had been initiated for both of us at Lord Mayor Treloar College.

Columb could also be a difficult person to know. On the one side, with his work as a counsellor at the Aled Richards Trust and the Red Admiral Project committee he was involved in helping people with HIV. Yet, at times he could make it difficult to contact him. Others who knew Columb, shared similar experiences to my own. I would like to believe that those times when he chose to be alone were the moments when he charged his batteries, so that he was able to give in the long term. He was passionate about many things: the lack of HIV care at his haemophilia centre, the validity of answers dished out about HIV care and representing heterosexuals who were HIV positive. Columb refused to take "no" for an answer.

Columb was part of the Birchgrove Group, he had attended many of our workshops and activities. I respected his honesty in presenting his true self to those whom he met. He cared deeply about the needs of people with haemophilia and HIV and the strength of these feelings were often overwhelming. For me, his life represented a noble struggle.

PETER HUGHES

1939-1995

Peter was only diagnosed with haemophilia in 1976. By this time his life was full of things he enjoyed, far too much to let a word like haemophilia, or an illness trouble him or stop him doing what he wanted.

Our first meeting was a few years ago at a lecture on haemophilia for health care workers organised by two social workers. We had volunteered to try and answer any questions that were put to us on what it's like living with haemophilia and all its consequent complications. On more than one occasion I was grateful to Peter for saving my bacon when I dried up during a difficult reply. Although I was diagnosed as a small child, Peter was far more knowledgeable and informed than me. This was very much him all over; what ever he took up he always wanted to know everything about it.

It's also true to say that when Peter became ill he wanted to know all the details and would read and find out as much as he could. I'm glad to say that he wasn't afraid to ask questions or challenge opinions, and refused to be fobbed off with any old answer. He was always ready with more than one response to some of the questions he wanted answers to. Peter was straightforward and to the point which is one of the things I liked so much about him; you could always ask him something and be sure of an unbiased answer with all the pros and cons weighed up.

He campaigned on many fronts, to the Haemophilia Society and the Macfarlane Trust and on so many issues, with the Manor House Group, and the Birchgrove Group. Where he got his energy from I don't know, because Peter hadn't enjoyed good health for some time. I was only able to attend our local haemophilia society meetings thanks to Peter who gave me a lift to and from Walsall. Even though he was having problems with his health he wouldn't let it get the better of him. He never used haemophilia as a crutch, to get out of something he didn't want to do. One of Peter's strengths was his sense of humour, even after we had talked about subjects most of us would rather not think about there was always room in our conversation for humour. Peter passed away on the 21st of March 1995 and he will be missed by his family and his numerous friends.

THE END OF INNOCENCE

SIMON GARFIELD FABER & FABER, HB, £17. 50

Garfield's book, subtitled *Britain in the Time of AIDS*, is a sober and sympathetic account of the effect that the Human Immunodeficiency Virus has had on the cultural, social and political life of Britain. Though Garfield writes objectively about death and loss, he does not assume a position of journalistic detachment from those he speaks to, neither does he let his own emotions swamp the narrative in excessive pathos.

Structured in two parts, the first begins with an account of a man who died in a Manchester Hospital in 1959, and who, some twenty-five years later, was discovered to have died of an AIDS related illness. Thereafter, Garfield charts the first infections among Britain's Gay community; the medical professions initial confusion and reaction to this strange new disease; the increasing spread of AIDS among heterosexuals, and among intravenous drug users. In the chapter that has most relevance to ourselves, Garfield interviews Simon Taylor of the Haemophilia Society, and Dr Peter Jones of the Newcastle Haemophilia Reference Centre, and paints an accurate picture of infection among haemophiliacs through use of contaminated factor 8. As the subsequent deaths of over 600 HIV positive haemophiliacs indicates, it's a sorry tale of governmental neglect and complicity, one that led to the compensation campaign of the late 80's, and to the eventual "recompense."

There follows a detailed account of the Government's sometimes ill-advised campaigns to inform and educate the public about how the virus was transmitted (through collision with an iceberg, apparently), and of who was most at

risk (little old ladies?). Garfield scrutinises the proliferation of charities and self-help groups, and questions the damage done to morale within such organisations as the Terrence Higgins Trust, Positively Women and Act-Up by endless infighting and politicking.

The second part of the book takes the form of a journal, running from August '93 to July '94 and includes a moving interview with the late Derek Jarman. In fact the interviews with those who are HIV positive, both famous – Jarman, Holly Johnson, Jimmy Somerville – and those not in the public eye, offer a positive counter to the popular perception of infected people as victims just waiting to die.

Other issues raised in the book include treatment, relating the great hopes initially held out for AZT and the subsequent pessimism with the news of the Concorde trial results; the role of public figures in helping gain acceptance for infected people – for example, the interest and compassion shown by Princess Diana to AIDS patients; and the AIDS backlash instigated by the Sunday Times, in which it's medical correspondent Neville Hodgkinson wrote of Peter Duesberg's challenge to HIV/AIDS causation. Fully revered and indexed, this book deserves a much wider audience than simply those whose lives have been effected, directly or indirectly by HIV. It is a humane and compassionate account of AIDS in Britain; it is, to quote the author, "a good package," which ends with the hopeful reminder that "We have travelled far."

SOME PEOPLE

Some People
People are scared of the unknown
Some people are scared of ghosts
Some people are scared of catching AIDS
I'm scared of things I do not know about
I'm scared of strangers
I'm scared of losing friends
I'm scared of death
I'm scared of footsteps on the dark
I'm scared of making a fool of myself this evening
I'm scared being here!
But I'm not scared of catching AIDS

I know what to do to look after myself
I'm proud of my friends with HIV&AIDS and I
will never be afraid of them
I get scared when people say
"It won't happen to me"
But won't find out the facts
People used to be scared of the first motor cars
They ran away and thought they were
monsters
But they got used to them and learned how to
cross the road safely
If people get used to HIV and learn how to live
safely that fear may go away too.

© J. Gower (age 10) 1992

BY GREGORY J. HAAS

The following is an extract from an article written by Gregory J Haas for the Committee of Ten Thousand on the different Hepatitis viruses. The full length article is available as an information leaflet from the Birchgrove Group.

HEPATITIS A (HAV) is the most common cause of acute viral hepatitis. It is primarily spread through contaminated body waste, particularly faeces, and therefore can be spread from person to person and through contaminated water. HAV is the hepatitis that is frequently contracted by travellers to developing countries. It has recently been confirmed that HAV can be transmitted through antihaemophilic factor concentrates. These transmissions have happened despite factor concentrates being virally inactivated by a solvent detergent procedure. Transmission via blood products treated with solvent detergents is possible because HAV does not have an envelope (the part of the virus destroyed by the detergent).

HEPATITIS B (HBV) can cause either acute or chronic hepatitis and is transmitted by blood and blood products, sexual contact. Nearly everyone who used antihaemophilic factor concentrates before they were heat-treated was exposed to HBV. Most people (about 65%) of those exposed to HBV recover from the infection without any symptoms. Approximately 25% develop acute symptomatic hepatitis.

HEPATITIS C (HCV) For years any cases of viral hepatitis that could not be identified as either HAV or HBV were referred to as non-A, non-B hepatitis. It was well known throughout the 1970s and 1980s that the large number of such cases were caused by a virus, but it was not until the third hepatitis virus was characterised in 1988 that hepatitis C was named. HCV is transmitted primarily through blood and blood products, although there is evidence that it can be transmitted sexually or via household contacts. A very high percentage of persons with haemophilia are HCV-positive. Collected blood is screened for antibodies, however, cases of HCV transmission through blood products - particularly IVIG - continue to be reported. There is no vaccine to prevent infection with HCV. An HCV infection is documented by the presence of antibodies to the virus. In contrast to the situation with hepatitis B, the development of antibodies to HCV does not mean that the body has recovered

from the infection or that the body has an immunity to hepatitis C. The antibodies which are detected by the blood test do not effectively neutralise the virus. That means that hepatitis C disease can progress even while antibodies are present.

HEPATITIS D (HDV) (also known as the Delta Agent) is a defective, parasitic virus that does not have an envelope. In order to replicate, HDV needs to crawl into the shell (surface antigen) of hepatitis B. Therefore, it is impossible for someone to be infected with HDV unless he or she is also actively infected with HBV (and has not developed antibodies to HBV). HDV can cause both acute and chronic disease and is transmitted in ways similar to that of HBV. A 1982 study concluded that 48% to 80% of persons with haemophilia were also positive for hepatitis D.

HEPATITIS E (HEV) is transmitted in similar ways to hepatitis A virus. HEV causes acute hepatitis and is not associated with chronic liver disease. HEV has caused epidemic outbreaks in numerous parts of the developing world and sporadic outbreaks of hepatitis in industrialised countries. Collected blood is not screened for hepatitis E.

HEPATITIS F, G, H...? The common characteristic of hepatitis viruses is that they all infect liver cells. Hepatitis viruses can, however, infect other cells and organs as well. Hepatitis C virus has, for example, been found in the cerebrospinal fluid. Hepatitis specialists believe that there are at least three non-A, non-B, non-C, non-D, non-E hepatitis viruses. They will not be named until the actual virus is isolated and characterised. The existence of these mysterious viruses is a powerful reason for blood and blood products to be virally inactivated for as broad a spectrum of viruses as possible.

CONCLUSION Some known viruses are still not screened for, and methods to more completely eradicate viruses from blood and blood products are not yet implemented. Furthermore, the treatment of hepatitis and liver disease is woefully inadequate. As persons with haemophilia, we have a responsibility to advocate for more aggressive research into how to improve the health of our livers.

LONG TERM SURVIVAL

The long term effects of HIV on individuals who are infected with the virus are relatively unexplored. Once again many haemophiliacs are boldly going where no-one else has gone before. People who have coped with their HIV status relatively well for the early years of their diagnosis can begin to encounter a type of "mid-life crisis". Ten years after infection you begin to think, "Why am I still alive, when so many others have died? Maybe I'm going to be next, it has to be my turn soon! With so many haemophiliacs having died its inevitable that HIV will get me in the end!" These disturbing thoughts and feelings can begin to surface for long term survivors because of the time factor; ten years can give you a long time to think!

Obviously, not all long term survivors react in the same way. Some people experience extreme and continued concern about their health, even though they may not have developed new symptoms or had a decrease in their general well-being. Some people experience a gradual and re-occurring depression that demotivates and disables them; there are so few encouragements to survive, so little good news in a wealth of grim statistics. Some people are forced into denying that HIV is present in their system, a denial of their health situation which at other times they have fought to understand.

For many people, the overall progression of HIV disease appears to lead to a diminishment in their energy. People who felt able to undertake jobs, families and normal lives begin to experience increasingly limited levels of stamina and fitness. "I just can't do it anymore!", "I feel like a clock which is slowly running down", or, "I always feel like I've had several late nights, and not enough sleep to recover".

At some time in the progression of HIV disease, long term survivors begin to make changes to their lives which they feel reflect the situation that they are in. People often reduce or give up work. This of course, not only has financial implications, but has a great significance to a person's overall state of mind. Others can create dramatic changes within relationships with family or friends and these are often catastrophic for a person's ability to lead a stable, stress free life. Long term survivors often begin to need increased support, whether from health professionals, therapists, friends or family. The reasons for this increasing dependence and lack

of ability are difficult to pinpoint. It may be physical, due to the increased viral load in a persons system, a slow degeneration of general health and well-being, or it may be psychological, an inevitable response to the years of uncertainty and fear. Without intervention, this process of mental and physical deterioration can spiral down to severe health problems, AIDS related illnesses and a physical and psychological situation from which it may not be possible to recover.

Sometimes I feel that because I have not become ill that I should ignore my HIV status, and its potential threat to my health, and carry on as if everything in the garden was rosy. But then a more rational side of my nature tells me to face the facts. Just because my house hasn't burnt down doesn't mean that I shouldn't take out insurance. Surely, I would be stupid not to invest time, energy and concern, into individuals or groups such as Birchgrove that can offer me support and understanding, and hopefully become a safety net for the future. Even though illness is not presently a problem, it doesn't mean that the awareness of the best forms of health care and the informed support from family and from the community, will not be necessary for an actual moment of crisis.

And now new fears are beginning to edge into my midnight thoughts. No longer, "Will I be here next year?" But, "Should I have decided to prepare for the worst so soon? Should I not have looked for that relationship? Should I have tried for children?" The nightmare begins to form of a self-help group of positive haemophiliacs who are gathering for their umpteenth anniversary, and as they sip their horlicks and eat their digestive biscuits the discussion turns again to lack of pension provision and all those wasted years of sitting around worrying about the future.

At what moment can we call a halt to the endless speculation about our futures? When do we stop worrying whether to take on that commitment or make that long term investment. Will we ever be able to feel free enough to be able to follow our instincts and to live life to the full and forever?

Dear Editor

All the information and literature on AIDS that I have found so far seems to be concerned with the young, homosexuals, bi-sexuals, drug abusers and their partners – and with T4 cell counts above 200. But what about the happily married, middle-aged heterosexual who, after a long and increasingly severe illness, has been unexpectedly diagnosed without any warning or counselling? At that point my husband's T4 count was just 20! We were sent home with a handful of pills for herpes and candida, some morphine, a prescription for food supplements and a warning that he could die at any time. But he didn't. Now, six months later, we don't know what to hope for or expect. He is much better and has regained one of the two stone in weight that he lost before. But he still feels so ill, so tired and weak, so nauseous, so full of pain and depression – is he improving or fading away? The doctor says, 'You have taken up your bed and walked! You may die tomorrow or live another ten years – I don't know.' But is that ten years of constant illness? Can he hope to feel better with such a low cell count? And how do we cope with his constant fear that other people will discover his secret diagnosis – his dread of the totally unjustified stigma that he is sure would follow in this old-fashioned, rural community?

No one seems at all interested in how he may have become infected. (Just how do they compile all those statistics without asking questions?) The doctors take a 'Nudge, nudge – wink, wink' approach implying, 'We're men of the world. We understand – but we wouldn't want the wife to find out, would we?' They won't listen when we say that the first symptoms appeared in 1980 and have been present most of the time since then. They won't answer when we ask whether it could possibly have been the massive blood transfusion he had in 1968 that is to blame – or, even more worrying, could it have been through the normal, heterosexual activity of a handsome bachelor in the sexually liberated '70s. If so, how many more 'not at risk' middle-aged people are being told, wrongly, that their symptoms are self-induced by over indulgence in alcohol and nicotine or a mid-life crisis? Our hospital is 50 miles away. We see the doctor once every six weeks and a Social Worker once a month. Apart from that we are on our own, trying to come to terms with an incomprehensible diagnosis and a hopeless future.

I would welcome friendly communication from anyone who can identify with our situation.

Name and Address Supplied

Dear Editor

I read with interest a letter on the front page of your issue number 4 entitled "The PAS Interview - Washes Whiter". I was offered an interview with PAS as was your correspondent. However, I had a totally different experience and I hope you will publish it so that your readers are made aware of both sides of the story.

I arrived for the interview in a state of trepidation. After all it's a hell of a subject and it's not everyday that you are in the position of opening your heart to a total stranger. However, the interviewer was very friendly and put me at

ease straight away. After making me a cup of tea and ensuring that I was comfortable the interview got under way.

As would be expected my interview went along the same lines as your correspondent. Incidentally, my interviewer mentioned that this was her first interview as well. However, I never felt uneasy. The point of the interview was to understand our needs and to do so there is a need to understand ourselves. I was never put in the position of being forced to answer a question. Had I not wished to give an answer I would not have done so. This was made perfectly clear at the begging of the interview by the interviewer. Recording equipment was present but not ominously so.

We talked for over two hours and I left feeling refreshed and overall "good". I would liken it to a therapy session; a chance to talk and get rid of some of that bottled up emotion. It was my decision to attend the interview. No one forced me to go. I feel sorry that your correspondent had such a bad time but perhaps he went looking for the wrong thing. He makes a comment, "I attended... at the appointed hour prepared to undergo the ordeal". With that kind of forethought, how else was the interview expected to go?

You also mentioned that you have received a number of reports concerning the initial PAS interviews. I find it hard to believe that they were all so negative.

Derek Martindale

Dear Editor

I wish to respond to Andy Cowe's letter in #5 of The Birchgrove, as it covers some points that I think are very important for the Birchgrove Group and the Haemophilia Society.

Your worries around "survivors guilt" are touching but are experienced just as strongly by those of us infected who have seen friends die. The feeling is not just one of "why not me?" but also, "is this my future playing out in front of me?"

You have missed the point of the commentary; though you might have taken ten years to say you were lucky not to have been infected, many others have said this before you. It is the following point which was crucial, in that it had never been said before: "... I want to come and help others who have been infected."

This does not mean that no non-positive haemophilic helped in the care of those who were HIV positive – simply that it was the lack of any public involvement that was visible to those of us with HIV. The lack of any discernible response at all from uninfected haemophiliacs is the point that pisses me off. Added to that is the feeling among some Haemophilia Society members that we, the unclean, should quietly die without a fuss to make their lives a little easier.

On your last point I think you are absolutely right: we need to communicate more effectively. Perhaps Andy, in your role as editor of the Bulletin, which is read by uninfected haemophiliacs, you could initiate this process of communication and reconciliation.

Robert James

PARVOVIRUS

Continued concerns have been expressed about the viral contamination of factor VIII. It is known that current methods of heat treatment may not remove all risk of viral transmission, including the risk of human parvovirus B19. This article is an examination of the effects of the human parvovirus.

Infection with parvovirus is very common in the population. Infection occurs most commonly in childhood between the ages of 4 and 12 years. Most people do not display any symptoms or only have mild problems which are associated with respiratory or breathing difficulties. The most common illness due to Parvo infection is a rash similar to rubella, which when it occurs in children is often called, fifth's disease or slapped-cheek disease.

With Parvo infection, there may be associated arthritic problems and this is very common in adults, (about 80% of cases). The symptoms are an arthritis like condition which affects the joints in both hands and feet. It usually resolves within two to four weeks, but may persist for longer.

Anaemia, the interruption of the production of red cells in the body, occurs in all infected individuals, but only becomes evident in those with an abnormally low number of red blood cells, or those whose red cells have a shortened life span and who are already anaemic. Parvo infection in these individuals causes a period when the person is unable to make or develop new red cells for the blood system. This can be severe, but does resolve.

"patients who are unable to mount an immune response develop a continual and relapsing anaemia"

In patients who are unable to mount an immune response, e.g. HIV positive individuals, parvo infection persists and eventually the patient develops a continual and relapsing anaemia. This is due to the complex interaction between the strain of the virus, the age and constitution of the person and the point during the person's life at which infection occurs. Parvovirus replication will always be extensive in rapidly dividing tissues. This causes the death of the tissue cells. It is also assumed that the rash and arthritic side affect of Parvo infection is a response that is triggered by the functioning of the immune response which is working to clear parvo virus from the system.

INTERNATIONAL HEP C CONFERENCE

The UK's first International Hepatitis C Conference is being hosted by Mainliners Ltd in partnership with Mid Kent Health Care Trust this summer. This full day conference will be held in the Regent's College Conference Centre, Regent's Park, London, NW1, on Wednesday 28th June 1995.

The aims of the conference are:

- To bring together people working in the field of government, health, voluntary and private sector in order to ensure inclusion of Hepatitis C on the national agenda.
- To highlight the impact of Hepatitis C across a range of different groups including drug users, people with haemophilia and those living with HIV and AIDS.
- Increased funding is essential to support continued developmental work on support groups and other initiatives.
- To make recommendations, and produce a full report aimed at funders, policy makers and practitioners.

This conference will address these issues from the viewpoint of both social services and health authorities. It offers a unique opportunity for clinicians, health and social care professionals, counsellors, health educators and those responsible for setting policy to consider and discuss the issues with experienced speakers who are dealing with these problems on a day to day basis.

Delegates will be able to attend seminars and workshops which will encourage input and discussion with both the panel and other attendees. A comprehensive package of conference documentation will be provided as a valuable source of reference and to enable delegates to report back to their own organisations.

Further details from:

Christine Beveridge or Basil Williams on 0171 738 4656 or 0171 738 3792

This article is continued from Birchgrove 5

As I return from a seven day respite in the mountains I am confronted with the news that someone I care about has been told that they have a very short time left in this life. We must live and confront this reality each and every day along with our wives, children, mates, parents, siblings and friends. There is no hiding from this basic reality. However, our response as individuals and as a community is where we can make a difference. It is the defining moment in this community's history. Will we forever change the power relationships and the business of Haemophilia, or will we continue to take direction from the very organisations that were central to the infection of nearly half of our community?

The corporate irresponsibility and regulatory breakdown that led to the AIDS disaster continues today and without substantial change it will occur again. Parvo virus is a good example of another warning sign, that if ignored, could have disastrous results for people with Haemophilia. Recent history has taught us that if we do not advocate for ourselves we will continue to remain expendable. We have demonstrated that when we are organised and united in purpose we can change the status quo.

Understanding the lonely existential reality of coping with this crisis is imperative if I am to be able to process the feelings, the sadness, despair and hopelessness, and move on to responding through empowerment and collective action. We must work to build a community with designed and controlled support structures that address the challenges facing ourselves and our families.

It is easy for anyone of us to lose our way attempting to cope with this hellish reality. Denial certainly is a factor here and is easy to fall into. However, it must be opposed, struggled with and overcome if we are to make progress. We need each other if we are to succeed in making the changes necessary to protect the interests of this community. Isolation and alienation, while a necessary part of the process of coping, cannot be allowed to be the dominant themes of our lives. It is patently clear that the treatment centre psycho/social programs are not equipped to encourage and nurture empowerment for people with Haemophilia. Their brand of partial empowerment stops short of the real thing continuing to view persons with Haemophilia as "wards" of the centres. Power continues to flow

downward from the medical staff to the patients. This does not negate the time when the centres played a positive role in the development of strategies like home treatment that did serve to empower persons with Haemophilia. Unfortunately that model was not carried to its fullest. We gained a degree of power; however that change was still within the context of medical ascendancy.

This all changed with the onset of the AIDS crisis. It is now painfully clear that the level of independence given was insufficient in the context of this disaster. Ultimately the limited independence given propagated the illusion that we were in control of our lives. We accepted this picture without collectively questioning the context within which it was occurring.

We failed to see what was right there in front of us; the conflicts of interests that permeated the Haemophilia world. More and more the drug companies exerted their influence and control (both overt and covert) in all areas of haemophilia. By the mid 1970's the companies were intimately involved with the doctors and the treatment centres. What many in the community thought was an extended treatment family was in fact a conflict of interest escalating toward the boiling point. Why question a good thing? A few courageous people attempted to sound a warning about this growing conflict. Yet those who took a stand were ostracised and labelled as radicals and trouble makers.

As long as there are staggering profits to be made there will always be companies producing factor concentrates, that is the bottom line. This is not about companies producing products because of an altruistic desire to help us. It is about profit, nothing more, nothing less. If Hepatitis and AIDS did not educate us to that fact then the denial is even greater than I had imagined. So my friends, where do we go from here? Since we have nothing left to lose, this seems like a moment for positive change. We organise, support, advocate and take control over our lives. We proceed with dignity and self-respect toward our collective goal of economic and social justice for ourselves and our community.

Corey Dubin is the vice-president of The Committee of Ten Thousand, an American advocacy and support organisation for those infected with HIV through tainted blood and blood products. Copyright © Corey S. Dubin

"The corporate irresponsibility that led to the AIDS disaster continues today"

ROUND ROBIN

I seem to be seeing robins recently, although I thought they were only a winter visitor in my part of the country. Obviously not so. Well not anymore; probably something to do with global warming. Seeing all these happy little birds gave me an idea: when I was a computer operator we had what we called a round robin backup system. Which meant that the same disks were used over again but in a particular sequence. I thought to myself, that's just what we need as a system so that our committee see all the interesting literature that turns up at the P.O.Box. So I've put it into operation.

It then occurred to me that others might be interested in the same literature. Whilst I can't set up a round robin system for everyone, I can at least give you an outline of some of the currently available literature and information about groups. Please remember that these are only suggestions, and always consult your centre director or doctor about medical treatments.

The London B.P. group produce a three weekly newsletter. It contains much information gleaned from many areas, including letters and various contact listings. It's free to anyone who is HIV Positive write to: *Body Positive, 51b Philbeach Gardens, London. SW5 9EB or phone 01718 351045.* They are very helpful and sympathetic.

A very good source of medical information can be found in the NAM update, again free to Positive people, it contains specific articles about new drug therapies, explanations of individual medical conditions, details about drug trial updates, and other HIV specific information. Write to: *NAM Publications, 52 The Eurolink Centre, 49 Effra Road, London. SW2 1BZ or phone 01717 371846.*

The latest find is Equilibrium. I have read the pilot issue cover to cover; it's a neat A5 format, and packed with useful and informative articles. Write to: *BM Equilibrium, London. WC1N 3XX subscription is 10 for a year.*

The Hepatitis C Support Group is a group of people offering support to those infected with the HCV virus, with or without other particular infections (such as HIV). They are a small, London based group but hold regular monthly meetings. Write to: *205 Stockwell Road, London. SW9 9BR or phone 01717 377472.* They don't have a newsletter, so if you can't attend but want a copy of their useful minutes from the last meeting, send them an sae.

WHAT LONG TERM REALLY MEANS

"Your looking well", I hear it every day; doesn't it make you puke? If one more person looks at me with those doubting eyes, and says, "You look well!", I think I'll bloody kill them! How the hell should I look? It can really get to you still being well after nearly 15 years of HIV infection. "Why me? Why am I so well? Why did others die so early? What happened to what's his name?" "Oh haven't you heard, he died last week". I've lost 14 close friends and colleagues to AIDS and have been involved in the lives of 16 other haemophiliacs who have died of AIDS.

It really makes you think. Why have I been spared the infections and complications that come with being HIV positive? But, then I think, I must be doing something right to have remained so well, for so long. I shouldn't complain really. I have always been a bit of a rebellious type, even before I got HIV. I lived my life, my way, and did all the things that I wanted to. Most of them without the blessing of my Haemophilia Centre Director.

When I was first told my status, they said I had two years to live. Then two months later, I was told I had been positive for five years. What happened to the two years?

I really believe I can win this struggle, but you always have a bit of doubt in your mind. The mixed emotions, whether to live each day as it comes, or to plan for a long and happy future.

On a good day, I think, "We can't do that, as we can't afford it", then the next day I'll go and blow a hundred quid on something I don't really need. Those are the times when the doubt creeps in and you think "Oh, to hell with it, I could be dead next year, so why worry?" This can make for difficult relationships with those who love you most. They don't want to stop you from doing things, or having things, but they need to look ahead. When or if, I kick the bucket, they'll be left to look after the children and come to terms with losing a loved one.

I know I tend to concentrate on what, or how I'm feeling, or what I want, and I really try to stop myself from doing it. But let me tell you, it can be really hard at times. Sometimes I find it really difficult knowing that I could drop dead within six months, or begin to lose my marbles and forget that I'm wearing my pants when I take a crap.

"Silence=Stigma" Advocate

Many AIDS activists say that the stigma attached to AIDS will continue unless individuals, especially famous ones, acknowledge their illness. A. Cornelius Baker, director of public policy and education at the National Association for People With AIDS, said that AIDS is more likely to be hidden if the person who has it is a gay man, particularly if he is a celebrity. For example, journalist Randy Shilts, who died in 1994, has been the object of scorn because he only revealed his illness after his health declined significantly. Despite Shilts' status as a prominent historian of the AIDS epidemic and perhaps the first openly gay reporter in mainstream media, he remained silent for several years about being HIV-infected. Most often, however, the AIDS closet involves the suppression of AIDS as the cause of death in obituaries and obituary notices. Often survivors avoid naming AIDS as the cause of death, using instead a kind of code where young men die from "long-term illness" or "heart failure." Although activists hope for more openness, they understand why many people do not choose it. "There has to be a respect for privacy," said Baker. "You have to allow people to die in the fashion they choose."

"Marijuana: Defying Laws to Help the Ill" Los Angeles Times
The Cannabis Buyers' Club is part of a growing movement aimed at earning sick people the right to use marijuana. Nationwide, thousands of people with AIDS, cancer, glaucoma, epilepsy, and other diseases defy the law daily to treat their ailments or ease their pain. While advocates of the drug cite anecdotal evidence that the plant can reduce nausea from chemotherapy, reverse the wasting syndrome associated with AIDS, and ease muscle spasms in paraplegic people, others say there is insufficient evidence to prove the marijuana is beneficial. Some even suggest that smoking it could be harmful, particularly for AIDS patients susceptible to lung ailments. For almost three years, AIDS researcher Donald Abrams of the University of California at San Francisco has sought federal approval to conduct a clinical trial to determine whether smoking marijuana can help patients overcome the AIDS-related wasting syndrome. The Food and Drug Administration, however, has refused to authorize the research. "People in Washington are putting up barriers," Abrams said. "In my opinion, it's becoming very ridiculous. The trial will go on if the science survives the politics."

"2-Year Nightmare Ends for Woman Wrongly Told She Had AIDS Virus" Los Angeles Times
For two years, HIV dominated Vernelle Lowder's life. In the end, however, she found she was never infected at all. In 1989, Lowder received a blood transfusion during surgery at a hospital in Waycross, Ga. Ten years later, after her blood was drawn during a checkup for a thyroid problem, she was informed she was HIV-positive. In 1992, her doctor put her on AZT, an AIDS treatment drug that brought on side effects including vomiting and fatigue. Lowder arranged to have legal custody of her children transferred to her mother, planning to commit suicide. When she joined a local support group for AIDS patients, however, the counselors-naming that her T-cell counts had remained consistently high-suggested that she be re-tested. In Nov. 1992, Lowder learned that she was HIV-negative. Last year, a jury awarded her \$500,000 for pain and suffering, but closed the clinic and said the majority must be paid by the Florida Department of Health and Rehabilitative Services (HRS)-the agency that performed the test. Now, Lowder's attorney is seeking a legislator to sponsor the act that would raise HRS's damage payment from the \$100,000 capped by statute for state agencies to the \$350,000 ordered by the jury.

"Danish Haemophiliacs Lose Compensation Claim" Lancet
A Danish High Court has turned down a claim by the Danish Haemophilia Association, which was acting on behalf of eight Danish haemophiliacs who claim to have acquired HIV through therapy with factor VIII in the mid-1980s. The court, however, awarded one of the eight haemophiliacs Dkr 18,718 (1,817 pounds) against the National Board of Health and the Ministry of the Interior. The court said that they should not have allowed the use of non-HIV screened factor VIII after Jan. 1, 1986. The haemophiliac who was awarded compensation was chosen for the token award because he was the latest of the eight to have become infected. The other seven haemophiliacs were not compensated because the time of their infection could not be proved. It also could not be proved that any of the defendants, including factor VIII producer Novo Nordisk, could have acted in any other way than they did. The plaintiffs had wanted the court to determine who should bear responsibility for the HIV infection.

"Latex a Good HIV Barrier, but Research Still Indefinite" AIDS Alert
After nearly a decade of research, it is still not definitely known whether condoms leak HIV. While the Food and Drug Administration (FDA) and the Centers for Disease Control and Prevention have repeatedly assured the public that intact latex condoms provide a continuous barrier to HIV, several studies contradict that conclusion. The Mariposa Foundation conducted the most significant research-a study of 31 brands of latex condoms that were tested at conditions that exceeded realistic situations. The study confirmed findings of a study by the National Institutes of Health and the University of California at Los Angeles suggesting that leakage of HIV occurs in some brands of latex condoms. One criticism of the study was that it used virus-like

particles, and not HIV. The four lowest-ranking brands showed at least a 6 percent failure rate-Concept Plus had a 100 percent failure rate, and was recalled several years ago. In 1992, the FDA awarded a two-year \$545,000 grant to Princeton Scientific Instruments Inc. to develop optical methods of detecting holes in condoms on a mass scale-which suggests to Dr. Jerry Nelson of Nelson Labs, which helped with the Mariposa study, that the agency is not convinced that current screening standards are adequate.

"Report Says Haemophilia Foundation Knew Early That AIDS Was Probably Spread by Blood" New York Times
The Philadelphia Inquirer reported Sunday that the fact that AIDS was most likely a blood-borne virus that pharmaceutical companies could eliminate from blood-clotting medicine commonly given to haemophiliacs was known to executives of the National Haemophilia Foundation as early as 1982. More than half of the 20,000 haemophiliacs in the United States have become HIV-infected from tainted clotting factor, and approximately 3,000 of them have died. As evidence, the inquirer cited sworn testimony and documents from a class-action lawsuit filed last year in Federal District Court in Chicago by patients and their families against the foundation and four drug companies. The lawsuit claims that the defendants continued to sell and promote certain clotting products even though they knew that some blood donors were at high risk for HIV infection. The drug companies-Rhone-Poulenc Rare and its subsidiary, the Armour Pharmaceutical Company, Miles, Inc., the Baxter Healthcare Corporation, and the Alpha Therapeutic Corporation-said they responded to the AIDS crisis as soon as possible during a time when very little was known about the disease. Drug companies have won all but one of 14 jury trials of lawsuits filed by haemophiliac patients or their survivors-the 14th case is being appealed. Related Stories: Philadelphia Inquirer (11/23/94); Baltimore Sun (10/24) P. 1A

"U.S. Epidemiologist Witness at Canadian Inquiry" Toronto Globe and Mail
The first witness in the final stage of the \$12.5 million judicial inquiry into Canada's blood system will be Dr. Donald Francis, a former epidemiologist at the U.S. Centers for Disease Control and Prevention. Francis has been one of the most acerbic critics of governments' slow response to the AIDS epidemic. In his interim report last month, Mr. Justice Horace Krever, who is heading the commission of inquiry, warned that the tainted blood tragedy could be repeated with a new contaminating agent. He said that changes are necessary to "minimize the likelihood of such a calamity." The final report, to be completed by the end of the year, will examine the decisions that led to the infection of more than 1,000 Canadian haemophiliacs and transfusion recipients with HIV during the early 1980s. The commissioner's final report will also recommend a complete reworking of the blood system.

"Learning from the Tragedy of AIDS" Philadelphia Inquirer
On Wednesday, Donald Francis, a retired epidemiologist with the U.S. Centers for Disease Control and Prevention (CDC), testified in Canada before the Commission of Inquiry on the Blood System. One of the first scientists to study AIDS, Francis testified that the CDC made a mistake in not being more forceful in the early days of AIDS. He admitted that the exact cause of AIDS had not been identified in the early years of the epidemic. He noted, however, that lack of public knowledge had not prevented public health officials from taking strong measures to block other threats, such as Legionnaires' disease and toxic shock syndrome. Francis also said that there was little hesitation among government officials to issue early, written warnings to health-care workers about tainted blood. That effort began in November 1982, long before HIV was identified. The warnings came just four months after the National Haemophilia Foundation first informed its members that the CDC had found three HIV-infected haemophiliacs. Francis said that he and Bruce Ewart, the foundation's main contact at the CDC, were shocked to see that the foundation's newsletter urged people to continue using factor VIII. The newsletter said that although a virus might be causing the disease, there was little risk and that the "CDC is not recommending any change in blood product use." Francis claimed that he and Ewart never said any such thing.

"Heart Muscle Disease Related to HIV Infection: Prognostic Implications" Journal of the American Medical Association
To determine the natural course of heart muscle disease in HIV-infected patients, Cuneo et al. studied HIV-infected adults to detect myocardial dysfunction and time to death. Forty-four of the 296 subjects were diagnosed with cardiac dysfunction. In contrast to other forms of cardiac dysfunction, dilated cardiomyopathy was strongly associated with a CD4 cell count less than 100. Compared to those with normal hearts, patients with dilated cardiomyopathy had significantly reduced survival rates. While 101 days was the average survival time for those patients with cardiomyopathy, those with normal hearts and a CD4 cell count less than 20 lived 472 days. There were no significant differences in survival for participants with borderline left or isolated right ventricular dysfunction. Even with the reduced cell count with which dilated cardiomyopathy is associated, the prognosis for HIV-infected patients with dilated cardiomyopathy is poor. Isolated right and borderline left ventricular dysfunction, however, are not linked to diminished CD4 counts and do not carry adverse negative prognostic implications.

"Health Heroes: AIDS' Longevity
Americans may learn most of what they know about fatal diseases-including cutting-edge research, the best treatments, and the latest experimental drugs-from press coverage of an ailing celebrity. Actor Rock Hudson's disclosure in 1985 that he had AIDS brought the disease out of the closet and into greater public discussion. Also in 1985, Hudson's close friend, Elizabeth Taylor, cofounded the American Foundation for AIDS Research (AFAIR), which has awarded more than \$71 million in grants to 1,400 AIDS research groups. Ryan White, a 13-year-old haemophiliac who contracted HIV through a blood-clotting product, became an instant celebrity when he was temporarily banned from school near his hometown of Kokomo, Ind. He spoke to other youths about AIDS, and testified before the President's Commission on AIDS in 1988. In 1990, after White's death, Senators Orrin Hatch and Ted Kennedy cosponsored the "Ryan White Bill," to help cities finance AIDS care. Other heroes include Elizabeth Glaser, cofounder of the Pediatric AIDS Foundation, and former NBA legend Magic Johnson, who has been a major player in educating children about safe sex.

"German Fund to Help Victims of HIV-Tainted Blood" Reuters
Germany's Health Minister, Horst Seehofer, said on Wednesday that his country will make monthly payments to thousands of people who contracted HIV in Germany's largest AIDS scandal. The federal and state governments, the German Red Cross, and pharmaceutical companies plan to create a fund to help people made ill by tainted blood or blood products during the 1980s. Seehofer told the German parliament's health committee that the federal government would contribute 100 million marks (US\$572 million) to the fund, while the German Red Cross and pharmaceutical companies together would contribute another 100 million marks. Regional states will pay 50 million marks (US\$36 million) into the fund, which will make monthly payments for 15 years to people infected before 1988 with HIV-contaminated blood. Victims who contracted HIV will receive 1,500 marks (US\$1,103), while people who develop full-blown AIDS will receive twice that amount from the fund that still must be created. Victims and opposition parties immediately attacked the 250 million mark (US\$180 million) fund, saying it was miserly. The German Haemophilia Association and the Haemophiliacs' Interest Group said the plan fell short of what they expected or what was fair given the city of Bonn's admission that most cases could have been prevented with proper blood screening. Victims were either haemophiliacs whose long-term treatment was based on a blood product to prevent bleeding, or hospital patients given a similar medicine during operations.

"Haemophiliacs Would Get More Time to Sue" Philadelphia Inquirer
On Monday, a New Jersey Assembly panel voted unanimously in favour of a bill that would give HIV-infected haemophiliacs additional time to sue drug companies whose medicines were tainted with HIV. The vote came just two weeks after the state Senate Judiciary Committee unanimously approved the same measure. The bill will now go to the full Assembly and Senate. The legislation would open a window in New Jersey's statute of limitations, giving haemophiliacs one year to sue one or more of the four pharmaceutical companies involved. Proponents of the measure claim that lawsuits filed against the drug companies are in danger of being dismissed because they were not filed until after the two-year statute of limitations had expired. The plasma industry, however, says the bill is unconstitutional and contrary to the goals of personal injury lawsuit reform.

"Haemophiliacs See Betrayal" Richmond Times-Dispatch
A class action lawsuit filed in federal court in Chicago claims that four drug companies knowingly distributed blood clotting products that were tainted with HIV. The lawsuit also states that the National Haemophilia Foundation, a research and information group partly financed by blood-product manufacturers, misled the public about the severity of the AIDS threat. The defendants claim they acted properly, and that blood was screened for HIV as soon as the test was available in 1985. "We thought we did a pretty good job but, in retrospect, it didn't stop an enormous tragedy from occurring," said Susan Horsthal, an attorney for Rhone-Poulenc Rare Inc. and its Armour Pharmaceutical Co. subsidiary. Last August, a group representing HIV-infected haemophiliacs and their survivors rejected a \$160 million settlement offer from Rhone-Poulenc and Baxter International Inc.

"Tobacco Firms Are Buoyed by Haemophiliac Decision"
Last week, the Seventh U.S. Circuit Court of Appeals in Chicago refused to permit a group of haemophiliacs to continue with a class-action suit alleging that they contracted HIV from blood-clotting medicine. The decision gives hope to tobacco companies fighting a class action on behalf of allegedly addicted smokers. The appeals-court panel said the two-step trial procedure could force the four pharmaceutical companies named in the suit into bankruptcy-court proceedings, causing irreparable harm, and that the class certification was an abuse of judicial discretion. The trial judge in the case designed the two-step procedure to allow one jury to first determine whether the pharmaceutical companies were negligent and, if so, to allow individual members to then pursue claims for damages. Lawyers for the approximately 20,000 haemophiliacs said they will seek a review by the full seven-member appeals court.

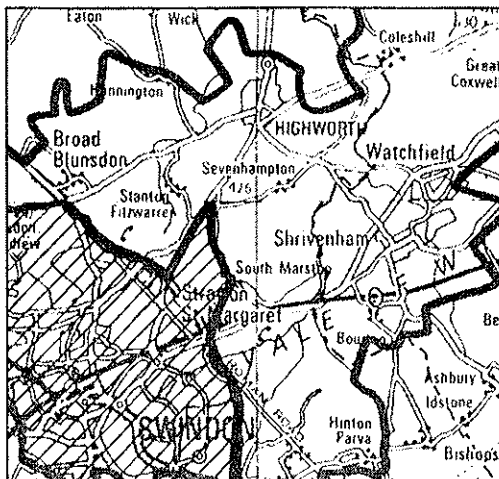


BIRCHGROVE WOODLAND SITE

The Birchgrove Group, in co-operation with the The Woodland Trust, is planting a commemorative woodland. The Birchgrove Woodland site will be part of the Great Western Community Forest, which covers approximately 75 square miles. We believe that the planting of 1,200 trees will be an appropriate representation of the lives of those haemophiliacs who were infected with HIV.

The Birchgrove Woodland site lies on the edge of Swindon, in the Parish of Stratton St Margaret (Ordnance Survey Map N^o, 173, Grid Reference SU170999). The Birchgrove Woodland will be an important green space for local inhabitants and for visitors from further afield. It is currently farmland, but tree planting to transform the site will begin in Autumn 1995. The design of the woodland is currently being laid out, the placing of grassy areas, the creation of views, the main entrance points and routes for walkers will soon be decided. Suitable tree species are being chosen which are appropriate to the locality.

We hope that this community forest will be a suitable reminder of the continuing cycle of nature and its message of hope and renewal. We know that our woodland grove will become a peaceful place for people to visit and think of those who have had their lives so profoundly affected by HIV.



the woodland project

Please help us to create this Woodland Grove, just £25.00 will pay for a tree to be planted and maintained. A certificate of sponsorship will be forwarded to you on receipt of your donation.

If you wish to have a named person on your certificate of sponsorship please enter below.

Name to appear on the certificate:

.....

Name of sponsor:

.....

Address:

.....

.....

.....

.....

.....

I enclose a cheque for £.....

Please make payable to:
The "Birchgrove Woodland Project",
and send to: The Birchgrove Group,
PO Box 313, Canterbury Kent CT1 1 GL.

Although sponsorship of the Woodland Grove has been progressing well, we are still keen for people to sponsor individual trees. We also are looking for people or organisations who are willing to become patrons or corporate sponsors for this woodland project. Further details are available about these schemes.



BIRCHGROVE IS A FORUM FOR:

- The treatments of haemophilia and HIV
- Taking best care of ourselves, through informed debate
- Staying healthy with both haemophilia and HIV/AIDS
- Ways in which HIV affects love and sexuality
- The social and psychological aspects of haemophilia and HIV

WE BELIEVE THAT PEOPLE WITH HAEMOPHILIA AND HIV

- Can be empowered and enabled to deal with HIV/AIDS through relevant information and mutual support
- Can improve their health and extend their lives by expressing feelings and confronting the issues directly
- Have needs that are best understood by drawing on the experiences of those in the same situation
- Should be heard and have their needs recognised and not suffer in fear and isolation
- Have a role in the work of the HIV/AIDS community to inform and challenge the ignorance that exists about HIV

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

Birchgrove Newsletter Back Issues

- BIRCHGROVE newsletter Issue 3
- BIRCHGROVE newsletter Issue 4
- BIRCHGROVE newsletter Issue 5

Birchgrove Information Leaflets

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

We can also supply the following items.

- "Living with Haemophilia and HIV" £2.50
- Red Ribbons (Cloth) 50
- Red Ribbon Badges (Enamel) £2.50
- Birchgrove Group Pens £1.00

Name:

.....

Address:

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.....

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Send to: The Birchgrove Group,
PO Box 313, Canterbury Kent CT1 1 GL.

CREUTZFELD-JAKOB DISEASE

In November 1994, the American Red Cross recalled 164 lots of anti-haemophilic factor (AHF) and albumin due to the potential contamination of this product with the causative agent of Creutzfeldt-Jakob disease (CJD), a rapidly progressive and invariably fatal disease of the central nervous system. One donor with CJD contributed plasma for all of the lots. At least 205 lots of products may have been contaminated by one donor. This questions the safety of pooling plasma from as many as 20,000 donors in order to produce plasma derivatives such as antihemophilic factor. Because the affected products include albumin all grades of AHF, including the highly purified and synthetically made recombinant factor are potentially at risk.

The cause of CJD is still controversial. Some researchers think that CJD is caused by a prion, an infectious agent that is not a bacteria or a virus but an abnormally structured protein. Others believe that the CJD agent is a "slow" virus. CJD has never been shown to be transmitted through blood or plasma products; however, it can be transmitted by human tissues, as well human-derived growth hormone. The potential for blood transmission is particularly frightening. It has been shown that the CJD agent is not inactivated by heat, ethanol, UV or ionising radiation. There is not yet any test for the presence of the CJD agent in the blood.

Symptomatic CJD disease progresses rapidly, with the average survival time being eight months. Symptoms include progressive mental deterioration, memory loss, mood changes, loss of motor control, and headache. CJD disease is often mistaken for Alzheimer's disease. CJD causes irreversible dementia and leads to death. The course of disease is not fully known. CJD disease in humans is closely related to Bovine Spongiform Encephalopathy (BSE - also known as Mad Cow Disease) in cattle, and scrapie in sheep. Both can be transmitted among animals by eating the contaminated meat of infected animals. There does not seem to be a great danger to humans from eating contaminated meat.

For a community already decimated by AIDS, the possibility of new diseases transmitted through the blood supply is always a real threat. As CJD shows, we cannot assume the safety from transmissible agents in the factor products we use. But one way to lessen that threat is to use smaller pools of plasma to produce the products.

by Rich Colvin, Corey Dubin and Greg Haas