



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 its 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?