

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

The 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?

Frustration 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

We 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

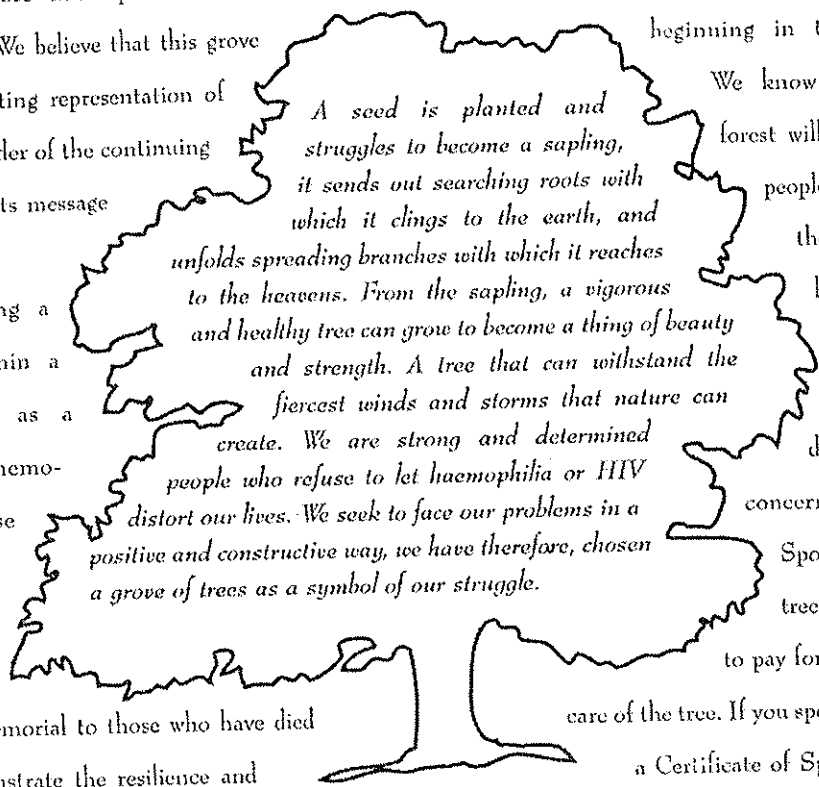
The Birchgrove Group is planning with the help of the Woodland Trust to create a living and lasting testament to all those haemophiliacs who were infected with HIV. We believe that this grove of trees will be a fitting representation of our lives and a reminder of the continuing cycle of nature and its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

London

SW1H 0QG

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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"Lifeline: AIDS Vaccine" USA Today 01/27/95

A scientific advisory panel urged the Food and Drug Administration to heed AIDS patients' pleas for wider testing of the country's first therapeutic vaccine. The Immoqan vaccine was developed by Dr. Jonas Salk, inventor of the first polio vaccine, and is intended to keep HIV-infected people healthier longer.

"Haemophiliacs Urge New Jersey to Allow AIDS Suits Against Pharmaceuticals" Tribune Business News (01/27/95); Shaw, Donna

Advocates for haemophiliacs asked a New Jersey state legislative committee on Thursday to approve a bill permitting lawsuits against drug companies whose medicines were once contaminated with HIV. The bill would exempt one year from the state's statute of limitations, allowing haemophiliacs or their estates to sue the drug companies despite the ten years or more since infection. The government estimates that 8,000 to 10,000 haemophiliacs were infected with HIV in the late 1970s and early 1980s as a result of contamination in their blood-clotting medications. Elena Bosstick, executive director of the Haemophilia Association of New Jersey, explained that "patients were frequently advised that HIV was not clinically significant and would not necessarily cause any disease."

"Latent AIDS More Dangerous Than Thought" Reuters (01/26/95); Kenen, Joanne

There is increasing evidence that HIV is involved in a subtle struggle with the human immune system from the beginning of infection and is reproducing so abundantly that mutations form, creating drug resistant variations. The immune system eventually surrenders. John Coffin, the author of a new study on the "latent" stage of HIV infection, said this is the bad news from the study. The good news, he said, is that a better understanding of the disease can guide researchers toward treatments that may be able to boost the immune system and enable it to hold off the virus. Coffin is a professor of molecular biology and microbiology at Tufts University Medical School in Boston. His research team came up with a model that shows that HIV is more dynamic in its earlier stages than previously thought. The work expands on research recently published in the journal *Nature*, which shattered some beliefs about AIDS and prompted experts to start thinking about new and earlier treatments. "It seems the real disease caused by HIV occurs during the period when almost nothing seems to be happening," wrote Coffin in the journal *Science*. AIDS does not suddenly happen after years of uneventful HIV infection, he said, but is the product of years and years of accumulated damage.

"UCSF Study Identifies Helpful and Unhelpful Behaviours for Friends and Family of Persons With AIDS" Business Wire (01/26/95)

A new study from the University of California at San Francisco (UCSF) has found that the friends and family of AIDS patients can be invaluable sources of support and strength for the patient, but they can also unintentionally say or do things that are unhelpful or offensive. Often, the friends and family members are uncertain or confused about how they can provide the most support to their loved ones. The UCSF study identifies helpful and unhelpful behaviours from the point of view of a person with AIDS, and provides guidance for those who care but are not sure how to offer support to an AIDS patient. Some of the unhelpful behaviours include avoiding interaction, acting embarrassed or ashamed, breaking confidentiality, and criticising one's medical care. Helpful behaviours include expressing love or concern, interacting naturally, and offering practical assistance.

"More Pregnant British Women Found With AIDS Virus" Reuters (01/26/95)

A British government study has found that more pregnant women in London are becoming HIV-infected, while homosexual men continue high-risk behaviour that puts themselves and others at risk. Thirty percent of the heterosexual men found by clinics to have HIV had already been diagnosed as HIV-infected, but 74 percent of homosexual and bisexual men and 52 percent of heterosexual women had previously been diagnosed. The health department report showed that drug users and homosexual men were still the most at risk from AIDS. The number of pregnant women diagnosed with HIV in London jumped from one in 1,220 women in 1990 to one in 570 in 1993. There were 2.7 cases of AIDS per 100,000 population in the United Kingdom in 1993, compared to 14.1 in Spain, 9.9 in France, and 8.0 in Italy.

"Virologic and Immunologic Characterisation of Long-Term Survivors of Human Immunodeficiency Virus Type 1 Infection" New England Journal of Medicine (01/26/95)

Although most HIV-infected people develop clinical or laboratory evidence of immunodeficiency with 10 years of seroconversion, a few infected people remain healthy and immunologically normal for more than a decade. Coo et al. studied 10 seropositive people who were asymptomatic and had normal and stable CD4 lymphocyte counts despite 12 to 15 years of HIV-1 infection. Plasma cultures were uniformly negative for infectious virus, but perleuc-associated HIV-1 RNA was detected in four subjects. Standard limiting-dilution cultures detected infectious HIV-1 in peripheral blood mononuclear cells (PBMCs) in three patients, while CD8-depleted culture found infectious virus in another. A quantitative polymerase-chain-reaction showed that all 10 subjects had detectable, but low, titres of viral DNA in PBMC. While there was no *in vitro* evidence of host CD4 lymphocyte resistance to HIV-1 infection, long-term survivors had a vigorous, virus-inhibitory CD8 lymphocyte response and a strong neutralising-antibody response. Coo et al. concluded that those people who remain asymptomatic for many years despite infection with HIV-1 have low levels of HIV-1 and a combination of strong virus-specific immune responses with some degree of alteration of the virus.

"Report Says Haemophilia Foundation Knew Early That AIDS Was Probably Spread by Blood" New York Times (10/24/94)

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For those of you who may be travelling abroad this year remember the importance of a suitable vaccine. Again for those of us lumbered with HIV, you can become quite ill, if you have an unsuitable holiday jab. There are three main types of vaccine, sub-unit, inactivated and live attenuated. The first two are O.K., however the third type because it's live provides a potential danger that a damaged immune system may not be able to control even the weakened or low dose of organisms found in these live vaccines. The oral typhoid vaccine should never be given to people who are immunosuppressed. So please discuss with your centre director well in advance of your departure, what they feel you require so that you are protected and not infected.

Well, that's about it from me for now. I hope that you all enjoyed your Christmas and New Year celebrations. No doubt 1995 will present us all with problems, but do remember that we are here, ring or write. We will always do our best to promptly answer your questions. I'd also like to welcome the new members that we are hearing from, now that the newsletter's become more widely distributed, and the group's existence is slowly being acknowledged. You all take care now.



"Lifetime: AIDS Vaccine" USA Today 01/27/95

A scientific advisory panel urged the Food and Drug Administration to heed AIDS patients' pleas for wider testing of the country's first therapeutic vaccine. The Immogen vaccine was developed by Dr. Jonas Salk, inventor of the first polio vaccine, and is intended to keep HIV-infected people healthier longer.

"Haemophiliacs Urge New Jersey to Allow AIDS Suits Against Pharmaceuticals" Tribune Business News (01/27/95); Shaw, Donna

Advocates for haemophiliacs asked a New Jersey state legislative committee on Thursday to approve a bill permitting lawsuits against drug companies whose medicines were once contaminated with HIV. The bill would exempt one year from the state's statute of limitations, allowing haemophiliacs or their estates to sue the drug companies despite the ten years or more since infection. The government estimates that 8,000 to 10,000 haemophiliacs were infected with HIV in the late 1970s and early 1980s as a result of contamination in their blood-clotting medications. Elena Bostick, executive director of the Haemophilia Association of New Jersey, explained that "patients were frequently advised that HIV was not clinically significant and would not necessarily cause any disease."

"Latent AIDS More Dangerous Than Thought" Reuters (01/26/95); Kenen, Joanne

There is increasing evidence that HIV is involved in a subtle struggle with the human immune system from the beginning of infection and is reproducing so abundantly that mutations form, creating drug-resistant variations. The immune system eventually surrenders. John Coffin, the author of a new study on the "latent" stage of HIV infection, said this is the bad news from the study. The good news, he said, is that a better understanding of the disease can guide researchers toward treatments that may be able to boost the immune system and enable it to hold off the virus. Coffin is a professor of molecular biology and microbiology at Tufts University Medical School in Boston. His research team came up with a model that shows that HIV is more dynamic in its earlier stages than previously thought. The work expands on research recently published in the journal *Nature*, which shattered some beliefs about AIDS and prompted experts to start thinking about new and earlier treatments. "It seems the real disease caused by HIV occurs during the period when almost nothing seems to be happening," wrote Coffin in the journal *Science*. AIDS does not suddenly happen after years of uneventful HIV infection, he said, but is the product of years and years of accumulated damage.

"UCSF Study Identifies Helpful and Unhelpful Behaviours for Friends and Family of Persons With AIDS" Business Wire (01/26/95)

A new study from the University of California at San Francisco (UCSF) has found that the friends and family of AIDS patients can be invaluable sources of support and strength for the patient, but they can also unintentionally say or do things that are unhelpful or offensive. Often, the friends and family members are uncertain or confused about how they can provide the most support to their loved ones. The UCSF study identifies helpful and unhelpful behaviours from the point of view of a person with AIDS, and provides guidance for those who care but are not sure how to offer support to an AIDS patient. Some of the unhelpful behaviours include avoiding interaction, acting embarrassed or ashamed, breaking confidentiality, and criticising one's medical care. Helpful behaviours include expressing love or concern, interacting naturally, and offering practical assistance.

"More Pregnant British Women Found With AIDS Virus" Reuters (01/26/95)

A British government study has found that more pregnant women in London are becoming HIV-infected, while homosexual men continue high-risk behaviour that puts themselves and others at risk. Thirty percent of the heterosexual men found by clinics to have HIV had already been diagnosed as HIV-infected, but 74 percent of homosexual and bisexual men and 52 percent of heterosexual women had previously been diagnosed. The health department report showed that drug users and homosexual men were still the most at risk from AIDS. The number of pregnant women diagnosed with HIV in London jumped from one in 1,220 women in 1990 to one in 570 in 1993. There were 2.7 cases of AIDS per 100,000 population in the United Kingdom in 1993, compared to 14.1 in Spain, 9.9 in France, and 8.0 in Italy.

"Virologic and Immunologic Characterisation of Long-Term Survivors of Human Immunodeficiency Virus Type 1 Infection" New England Journal of Medicine (01/26/95)
Although most HIV-infected people develop clinical or laboratory evidence of immunodeficiency with 10 years of seroconversion, a few infected people remain healthy and immunologically normal for more than a decade. Cao et al. studied 10 seropositive people who were asymptomatic and had normal and stable CD4 lymphocyte counts despite 12 to 15 years of HIV-1 infection. Plasma cultures were uniformly negative for infectious virus, but pericard-associated HIV-1 RNA was detected in four subjects. Standard limiting dilution cultures detected infectious HIV-1 in peripheral blood mononuclear cells (PBMCs) in three patients, while CD8-depleted culture found infectious virus in another. A quantitative polymerase-chain-reaction showed that all 10 subjects had detectable, but low, titres of viral DNA in PBMC. While there was no in vitro evidence of host CD4 lymphocyte resistance to HIV-1 infection, long-term survivors had a vigorous, virus-inhibitory CD8 lymphocyte response and a strong neutralising-antibody response. Cao et al. concluded that those people who remain asymptomatic for many years despite infection with HIV-1 have low levels of HIV-1 and a combination of strong virus-specific immune responses with some degree of attenuation of the virus.

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WORLD AIDS DAY

by Gareth Lewis

The day starts with an early rise, hopefully in time to catch my radio interview on Radio 1. What a waste of time that was. Out of bed an hour early and it's time to get the kids off to school. I have to be up the office early trying to sort out the display and making sure we have all the information and the red ribbons ready.

The reason is we've been offered a stall in the University Hospital of Wales, with only 24 hrs. notice. We arrive to find there is only one table available and this is already full. So we have to improvise and we use the top of the display stand as a table. Actually it looks quite good with the Birchgrove information on top and the notice boards underneath. All the leaflets and news letters are displayed and we wait for the rush of people wanting to find out about World Aids Day.

Well things get off to a slow start, so I decide to take a walk up to the Haematology C5 ward to try and give out some Newsletters and see if anybody I know is actually in hospital. What a surprise! Not one Red Ribbon in sight and I'm greeted with, "what are these red ribbons for?"

So I explain that it's World Aids Day and that we have a stall downstairs. These are supposed to be the people who will be looking after me if I ever succumb to a HIV related illnesses. It makes me wonder whether we need to raise the nursing staff's

level of HIV & AIDS awareness. So come you haemophilia staff, wear those Red ribbons with pride. Show us that you really do care.

Well it's back downstairs and things are heating up. Even though we were only there to raise people awareness on HIV & AIDS, we found to our astonishment we were actually collecting a bit of cash. People were making donations for the Red Ribbon badges we were giving away and we made a total of £46.58. Not bad for a days work. My thanks to Janet for all her help.

I leave the hospital and go home for a bite to eat before making my way to town. This is for a Candlelight Vigil, which takes place annually on the steps of the Museum of Wales, in memory of all those who have lost the fight against HIV & AIDS. All voluntary groups are represented and after a service of remembrance, it is my role to read out names of haemophiliacs in Wales who have sadly died due to AIDS.

This night is one of the major events during World Aids Week in Cardiff. And it is a poignant way of remembrance, with nearly 400 hundred people with candles lit against a backdrop of quilts, made in memory of those no longer with us. My thanks to all those people involved for making this such a special night for all those affected and infected with HIV. Home about 11.00pm and off to bed ready for an other exciting day in the life of a Birchgrove Area Rep.

LETTERS

Dear Editor,

I recently attended the Birchgrove groups conference and found the experience a valuable and enjoyable one. The chance to meet with other people in the same position as myself and my family was hugely empowering to me and to hear of the different ways in which people have coped and continue to do so, with haemophilia and HIV.

There was much concern at the conference at what is perceived to be a lack of support from the Haemophilia Society to the group and much anger was expressed about this. The apparent disappearance of HIV as an issue within the society is sad, to say the least. Whilst the society should look to the future it must not forget those who have died and their families and friends OR those still living with HIV.

Aids is still a great stigma in society, it should not be in the Haemophilia Society.

Robert James

Dear Editor,

I read your "Commentary" column in the last issue of "The Birchgrove" with a great mixture of emotions, because it is the first time I have seen in print the view a person with haemophilia and HIV towards those with haemophilia who are not infected with HIV.

As someone with haemophilia who does not have HIV, I agree that the whole haemophilia community has been affected by HIV. I have suffered the pain of witnessing old and close friends living with HIV and dying with Aids. That may sound glib, but part of the pain is in the unanswerable question - "why not me?"

You say you have yet to meet a person with haemophilia who will say "I was lucky, I was not infected...." Well, you've found one. Let me offer a reason why it has taken a decade for those words to be heard.

I have never said those words outside my family. I would never have said them to someone with HIV for fear that I might be insensitive or appear boastful about something over which I had no control.

I can only imagine the shock of an HIV positive test result - I can only speculate as to whether I would cope as well as most seem to do. I do know that I count myself greatly blessed to be HIV negative, and in gratitude for that fact I am happy to do whatever I can for those who have haemophilia with HIV.

It came as a surprise that you would want to hear these words, but perhaps that shows how badly we need to be able to communicate with others. I hope "The Birchgrove" will continue to act as a catalyst in this process and wish you every success in the group.

Andy Cowe

10TH INTERNATIONAL CONFERENCE ON AIDS

by Terkel Anderson

Following a session dedicated to haemophilia and HIV at the Conference on AIDS, a resolution was passed calling for governments to investigate the events which lead to the late introduction of safety measures ... and to issue an official apology to those who became infected through negligence or delay.

The authorities were also urged to take measures to relieve the suffering of people with haemophilia and HIV (e.g. educating against discrimination and prejudice) to prevent any possible recurrence of this terrible tragedy....

After the presentations, the stage was backlit and a number of Japanese persons with haemophilia appeared in silhouette expressing their fears and bitterness. This was at the same time like a symbolic opening and closing of the Conference. A reflection of the frustration and sadness felt by the audience, all too familiar with the devastating effects of this disease and the code of silence that keeps it from getting the attention it deserves. Maybe nothing changed during the conference, but at least our collective protest was heard.

A TALE FROM VIENNA

by Robert James

I recently spent six months in Vienna as part of a course and while there had the opportunity to look at the system for people with HIV in Vienna and some other parts of Austria.

Austria is a country that looks back to glorious days of the Hapsburg Empire that made it an important power in the world. It is officially a Catholic country and a number of the social care agencies are funded by the church, though few in the Aids field. Much prejudice still exists in Austria, one Austrian I met felt extermination was the best Aids policy, similar to the approach during the Nazi time. (Adolf Hitler is sadly still the most famous Austrian). The major Aids helping agency in Vienna is Aids Hilfe Wien, which is split into two sections. One deals with the medical aspects, provides testing, medical advice and psychological counselling and the other is social work oriented.

The agency takes an enabling view, attempting to give people the opportunity to do things themselves rather than patronise them. The vast majority of people contacting the social work centre are already positive and want some advice or help. The centre does not claim to offer therapy, as that is part of the medical sections job. However the staff are there to listen and advise people. Herr Herdina, the chief social worker at Aids Hilfe Wien has little interest in the medical side of things. How high people's T-cell scores are or hassles with septrin are only dealt with if they intrude into his work with people.

AKH, the general hospital in Vienna, finally designed two wards for people with Aids last year, the chest ward and the dermatological ward. Before this in-patients, could end up on almost any ward depending on the nature of the complaint and availability of a bed. The problem now is to ensure people are not sent there for every tooth removal and used for specific Aids related issues!

Herr Herdina felt about one-third of his clients were gay men, and two-thirds intravenous drug users or ex-IVDU's. This is unlike the official picture of reporting of Aids cases in Vienna that has twice as many gay men as drug users. The numbers of people diagnosed as HIV positive has risen successively over the last three years in Vienna.

Testing is available in a huge variety of places, agencies and individual doctors or laboratories; over 50 are listed in the Handabuch Aids alone. Much testing occurs at the Aids Hilfe Wien's health centre and they offer treatment. The Austrian health service will not pay for AZT for foreigners, although they can receive basic medical advice and first aid there.

A Body Positive group exists, called Club Plus. It meets weekly with a mixture of social events and more support oriented meetings. It is mainly gay men, but a 'straight' support group also exists sporadically. There is also a woman's group that meets weekly separately to Club Plus. Best of all, there are English speakers in every agency including Club Plus! (This is useful because Austrian's speak an execrable German, almost as incomprehensible as the Swiss-German accent.)

The majority of leaflets in Austria come from Germany, including basic information leaflets in German, English, French, Serbo-Croat, Polish, Turkish and Arabic. Other specific leaflets only in German cover more specific topics such as issues for drug users, gay men, people in prison and one eye-opening one on safe S & M.

I also called in on the Haemophilia Society in Vienna who were helpful and very interested in what happens on Britain and the Birchgrove Group. They did receive some compensation from the Austrian government, although not a great deal but no self-help group for positive haemophiliacs exists. Haemophilia and HIV also have a much lower media profile there than here. (Yes, it is possible!) And the first positive haemophiliac to admit it in any form to the media, did so while I was in the country, just 10 years after infection. So if anyone wants a copy of safe S&M practices in German or a free map of the city, you've only got to ask!

HEALTH CARE QUESTIONNAIRE

At the Conference in Manchester, a questionnaire which looked at the Health Care needs of HIV positive haemophiliacs and their families was distributed. If you took one and haven't yet returned it, please send it to the PO Box by 15th March 1995. If you took one but do not wish to return it please write and let me know, as this will be useful in the research. Caroline Gibson.

WEIGHT WORRY

by David Gibson

It goes like this, usually every Wednesday we go shopping at our local ASDA. As we enter, my pulse races as I spot the NSS Newsagents. There outside the entrance is the, "I SPEAK YOUR WEIGHT MACHINE".

Well actually it doesn't, but it does give you a nifty little printout, and it doesn't say "One at a time please". So after making sure that I have a 20 pence piece in my hand, I carefully approach. I check there are no overweight, middle-aged ladies with shopping trolleys around, who might wonder what this tall, healthy looking person is doing on a weighing machine in a public place.

In goes the 20p. Up flashes the questions: sex? — the answer is male or female not "Yes please". Frame size? — nothing to do with Zimmers this time. And finally height — nobody over 6' 6" or under 3' 6" (no chance for Meg then).

Then as your pulse races, the beads of sweat appear on the beaten brow, at last the "ready" light is lit. I press the button marked "print". Beep, Beep, Beep goes the machine, how I wish it wouldn't do that, people look in my direction, they may suspect!

Out comes the small piece of paper with that important figure on it. Yippee! I shout, the middle aged over weight ladies clutch at the chest as they shout, "What the bloody hell was that!" Crash, there is a collision, ASDA eyes at speed, very messy. Caroline rushes over, "What, are you alright?" ... "Yes" I cry with pleasure, "Look, 14 stone." Great!" says Caroline "What weight were you last week?" ... "13 stone 3 pounds" I reply!

*Nature — some men sears a Sapling —
Sometimes — scalps a tree —
Her Green People recollect it
When they do not die —*

*Fainter Leaves — to Further Seasons —
Dumbly testify —
We — who have the Souls —
Die oftener — Not so vitally —*



THE CHALLENGE OF THE FUTURE... MANCHESTER-NOVEMBER 1994

The Birchgrove Conference was held in Manchester at the end of November 1994. The challenge was not just funding a conference in the current financial climate but holding a conference that would encourage people to look at the problems that face a group of people with haemophilia and HIV. We will all discuss the problems and difficulties that face us in everyday life, the challenge is to begin to look for answers to the questions.

The workshop sessions were intended to be stimulating and "challenging". But we were surprised that the sessions that could have been confrontational turned out to be constructive and that a workshop that was meant to be safe and uncontroversial turned out to be a scene from "Custer's last stand!"

People were asked to discuss questions that focussed attention on who should be meeting the needs of those affected and how this should be done. It was not a surprise to discover that most people instantly think of the Haemophilia Society and the Macfarlane Trust.

The Saturday afternoon session which used some local dramatic performers, was not just thought provoking but also was quite well acted! It provided a wider view that took in the problems of a wife whose needs were continually ignored,

Jody Wells as a treatment

I'd been familiar with Jody Wells' writings on and his attitudes to HIV and AIDS for a few months, mainly through his radical and thought provoking magazine, Continuum. Most of Jody Wells' energy has been devoted to questioning peoples attitudes to the equation HIV=AIDS=Death, mainly through workshops, seminars and the pages of Continuum. A brief summary of his views would range from AZT to Septrin, his scepticism about the validity of the current HIV tests; his questioning of the very existence of the HIV virus and whether it is the cause of AIDS; his doubts about about T-Cell counts; his advocacy of alternative therapies; vitamin supplements and the strengthening of the immune system.

Unfortunately Jody Wells in the flesh is a different prospect to Jody Wells on the page. In his role as a facilitator, I expected him to run a smooth, rational and good-humoured workshop, that was not what happened. What should have been an informative and enlightening exchange of attitudes and ideas about HIV and AIDS, turned into something that bordered on a slugging match. Jody has admitted that he can be arrogant, but in this instance I think he went too far. To tell a person who has invested all his faith in a drug that it is going to kill him despite the contrary evidence, is not only arrogant but cruel. He succeeded in not only alienating a neutral audience, but also those like myself who were sympathetic to his message.

There was a palpable hostility to Jody Wells that centred on his anti-AZT stance. There was no discussion of many of the positive aspects of his research such as Vitamin B12 deficiency, the suppression of HIV by ascorbic acid; nobody praised his refusal to be seen as a victim or be treated as a guinea pig; and finally there was little enthusiasm for the anger that he has channelled into motivating those with HIV to become self-empowered.

Which is all a great shame - for though he has only himself to blame for alienating his audience, there is a responsibility for those affected to be open-minded and receptive to new ways of thinking. Jody Wells is a loud, angry voice, raging against fear, ignorance and despair. But it is neither a loud, angry voice, nor is it one that can be ignored. There are people out there who are prepared to listen. My own opinion is that haemophiliacs have little to fear from hearing his message.

Do not go gently into the night, rage rage against the dying of the light... Dylan Thomas.

Reflections from a Bar Stool

It's Saturday night in the residents bar at the Manchester Piccadilly Hotel and a band is playing for all its worth and they don't sound bad either. Everyone is either in a small group talking and telling jokes and enjoying themselves with new found friends, or just mixing in and out. Everyone seems to have discovered how it feels just to be themselves and how good it is to talk to others and not worry about what they should or shouldn't say to each other.

I found myself in a trio talking about so much. It's hard to put it down on paper without a lump in my throat and a smile at the same time. Finding someone to talk to, who really knows what your saying or how you feel is so good. Someone to talk with about issues and feelings that are so close to home. We've all come from different walks of life, but we've all had to try to come to terms with so much in such a short time. It's a wonder I've not ended up in a rubber room howling at the moon!

As the evening progressed I found myself talking to a mother about how she felt about the weekend and how she was trying to cope with her own feelings for her son, what she has seen within her family, the love she feels can only really be felt by a mother for her child. It made me think of my mother and what she must be thinking about when she turns on the television or picks up a newspaper. What goes through my mother's mind can't be much different to what I'd just been talking about. Who does my mother turn to? How does she feel?

I began to explain to someone else's mother that I can't talk to my own mum, because she has felt so much pain and guilt for years. She has felt it was her fault that I'm a haemophiliac. And when I told my mother about being HIV Positive I think that it was all just too much for her to cope with. In having met someone who understood me and who felt the same feelings, it was almost like having my own mother right there in front of me.

So I think I'm going to sit down and try and tell my mum that she has nothing to blame herself for and just maybe she could talk to me about what worries her and how she really feels.

a tired an inexperienced social worker and a "seen it all before" haemophiliac, who was very positive!

When we assembled again people were beginning to focus on the need for a Birchgrove Group. And it was at this point that we confronted the conference with the request to consider the proposed constitution and if it was acceptable, adopt it. Much haggling and some discussion and it was adopted unanimously!

David Royale, "Beattie" to almost everyone, gave us a grand performance for our conference overview. As a EuroCASO representative and part of the National Network of BP groups he was well placed to put some spice into the proceedings. We hope that he will continue his invaluable input into the Birchgrove Group.

Despite problems with the hotel, lifts that wouldn't function, rooms that were hot enough to boil a monkeys bum, the weekend went well. Many people had a good experience and as a group we came out tired, but stronger with a larger and more enthusiastic steering group to help share the responsibilities of a self-help organisation.