

# THE BIRCHGROVE



THE BIRCHGROVE GROUP, P.O. BOX 313, CANTERBURY, KENT CT1 1GL. TEL: 0345 697231

## WHAT PRICE BLOOD?...

ISSUE NO 5

by Mike O' Driscoll

**T**he National Blood Authority (NBA) – the unelected quango responsible for running The National Blood Service – intends to replace altruism with profit, according to Melanie Phillips, in the *Observer* on the 20th of November 1994.

In a scathing article that rightly condemns the motive of the NBA, Ms Phillips reveals how management consultants, Bain & Co., were commissioned by the Authority – at a cost to the health service of £600,000 to provide a report on transforming the blood products laboratory into a profit-making enterprise.

Among the proposals, are plans to close five out of the fifteen blood testing and processing centres in England and Wales, and to establish what are called blood stockholding centres. The NBA would also like to see fewer uneconomic blood donor sessions around the country, replacing them with larger sessions, which would no doubt increase the productivity and economic performance. And where is the evidence for the alleged inefficiency of the testing and processing centres?

Not in the Bain report, according to Ms Phillips, the British Blood service does not suffer a cash crisis, and apart from satisfying the vast majority of doctors, donors and recipients, it is also the most cost effective blood supply system in the world.

The refusal of the NBA to say where these stockholding centres are to be located, what supplies they will hold and how these supplies will be stored, shows the ignorance and shortsightedness of the quango.

Many doctors have voiced fears that patients lives will be put at risk, if as indicated, the new centres are located up to two hours from some hospitals. And what of the donors? Since the smaller donor sessions supply 30% of blood, will the NBA guarantee to increase the larger sessions by 30%? As Ms Phillips acutely observes, "in the name of the common good of economic efficiency, the NBA will take an axe to the bedrock value of the service, that priceless willingness by people to serve the common good." The report reveals enthusiasm for NHS reforms and how these reforms will lead to a more commercial environment for the service.

The implications are clear. Blood is to become a viable commercial commodity. If donors cannot be relied upon to donate altruistically at the new, larger sessions, then it follows that you pay them for their blood. And of course, you then have to recoup that cost — make a little profit. The National Blood Service becomes a "nice little earner", in which no doubt we will all have shares.

Except that it's not all right. There's a bitter irony in the fact. Those of us who are infected with HIV became so due to the use of contaminated Factor 8. It was purchased from the sort of commercially viable blood service that the NBA aspires to. With shareholders seeking high dividends, the cost of blood is bound to rise and concomitantly, so are it's derivatives. What price then High Purity Factor 8? Or will the NBA guarantee sufficient quantities of Pure blood products to the Health Service at affordable prices?

**F**rustration and anger was again forcefully expressed by people who are affected with haemophilia and HIV, at the Birchgrove Conference. Registrants believe that it is the role of the Macfarlane Trust to provide adequately for those who are affected.

The conference believes that the Trust is failing to respond to many of the existing identified needs. The Macfarlane Trust has failed to tackle or examine the wider range of problems and concerns which face those people who are affected by haemophilia and HIV.

We are therefore sending an open letter to the Chairman of the Trust and we have printed a copy of it in the centre of this newsletter. We know that many registrants believe that the Trust is failing in its duty of administering the funds allocated by the government. We believe that significant numbers of people are looking to the Macfarlane Trust to clarify and justify its current position.

## THE BIRCHGROVE WOODLAND PROJECT...

**A** seed is planted and it struggles to become a sapling, it sends out searching roots with which it clings tenaciously to the earth, and unfolds spreading branches with which it reaches to the heavens.

From the sapling, a vigorous and healthy tree can grow to become a thing of beauty and strength. A tree able to withstand the fiercest winds and storms that nature can hurl at it. The tree has to contend with many challenges throughout its life, and the

same can be true for us. We are strong and determined people who refuse to let haemophilia or HIV distort our lives. We seek to face our problems in a positive and constructive way, we have therefore, chosen a grove of trees as the symbol of our struggle to overcome the challenges of haemophilia and HIV.

This woodland grove will be a permanent and living reminder of the courage and determination of all those who have faced these problems.

Please help us create this living testament to those who have lived and are living with HIV, please sponsor a tree at a cost of £25.00. This donation will help pay for the grove to be planted and permanently maintained. A sponsorship application form is attached to the centre of this newsletter. On receipt of your donation, we will send you a Certificate of Sponsorship, which if required can record an individual's name.

Find it ironic that there is a code of silence that prevents people with haemophilia and HIV from getting the attention that they deserve.

The government keeps silent, so that the public does not realise that hundreds of us have died from the virus and that paltry sums have encouraged further isolation and anger. The Macfarlane Trust collude in this code of silence. They say it is to protect us and to keep our anonymity. The Haemophilia Society also has kept silent so that those who were not infected with HIV should not receive unwanted attention.

We keep silent. Telling someone that you have haemophilia will tar you with the HIV brush. But for how long can this go on? There is nothing shameful about having HIV, there is nothing shameful about having haemophilia. The more we are encouraged to keep silent, the less will be the quality of our lives.

These organisations have only given an impression of concern, they believe that they have our interests at heart. They sincerely believe they are giving financial and personal support to those affected in the face of isolation and alienation. Yet we are still confronted with these problems?

Some trustees have been reluctant to meet and talk with the Birchgrove Group. Yet the trustees that we have bumped into have, despite their original impressions of us, to their surprise, discovered good people, people willing to discuss and negotiate problems, people who just happen to have haemophilia and HIV.

I find it hard to deal with these organisations, and show my vulnerability. I do not see pain, frustration and anger as weaknesses that need to be suppressed. They see these feelings as weaknesses and it is they who cannot deal with these issues.

I have to present the whole of me, not just an acceptable part. My private side wants to remain quiet, calm and in isolation. There is a whole group of haemophiliacs who choose to live this way. This is their choice, but it is not mine, it is the choice of others in the Birchgrove Group.

When I see what is happening to us I cry from love, sadness and anger. I will not compromise, in a sense my tears are my truth and they are from my heart.

By: Corey S. Dubin

Continue to face this recurrent nightmare that I will awake and find no one there. All of the people I have become so very close with. People I have laughed with, cried with, fought back with, shared this holocaust with and may have to die with.

I frequently get lulled into some obviously false sense of security while we work together on a daily basis. I seem to distance myself from that basic reality that many of us have full blown AIDS or are headed that way. Then someone very close has a bout with some bizarre bodily failure and the feeling returns, that sinking depression and fear, and of course that pure unbridled anger at those who chose profit over safety. Those who signed the death warrants for three generations of persons with haemophilia. Those who consciously marketed dirty and deadly products.

Certainly I never thought I would find myself in the middle of the worst holocaust in medical history and of course if I had a choice this is not where I would be. That said however, the only righteous response is to organise and fight back with all we have. Otherwise we become defeated victims, going quietly. For us at the Committee of Ten Thousand, there is only one choice, to fight. Rather than whether we fight, the issue becomes how we as a community respond and cope with this disaster that has been visited upon us.

At least once a week I sit alone in my small studio and have a good, intense cry. The sense of loss and objective sadness is so overwhelming that I find if I do not spend the time letting it out life gets very crazy; as if it weren't already crazy. While I value the importance of the rage that I feel, I understand that the anger is also a mask for the sadness. An internal defence mechanism against getting lost in the sadness. Understanding both the sadness and the anger is a critical component of

staying sane and also a necessary step in the process of empowerment.

The difficult part is in finding the balance point between allowing the sadness to surface without getting stuck in the mud. Surrounded by all the death and devastation how do we individually and collectively prevent hopelessness and disempowerment. This is one of the fundamental challenges facing us all.

As community advocates we must address this part of the equation along with the greater struggle for economic and social justice. In fact, it is an important component of that larger struggle. Often in the desire to pursue the larger issues we neglect the emotional and soul based needs of all of us living this hell called AIDS. The isolation and alienation felt by us all must not be denied or invalidated, it must be processed and understood as part of the way through this disaster and forward to the future.

Another aspect of the healing process is focusing that intensity of emotion on accomplishing the difficult tasks at hand. This can only occur if we are working together as a community. As this is our path, only we are equipped to develop and implement support and advocacy structures that effectively meet the needs of ourselves and our extended families.

Our experience with the medical and psycho/social establishment has vividly demonstrated that only through community controlled, peer led programs can we respond with the sensitivity and respect necessary to support our dignity and self-respect. We have been individually and collectively abused by the medical and psycho/social providers that we believed were working in our interests. The Haemophilia/AIDS holocaust has been thrown back in our laps by doctors and therapists who say things like, "Why are you so angry". Each and every one of us

Editorial Board: Paul Jenkins, Cady Khudabux, Paul Kimberley, Gareth Lewis.

The views expressed in each of the articles are those of the individual authors, and not necessarily those of the Birchgrove Group. No assumptions should be made regarding the health status of any individual whose name appears in this publication.

The Birchgrove is a forum for discussion and seeks to encourage debate on the issues that affect people with haemophilia and HIV.

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## OPEN THE BOX....

who has chosen to take a stand and struggle for justice has been told, "Lets just get past AIDS" and by the way, "If you could only learn to deal with your anger."

This kind of abuse impacts us all on a deep level; It can wreak havoc on one's self-image. We begin to take responsibility for our infection. Somewhat similar to the women who takes responsibility for being raped or the child who concludes that he/she is responsible for being abused. This is fundamentally backwards and designed to protect the perpetrator of the violation at the expense of the person(s) violated. We allowed the medical establishment and the pharmaceutical companies the power to define the AIDS crisis and "how we should respond" to it. We believed that they were operating with our interests as a priority. This was not the case and they continue to present the how and why it happened as a "tragic yet unavoidable mistake". This definition has a singular purpose, the invalidation of both our struggle and our anger. Internalising this view has caused many in the community to question the validity of our struggle. It has damaged our collective and individual self-image and is misinformation at its most sophisticated.

The time has come to purge this false picture from our souls. We know, beyond a shadow of a doubt, what the truth is and who is responsible for this holocaust. We must take responsibility for the truth and all its implications.

The reality is that the anger is righteous and justified and those that are unable to handle what has happened are the staff of the treatment centres. We are dealing, dying and coping with the destruction of three generations of persons with Haemophilia. A holocaust that was absolutely preventable had the drug companies, government action and the medical establishment lived up to their responsibilities. This is the truth, plain and simple. We did not bring this disaster on ourselves and we have had enough of this manipulation. We are finished listening to those who seek to protect themselves by changing the frame of reference.

Of course we are left to cope with this holocaust, however, that does not mean "getting beyond AIDS" or stuffing our anger at those responsible. What it does mean is seeking the truth and demanding that those who chose profit over safety are punished for their actions. This while changing the business of blood to ensure that this can never occur again. It means taking responsibility for and control over our lives. This is the lesson and a very costly lesson; We must never allow others the power to define who we are as people and as a community.

*This is the first part of an article by Corey Dubin the second part will be printed in the next edition of the Birchgrove.*

*Corey Dubin is the coordinator of news & production for Coyote Radio, a central California based not-for-profit radio news, features and documentary production collective. He is also the vice-president of The Committee Of Ten Thousand, a national peer led advocacy and support organisation for those infected with HIV through tainted blood and blood products.*

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by Paul Jenkins

**W**e all received a copy of the Macfarlane Trust Survey, perhaps unsurprisingly, I was a little disappointed. There is a history to this survey and it is one in which the Birchgrove Group was involved. After our first conference in July 1993, the message became very clear. Not enough was being done for haemophiliacs with HIV, and if anyone wasn't doing enough, it was the Macfarlane Trust.

The Birchgrove Group worked on a report called *Living with Haemophilia and HIV*, a document which attempted to describe the special need that existed in our Haemophilia and HIV community. Its main proposal was to demand that more resources be put into the psychological and social needs of those who were affected.

As a way forward, we met with representatives from the Trust to discuss the document and air our mutual opinions. I was surprised that the opinion of the Trust was that if there were needs that were not being met, then registrants were certainly not expressing this. We pointed out that we were registrants, we had needs that were not being addressed and we were expressing this on behalf of many other registrants who had similar opinions.

Unfortunately, we were not seen by the Trust as being able to represent anyone, anywhere, anytime. The meeting was in deadlock, then Deborah Khudabux suggested that if the Trust felt unsure about the needs of its registrants why don't they carry out a needs-led survey. She recommended several companies that were experienced in carrying out suitable surveys.

This was all over a year ago. In subsequent meetings with other organisations, the message keeps on being repeated, "Just let's see what the Macfarlane Trust Survey discovers." Attempts to get people to examine the policies for those with haemophilia and HIV rebound against an invisible wall of expectation "What will the survey say?"

Well, I now have a fear. I am worried that the original needs-led survey has been overwhelmed by a new type of research: a Customer Satisfaction Survey. i.e. What do you think of the Trust's response times? Are they friendly? Would you use brand X? I'm no expert, but I can't see how questions about existing services are going to reveal what my needs are.

I am concerned that this research is looking for an answer to a different question, "What do people think of the Trust?" While this may be very interesting, it is not going to move the issues forward. Should there be a greater range of services for those with haemophilia and HIV? What about advice for those wishing to start a family? What about help for people to remain active and involved members of society? What about support for the bereaved?

I can see only one question in the survey, which does relate to developing services. "Would you still like the Trust to spend more on services, if this meant reducing the amount spent on regular and single payments?" Or in other words, "You know that money which goes into your family finances every month, the bit that helps with the gas bill, why don't you give it up, or some of it anyway and then maybe you could have some unspecified services from the mystery box!"

I am still left with a hope that someone will have the courage to face the unknown. A hope that somebody can decide not just to take the money, but be strong enough to face people's fears and open the box.



# WHOSE LIFE IS IT ANYWAY?.....

by Paul Hooper

Just because a doctor feels able to make a strong recommendation about a certain treatment or drug that he thinks you really should be taking, does that make the doctor right and you wrong for saying, "No I'd like time to think about that"? Or saying, "No" outright because you have already made your opinions and views known. Why is it then, that some doctors continually try and change your mind once you've said "no"?

AZT, ddl, ddC, septrin, pentamidine, the list of drugs and cocktails of combined drugs goes on and on. Each time I attend a clinic, it's all I hear, "Please, rethink starting to take AZT or even just Septrin on its own" and my centre director wonders why in almost a year I've only paid two visits to my clinic!

What does it take for some people to accept "no" for an answer? Do I have to climb over his desk and physically grab him by his jacket lapels and bawl down his lughole that I don't want a particular treatment. He tries so hard to convince me that it would be for the best? the best for him? the drug rep? the drug company? or does he really mean me? If I feel well, regardless of what my CD4 count is, then why should I just go along and take all these weird and wonderful concoctions?

## TEA FOR TWO....

by Cady Khudabux

In the last month, there have been interesting reports coming from the medical field and the general press.

Research at Oxford involved the discovery of five Gambian prostitutes, who have been repeatedly exposed to HIV but who carried no trace of the virus.

Two other studies in America have revealed that almost a billion HIV cells may be made in the body every day and destroyed just as quickly by CD8-cells multiplying at a similar rate.

Even more interesting is an article in the *Lancet* (17 December 1994) in which CD8-cell activity was found before any other sign of HIV infection in some people exposed to HIV infection without any actual infection. There are strong grounds for

After thinking long and hard about AZT, I went on it and in the end I was so ill I almost had to have a transfusion. I became so bad whilst taking AZT, that in the end I couldn't remember my own phone number. If I went to make a cup of tea, by the time I got the kitchen, I didn't know why I was there in the first place. If I did manage to remember, the kettle would boil but I'd just leave it. When I stopped taking AZT and went back to my next clinic my doctor said I should try going on a smaller dose, I said it wouldn't be possible because I had no plans to go back to taking AZT at all.

That happened some two and a half years ago now and still he tries to make me reconsider taking AZT, or shall we say, because I had an adverse reaction to AZT he personally thinks that I'm an ideal candidate for ddl and ddC and let's not forget to add some Septrin for good measure.

If you feel healthy and well, why should you start taking a load of drugs, if it's not what you want to do? I know my own mind, I make my own decisions, be they good or bad. I know my own body, I've lived with being a haemophiliac for 30 years, and HIV positive for 9 years. Although it won't stop me from doing anything I want to, I know my own limits and after all who's life is it anyway?

suggesting CD8 levels as being responsible for control of viral production in the body.

What does this mean me?

- T4 cells/CD4 cell counts (surrogate markers) are not the only things for me to look for
- I need to question any trial solely based on surrogate markers
- There is still hope, even if there are no T4 cells in the body
- If there are ways of naturally stimulating CD8 cells, there is no reason why I could not live longer than expected
- I need to remember that CD8 is just another marker.

No single person can be an expert in every HIV/AIDS field, this virus has affected too many groups, and covers too many areas of expertise to be understood from a single point of view.

# WHO'S STEERING US?

By Caroline Gibson

When I was first asked to write this article, two things sprung to mind, why me? and has anyone got a map? I believe that the steering committee of the last 18 months has managed to create a kitchen in which a meal can now be prepared. It is up to Birchgrove members to work with the new steering committee to find the pots, pans and ingredients to cook a meal that we all can share.

The meal is the growth and blossoming of the Birchgrove Group into a nationally recognised organisation for the support of HIV positive haemophiliacs, carers and families. I feel that the pots and pans are the links that we have forged with other agencies who can help us, whether advice, support or funding. Agencies such as Body Positive, The Haemophilia Society, The National AIDS Trust, The MacFarlane Trust and many others. The ingredients are you and I, the members of Birchgrove.

The starter to the meal is our families, parents, partners, other carers and our children, those already born and those yet to come. We need their full support in order for us to carry on, and for many of us they are the reason for living.

The main course is the "Birchgrove", becoming an organisation of motivated people with a common aim. We are no longer the "poor innocent victims", we are human beings with rights, needs and wants. We are entitled to have a say in what happens to us in our lives.

In order to do this we must embrace all people who are infected or affected by HIV and haemophilia, we must strive to represent them, effectively and honestly. We must give people the information to make sensible and informed decisions about their lives. We must support each other and be constructive, working as a team, united and responding to the opinions of the majority.

I feel that The Woodland Grove Project will be seen as the dessert, the long lasting sweet taste that completes the experience. It will be looked upon favourably as a fitting and lasting reminder of us all. It will be used by many people as a place of peace and tranquillity and in this special place, new seeds will forever be sown, ensuring that haemophiliacs with HIV will never be forgotten.



# Birchgrove Woodland Project

The Birchgrove Group is planning with the help of the Woodland Trust to create a living and lasting testament to all those haemophiliacs who were infected with HIV. We believe that this grove of trees will be a fitting representation of our lives and a reminder of the continuing cycle of nature and its message of hope and renewal.

We will be planting a grove of trees within a community forest as a permanent commemoration to all those haemophiliacs who were infected.

This grove of trees is not only to a memorial to those who have died but will also demonstrate the resilience and strength of those who are still affected.

We hope to create a visible demonstration of the scale and

significance of the tragedy that has affected the haemophilia community. We will be planting this grove of trees in a new 100 acre community forest site, at Stratton near Swindon,

beginning in the autumn of 1995.

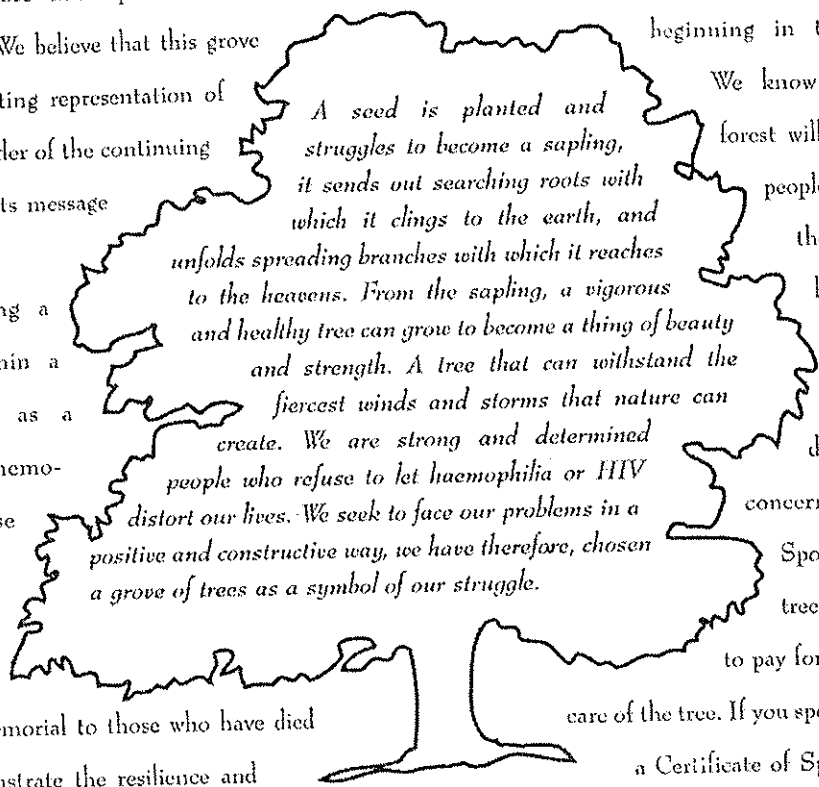
We know that this community forest will be a peaceful place for people to visit and think of those who have had their lives affected by HIV.

We are asking you to sponsor a tree as a demonstration of your concern for this issue.

Sponsorship of an individual tree costs £25 and this helps to pay for the planting and ongoing

care of the tree. If you sponsor a tree you will receive a Certificate of Sponsorship, which will give

information about this woodland grove and record an individual's name.



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: .....

..... Postcode: .....

I enclose £..... Please make all cheques payable to: The "Birchgrove Woodland Project", and send to:

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

# THE BIRCHGROVE GROUP

SUPPORTING THOSE INVOLVED AND LIVING WITH HAEMOPHILIA AND HIV

The Macfarlane Trust

PO Box 627

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To the Reverend Prebendary Alan Tanner,  
Chair, Macfarlane Trust, Chair, Haemophilia Society.

We, the undersigned, are very concerned about the manner in which the Macfarlane Trust is interpreting its role. We believe that the government in awarding haemophiliacs with HIV financial recompense were recognising a unique case, which involved considerable and very particular needs.

We feel that the current focus of the Trust is one of means related financial assistance. It fails to properly address many of the specific concerns of those that are affected by haemophilia and HIV. The Macfarlane Trust offers financial assistance in a manner which poorly recognises the effect of HIV on an individual's life and does not adequately encourage or support them in their continued fight for survival.

Specific concerns of those people affected by haemophilia and HIV are:

- the inappropriateness of means related financial assistance
- the failure to meet the changing needs of long term survivors
- the lack of support for bereaved wives, partners and families

We believe that the Macfarlane Trust is not adequately fulfilling its role, and that it is failing in its duty of administering funds given to it on behalf of those with haemophilia and HIV. We are supporting a call for the Macfarlane Trust to clarify and justify its current policies.

Signed in support of this call:

The National Birchgrove Steering Committee



The Birchgrove Group  
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