

THE BIRCH GROVE

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ISSUE N° 3

FROM VICTIMS TO SURVIVORS!

by Cady Khudabux

In an article published in the Guardian on 29 July 1994, the page one article read—“HIV victims may live 20 years”. We seem to be portrayed as “victims” by the press. At other times, we have been called the “innocent victims”. The fact is somewhere there are persecutors, I wonder who they are? Could they be the persecuting press?

The actual article was constructive and based on a paper in the British Medical Journal *Use of CD4 lymphocyte count to predict long term survival free of AIDS after HIV infection*, Andrew Phillips *et al*, 309, 309-13. But why do they have to go to such damaging lengths to get people's attention to read the article and at our expense? Could they not say “Hope for haemophiliacs, fooled by ignorance”.

In the Guardian article, John Meldrum of the National Aids Trust said the study highlighted the needs of long term resources for people with HIV. So far, the government and doctors thought we would be dead three years after the “settlement”, which was why the sums were so low in comparison to other government *ex gratia* payments.

Nick Partridge of the Terrence Higgins Trust made two interesting comments about

the paper. First, an employer dismissing a person with HIV may lose possibly 20 years of good work. Secondly, the study does not indicate any criteria of those long term survivors other than the age at when they were infected.

WIDER IMPLICATIONS

The conclusions of the paper suggested even with the current available treatments, up to a quarter of patients infected with HIV will survive for 25 years from the time of infection, this is without developing AIDS.

One important aspect left out in the paper was the implications of the extended survival time. What sort of planning needs to be made? I wonder if the care of haemophilia and HIV has been neglected due to the so-called prediction of short life expectancy. Our lives are always based on statistics and probability, in this case, CD4 markers. In 1985, the life expectancy was two years and we should not make any long term plans. Then it was three years, then five years and now ten years. This short-sighted view has been to detrimental to us. We need to see behind the person and beyond even our own expectancy, because in the last analysis, who knows?♦

THE CHALLENGE OF THE FUTURE

It is our pleasure to inform you that the national conference of the Birchgrove Group will be held in Manchester on the weekend of the 26th & 27th of November 1994. The theme of the weekend is the Challenge of the Future, we believe that this will be an opportunity for people to meet and look at the important issues that we all share and are concerned about. During the weekend there will be several opportunities for people to meet and talk. There will be a range of discussion groups and a structured discussion involving everyone and focusing on the repercussions of HIV on the haemophilia community. We hope that people will participate in and help to decide the direction of the weekend, and that people will actively take the opportunity to make this conference their own. *See Back Page*

LIVER DISEASE AND HIV

by Ian Richardson, T. Melester
and David Gold

The liver, a large organ located in the upper right portion of the abdomen, is the body's chemical factory. Disorders of the liver and the associated bile ducts and gall bladder can have serious complications. They involve many organs in the body, all of which depend on the liver's products to support their activity.

Liver problems are frequent causes of illness and death in people with HIV infection, even in those previously considered healthy. Both physicians and patients should be aware of the symptoms, methods of diagnosis, drug toxicities and available treatments for HIV-related liver conditions. Symptoms such as pain on the right side of the stomach, enlarged liver (hepatomegaly), jaundice (yellowing of eyes or skin), fever of unknown origin, fatigue, malaise, itching and abnormal liver function tests (LFTs) deserve early and complete evaluation. *(continued on page 6)*

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In *The Lancet* commentary (25.6.94) Duncan Thomas (Bio Prod. Labs.) said that we should "acknowledge that absolute safety is a mirage". It is a real neglect by society that we could accept this dilatory statement. More so, if we take safety to be a "mirage", in the face of thousands of people, who have died or been infected because of this complacency. It was a relief, to know I was not the only person to think this.

Through a joint letter in *The Lancet* (6.8.94), four doctors from USA and France found this "an incredible statement from a person in his position. To blandly accept anything else is to repeat the accepting attitudes of the past, which resulted not only in the tragedies of AIDS, but also in the infection of most haemophiliacs with HCV, a virus that is thought to persist in those infected, and for which physicians treating haemophiliacs are now faced with issues as when to intervene with liver biopsy and therapeutic agents that are not curative." I thought, at last, we are not bunch of raving looneys. There are some people in the world who found that comment unacceptable.

The previous letter in the same journal was even more enraging. It was from the chairman of UK Haemophilia Centre Directors Organisation, Brian Colvin. He wrote "Perhaps Thomas is right when he says that absolute safety is a mirage, but we cannot allow ourselves to be deflected from our duty to provide safe treatment for our patients." Thomas is wrong and there is no "perhaps" in this. The whole idea of medicine is based on the illness and the cure (Latin = *care of the person*) but not simultaneously. No life-saving drug should be given and then also put a person at risk with an illness, which will kill them or make them suffer for a long time. If physicians cannot understand this, who can? The weak statement from the chairman of UK Haemophilia Centre Directors Organisation is the typical attitude by the medical fraternity in UK and some, but not all, Centre Directors. In Britain we are ready to accept the passive norms and that to ask for quality is an illusion.

One step forward is a way the German federal health services are moving. It is the only country in the European Union that allows blood donation by paid donors. Their own recommendations are that the use of blood products by doctors should be reduced by a fifth, that a pool of regular donors is used and that products are kept in quarantine for six months before use. This direction may not be suitable for people with increased bleeding due to liver damage. This practice could be adopted in all the countries that are blood product suppliers. •

The Birchgrove Group has installed a contact telephone number. Anyone wishing to contact the Birchgrove Group regarding any of our activities or publications please ring 0345•697231 and this call will be charged at a local rate. This phone will be answered on Monday, Wednesday and Friday mornings by members of the Birchgrove Group, at all other times an answer-phone will take your message and we will contact you as soon as possible.

MEDICAL NEWS. . . .

BAXTER/RHONE-PLUOLENC RORER HIV SETTLEMENT REJECTED

A proposed settlement of \$160 million has been rejected by the plaintiffs, in this case, 12 US haemophiliac families. The suit was originally filed by these 12 US families, who estimate that 5,000-8,000 people may be entitled to compensation under the class action.

The lawsuit alleges that the above defendants along with Miles (incorporating Cutter), Alpha and the National Haemophilia Foundation (NFH) for:-

- failing to act and reduce the risk of viral contamination,
- failing to screen high risk donors properly
- failing to adequately warn users of the risks involved.

The last three defendants have not joined the proposed settlement. The NFH is involved as they play a part in the purchase of clotting factors in USA. The families involved have said the plaintiffs will have to offer sufficiently more money to settle the claim.

Scrip, 1950, p. 13

COMBINATION THERAPY

Triple drug therapies which completely suppress virus replication in selected conditions, have been identified. In a report given at the 10th International AIDS meeting in Yokohama, Japan, a number of presentations reflected the beneficial use of combination therapy in reducing the development of resistance to drugs used in treatment.

Scrip, 1950, p. 22

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ALTERNATIVE THERAPIES

The Macfarlane Trust will consider a grant of up to £200, which is to be used as an introduction to alternative therapy.

The only conditions being are these therapies are not available from your Haemophilia Centre and it must be from a registered practitioner.

A LONG TERM SURVIVORS WEEKEND....

by Paul Hooper

I must tell you about my weekend at Glenfall House in Cheltenham. It is a weekend run by the Long Term Survivors Group – to say I am glad I went is an understatement.

A haemophiliac, who should have attended the weekend with me, dropped out at the last minute. On Friday, I was taken to Cheltenham by a friend of mine from Birmingham Body Positive (BBP) called David. The weather was bloody awful and the motorway was just one entire sheet of rain from start to finish. When we arrived at Glenfall House the rain stopped and as I opened the door to walk in, all I could feel was an all embracing warmth. It was as though the house itself was welcoming me back home from a long absence. This, I am sure you can imagine, made me feel and act very positively indeed. Glenfall House is a very large Georgian house, with some of the most beautiful views of the surrounding hills.

After a brief and friendly introduction to the weekend (Brummies out-numbering everyone for a change!) we all went into dinner. Later on in the evening, I went out to partake in the local ale in the first ever visit to a gay pub. The only problem that I encountered on this visit was a strange look from a couple of women as I left the gents.

One of the several friends that I've made from the weekend was Steven from Luton – he asked me lots of things related to haemophilia and how it affect my everyday life, which I answered to the best of my ability. This to Steven seemed weird because he'd met two other haemophiliacs in the past and he thought that I was weird because I didn't moan and gripe about the haemophilia.

It's still Friday night, and after coming back from the pub I joined in a very long talk with David from BBP who drove me down to the weekend and all three of us (Steven from the pub) talked and went over lots of topics during the wee small hours. To cut a long story short, I cried like a new born baby and managed to get lots of problems and some fears off my chest.

David and Steven found out that a lot of my fears and other problems are the same as theirs, and this really broke the ice and made a very close bond between

the three of us. I did talk to Steven about a person, who was on the weekend that I knew but wasn't able to talk to because her husband was my old school mate. He broke the ice for both of us, and said that we should take a walk around the grounds and talk.

We both took up this opportunity and walked about for a while taking in the landscape and the view. Sitting down on a bench to talk we both opened up and for the first time I was able to explain by reasons for not coming to visit my old school mate and she understood exactly. I managed to rid myself of so much guilt that had eaten into me for almost two years. Plenty of crying took place and in the end we both felt so much better about lots of issues, fears were shared and hopes about the future too.

Having entered Glenfall House on Friday afternoon, by Saturday, Paul Hooper was not the same man, person or even human being that he was, for he had gone through such changes, shared so much, he's gone from here now. Problems aired, fears waylaid, doubts dismissed with plenty of laughter mixed in, had made me change and I left so much excess baggage behind me I feel totally renewed.

Let's start on Saturday. The day itself was so beautiful, clear and fresh it was like being in heaven. Sitting and taking part in a group discussion and the morning was akin to being with old friends. So much was talked about during this morning session that I couldn't take part in the afternoon, simply because it was too much for me at that time to handle. Don't get me wrong, the morning session wasn't intense, it was all I could manage for that time. Saturday evening meal finished, of which I had seconds, but no sweet because I didn't have any room left to eat it.

I had a good chat to Mike who had met a couple of the Birchgrove Group at the AGM of the National Network of Body Positive Groups in Glasgow (*editor – Paul Jenkins and Cady Khudabux*). Shortly after this, Steven and I got together again for more jokes and chat about this, that and the other. Something we both managed to laugh about was the fact that Steven was making comments about blokes that were coming in and out of the pub – instantly realising that was not my preference and

(continued on next page)

THE BIRCHGROVE

offers a forum for discussion on:

- The treatments of haemophilia and HIV, through information and debate
- Taking best care of ourselves, the HIV infection and AIDS
- Staying healthy
- Ways that HIV affects love and sexuality
- Financial, scientific and psychological aspects of HIV and haemophilia

THE BIRCHGROVE

believes that HIV positive persons:

- Can improve their health and extend their lives by confronting and expressing their feelings and by starting to deal directly with the situation that they are in
- Can be empowered and enabled to deal with their circumstances through relevant information and mutual support
- Have complex needs that are often best understood by drawing on the experiences of those in the same situation
- Need to be heard: although their numbers are small, their needs are important
- Should not suffer from the pressures of fear and isolation which can harm them in their work or in their communities
- Have a role in the work of the HIV and AIDS community to help inform people and challenge the ignorance that still exists

This newsletter has been made possible by the kind and continuing support of The National AIDS Trust.

A LONG TERM SURVIVORS WEEKEND (continued from page 3)

the blokes he was wowing over didn't mean anything to me at all. The daft thing was we both laughed our socks off about this. Towards the end of the night I had to go off to the gents again before the cab came, as I was the last but one to leave the pub, Steve was saying goodbye to the landlord and being the bloke that I am, I shook the landlord's hand too. But what a bloody shock I had when he not only shook by hand but gave me a kiss on the cheek. This did surprise me somewhat - but Steve being Steve made a quick joke about how he thought that the landlord fancied me. Thank God for A To B Cabs being prompt.

Somehow, I woke up Sunday morning at 8.15 to the sound of birds singing in the trees. Down to breakfast, tucking into toast and coffee, in front of most of the group, was a change for me and quite a surprise for them - to see me up with a few others. We were left to do what we wanted to do on Sunday and I had a walk around the grounds, sat and talked in the library and at 2.30 pm went and had my feet massaged as they were killing me.

Back at the library was a large sheet of paper that everyone was putting their names and addresses (me included) so that a contact sheet could be sent out later. After this we all took photos and started to say our farewells to one another, which I think is the worst part of a weekend - just as you start to make new friends it is time to leave. I said that if there was a space free (because these weekends are very popular now) I'd attend even if I had to use a wheelchair to move around the house.

My total outlook has changed for the better, I have made lots of new friends and I think that most of us will keep in touch with each other. •

For further details about The Long Term Survivors Group including future fates please contact:
Beatty on 0782 263482
16-17-18 December 1994

A man looks at the plastic rose in his doctor's hand, and collapses wheezing and gasping in the throes of an allergy attack. Think of that elderly man who "lost the will to live" when his pet dog died; of the terrified villager who wasted away when cursed by the tribal witch doctor, of the plucky mum of four who refused to give in to cancer. This is the mind at work, and you've been hearing about it all your life.

These stories are fascinating and uplifting. But in the past scientists have had precious little to say about them. Indeed, the whole subject of "mind over body" once languished on the far fringes of scientific respectability.

Now it has come in from the cold. Over the past decade, neurobiologists and immunologists have amassed a hefty wad of research papers pointing to links between the brain and the immune system. What is clear from all this research is that different moods turn the activity of immune cells up and down, sometimes for long periods of time. By these simple measures sleep and expressing your feelings are good for your immune system; depression, chronic stress from work and insomnia are often bad. The brain and the immune system "talk" to one another. That much is certain.

Psychologist Janice Kiecolt-Glaser and immunologist Ronald Glaser, a husband and wife team at Ohio State University College of Medicine, have been looking at this subject for the past decade. When first persuaded by his wife to join her in a mind-body study, Glaser was convinced that the experiment's premise - that the mind could effect the immune system - was poppycock. "Today, there's no doubt in my mind that this is real," he says.

By taking blood samples from medical students at several points during the year, the two showed that the students had sluggish immune responses during exam time, their natural killer cells and T-cells were operating below par, and gamma-interferon, a protein that stimulates immune responses, was also depleted. By contrast, the students' immune systems were feistier after the long, relaxing summer vacation. "Everybody now believes that the immune system is modu-

lated by the central nervous system," says Glaser. "The big question is: what does it all mean in terms of health?"

David Spiegel, a psychiatrist at Stanford University in Palo Alto, California was fed up with New Age therapists blaming patients for "causing" their cancers through negative thinking - or even "wanting" or "needing" them at some level. So he set out to show that psychological well-being, though clearly valuable, couldn't cure anyone of terminal breast cancer. To do that, he went back to a study he had conducted years ago, aimed at improving the mental well-being of women with breast cancer. What had become of those 86 patients? No, they were not cured. But one glance at a graph was enough to spot the trend. Those receiving group therapy and hypnosis as well as standard cancer therapy survived twice as long on average as those who had standard therapy alone. Stunned, Spiegel asked more than twenty sceptical scientists to study the data before he published. None found a fatal flaw in the work.

Spiegel doesn't know what ingredient of the therapy was crucial. Was it social support? The freedom to express bottled up emotions? Self-hypnosis to control the pain of cancer? Pain is certainly bad for the immune system. It suppresses natural killer cell activity. Self-expression on the other hand seems to promote a healthy immune system, when actors play out roles in which they are angry or joyful, their bodies release natural killer cells from the spleen into the general circulation, where they can do their work.

But, Spiegel doesn't yet know if the immune system is even responsible for the different survival rates he chronicled in the breast cancer patients. It is possible that the hormone, which is prolactin released during stress, stimulates tumours directly. Or maybe sleep or diet were improved along with mental well-being. Then again, poor sleep could be the cause of poor immunity: Michael Irwin, of the University of California in San Diego, has measured brain waves in sleep labs and shown that people with the most disturbed sleep have the most sluggish natural killer cells.

PAUL'S PRESTIGIOUS PORTION...

The immune system is a complicated mix of cells which don't all behave the same way under stress. "We tend to think of the immune system being up and doing its job, or being down and not doing its job," says Lysle. "But it's far more sophisticated than that." This complexity, however, seldom surfaces on the pages of popular books such as *You Can Heal Your Life*, by Louise Hay, or *Love, Medicine and Miracles*, by Bernie Siegel. Discipline your mind, suggest the authors, and your disease will melt away.

"It bothers me greatly when someone makes a blanket statement like 'You can cure yourself of cancer'," says Felten. "Because you cannot cure yourself of a grade IV malignant glioma." In fact, it's possible that some therapies might even make people worse. Spiegel Richardson and Fawzi use therapy to help a patient handle the illness, not vanquish it. In a common fringe therapy tool called visualisation, a patient is instructed to visualise his immune cells attacking and killing cancer cells. If a patient's cancer worsens, he may well feel that he is to blame for not visualising well enough, and will feel more stressed not less.

"We don't know how much difference mental well-being could make to the outcome of a disease," says Spiegel. "But we've got to get off this hook of saying either it has nothing to do with it, or that you can cure your body if you just fix it your mind." Today, few scientists need convincing that the brain communicates with the immune system. The evidence mounts every day. Tomorrow's agenda will be to explore what this talk might mean for our health. •

DIFFICULTY IN FINDING A DENTIST?

by Robbin Rippon, District Dental Officer

As District Dental Officer for two Health Authorities in Surrey I have been dismayed this week to come across someone who is HIV positive who has taken four days to find a dentist to treat his toothache.

What concerns me is the organisations he contacted for advice were unable to help. He contacted the District Council, the Family Health Services Authority, the Regional Health Authority and also local dentists. Eventually he contacted someone at the District Health Authority who suggested he contact the local Community Dental Clinic. He was treated in less than one hour after his phone call to the Dental Clinic at the local Health Centre.

It is important that people who are HIV+ know how to obtain a dentist. If there is difficulty finding a local family dentist to treat someone who is HIV+, throughout the UK every District Health Authority has a District Dental Officer (sometimes called a Dental Services Manager) who will know a way of getting dental care. This care may be from a local family dentist or it may be a Clinic health Centre Community Dentist that can help, but the District Dental Officer should know. •

by Paul Kimberley

A season of mists and mellow fruitfulness, well I know about the mist, once a week usually, and the other one sounds like a yuppie drink. No seriously, I have realised what an important part the weather has to play in our lives, "such a lovely day", "hasn't the rain been bad recently".

We hear expressions like these so frequently now, they do tend to just wash over us, but when it's a clear sunny day I feel so much better inside, Opus 3 even had a chart success with *It's A Fine Day*, two years ago.

Perhaps it's our ignored animal instincts that dictate we should be more active in summer, and less so in winter. Yet I find it quite hard to sleep once it has got light in the morning. The birds sing like they were connected up to the stereo. Something deep inside says "go on, off you go then - get on with things", and I think "oh yes", and get down in the kitchen and the clock says it's 5.30 a.m. Still it's a good excuse to put the kettle on. I'll just mention to you about a related event.

Our water supply here in Canterbury has become very poor in quality recently. In the end I thought - I'm not putting up with this any longer, so I went out and brought a filter jug. Now at this point I should just tell you how sceptical I have always been about this type of product. The flashy salesman at our local department store told me to descale the kettle first, and I would never have to do it again. Well, I won't tell you exactly what I thought at that point, as I usually descale it every fortnight, but I did as he suggested.

We started using filtered water for hot drinks and cooking, and you know he was right. There is just no sign of anything on the kettle element. So I then started to think about what deposits were building up in the kettle, were also going in me! So there you have it, if you are not a convert already try it. No one could have been more doubtful about it than me, but drinks do taste different, and so do vegetables cooked in filtered water.

I don't wish to put the wind up you all, but I recently received two catalogues one from the P.D.S.A. and the other R.S.P.B. They were almost to the same format, only with different goods, but on the first few pages were the Christmas cards. Yikes thinks me, it's months until then, but as we all know time slips by so quickly, some days I sit trying to work out what day it is, thinking yesterday was Wednesday, and then I realise it's Friday, and Thursday just never happened!

Well it only remains for me to wish you a happy holiday if you have not had one yet. If you have then I hope you enjoyed it, and perhaps get the opportunity to manage another one. Oh yes, the grass cutter went after an electric wheelchair, it was love at first sight, so it's back to me cutting the grass again - yuk! You all out there take care now, and the new motto is :- be dazzling, be dynamic, be daring. •

LIVER DISEASE AND HIV

(continued from page 1)

THE FUNCTIONS OF THE LIVER

The liver has many critical functions including filtering blood, eliminating toxins, secreting bile (a fluid that helps absorb and digest fat), and making clotting factors. It also converts sugar into triglycerides (lipids) and glycogen (a carbohydrate) to be stored for energy and, between meals, converts triglycerides, glycogen and amino acids into blood sugar to meet the body's immediate energy needs.

The work of the liver is particularly critical to the brain and central nervous system. These tissues receive their energy supply only from sugar, and so are extremely vulnerable to liver failure.

DIAGNOSING LIVER DISORDERS

Various tests are available for persons with liver disorders. These include tests for liver function and viral hepatitis. Computerised tomography (the familiar "cat" or CT scan) and ultrasound may also frequently be useful.

Liver chemistry tests are an initial means for measuring the liver's condition. For example, high blood levels of bilirubin, formed by the breakdown of haemoglobin, indicate that the liver is not adequately transferring excess iron from the bloodstream to the bile, and this is a specific indicator of liver disease. High blood levels of two common liver enzymes involved in amino acid breakdown (AST and ALT, also designated as "SGOT" and "SGPT" in lab reports) are a sign of acute liver cell injury. Such damage to cell integrity allows these chemicals to escape from the cells and is associated with viral hepatitis and the toxic effects of drugs and poisons.

LIVER INFECTIONS

The majority of liver diseases in patients with HIV are caused by viruses (especially hepatitis B and hepatitis C) or opportunistic infections (MAC, cryptosporidiosis, CMV). Recent studies suggest that the liver is an important site of HIV replication, too. There have been well-documented cases of liver inflammation during primary HIV infection, the initial flu-like syndrome that often precedes seroconversion, and this is a strong indication that HIV attacks liver cells directly. •

editor - There will be an information sheet on this topic of Liver Disease and HIV available in the forthcoming months.

by Gerry Healy

When the first session was over, we broke for tea & coffee. After ten minutes we were asked to come back to the group. One of the organisers introduced our special guest. The man spoke with an English accent, he told us he had Aids and was from the Terrence Higgins Trust (THT) in London, the first charity to be set up for HIV & Aids. Then he went on to talk about his own life and how he became infected.

I could relate to everything that John said and I broke down and cried, I was the only other person in the group living with the virus. The next thing I knew there were many people around me and giving me support and a shoulder to cry on. When the tears stopped, a special worker held my hand.

There was a question and answer session, followed by more information on the THT. After listening to this man speak, I forgot about his sexuality and how he became positive. This was a man with the same virus I had, but I had not suffered any infections so far. John came over to me and gave me a hug. Then he gave me a crystal and said "keep on fighting".

Two social workers came to me; one was seeing some HIV haemophiliacs at St. James' Hospital and asked me if I would come up from Cork to meet some of her clients. I had already been supporting a number of HIV haemophiliacs with CARA. The other social worker was counselling positive people from all the high risk groups. He asked me if I would set up a support group like Body Positive. I told him I would give him my answer before the end of the month as I had to talk it through with my wife and dad.

My video business was not going well and I was under a lot of stress in Cork. I did not have many people to talk to. As I did not want to put any stress on my wife and dad, I held it all in and we had to give up the business soon. I had to make the right decision for myself and as I was still a director of the Irish Haemophilia Society, I knew I had to give up some of my commitments.

All this started to develop and change my life. I did a course in community development and counselling. In Dublin we set up a Body Positive Group. During this time I was active in setting up a Positive Haemophilia Group and approaching the solicitors to get our case started for compensation.

While this was going on, I met a priest, who was working in the HIV field in New York. He gave me great support and advice and made me look at myself. I discovered I had been running away from the family that loved me. Someday, I will write a bit more about the wonderful support I have received and my fight to give support to others. •

LETTERS TO THE EDITOR...

Dear Editor,

We are lucky to have a good Regional Haemophilia Centre at the Royal Free Hospital in Belfast, but of course it is left up to the individual to maintain a lifestyle conducive to continued well-being. Some of us have been in touch with similar groups with regard to alternative treatments. There is such an array of philosophies one finds it difficult to assess the pros and cons of all of them. To be truthful, of all the problems we have encountered, the curtailment of our alcohol intake due to HCV is the most galling. As we are sure you will be aware from the London Weekend we are rather fond of the odd pint.

To conclude we intend to pursue as normal an existence as possible allied with a positive approach to our condition and life in general.

Hopefully by the time we get together again we shall no longer be 'the three musketeers'. D'artagnan come on your time is up!

Neil Kerr, Colin Fitzsimmons, Birchgrove, NI.

IN DEFENCE OF THE OLD ORDER...

by Corey S. Dubin

What is the role of social workers in the haemophilia community? What are the boundaries that delineate between good support and advocacy work and paternalism and interference?

Why are so many social workers connected to the haemophilia community going such great length in defence of the "old order"? Using anger as the new method of keeping us down. With increasing regularity we hear things like, "you know he just doesn't handle his anger very well" or "isn't he suffering from aids dementia". Anger and dementia are the new currency for deligitimising those in the community demanding to know the truth about how and why so many were infected. In years past it was "That patient is too independent for his/her own good", "you know the type, they do not take direction from the "staff" very well". Always questioning and challenging and demanding alternative opinions.

One of the primary responsibilities of social workers is to validate the feelings of the client, not to find ways of invalidating the individual's feelings. Repeatedly we find social workers in our treatment centres projecting their own inability to cope with the devastation of aids onto the client, invalidating feelings of anger and abandonment regarding our infection with HIV.

The haemophilia treatment centre comprehensive care model raises serious questions about the role of social work. As part of the treatment centre comprehensive team, the social workers first responsibility is to the medical staff and not the client. This has set up a difficult situation for the social worker, and even worse conditions for the client. Over the years, I have seen a few very good professionals resign from treatment centres, because what they believed was in the best interests of the client ran counter to the opinions and needs of the medical staff. Ultimately, the social workers at treatment centres answer to the medical staff and not the clients.

Being a social worker in the haemophilia community should not be about power and privilege over those you are employed to assist. When providing support and advocacy becomes control over clients, bad things tend to occur. Individuals become invested with sustaining and protecting the medical system of power and control. For many in this community this exactly what is occurring all too often.

The old order is in the process of decay, the power relationships are changing and we have no intentions of returning to the shadows and going quietly. This I know from the bottom of my heart. Those working with this community must embrace and support the new vision, or step aside.

One model leads to disempowerment, and disaffection, ultimately reinforcing our dependence and a sense of powerlessness in this community. Our situation is that of a developing country experiencing the process of decolonisation. Not only must the colonial power be replaced. In this case the medical establishment and the drug companies, we must also decolonise our souls by reconstituting ourselves as empowered both as individuals and as a community in control of our own destiny. This is the external and internal dynamic we face and this is the challenge.

In stark contrast to the colonised model is a community based and controlled structure which fosters a sense of power, independence, and the ability of this community to self-identify both individually and collectively. For too many years we have only been defined as individuals and as a community by the social workers and the medical establishment.

For many in this community the first model was an important contributing factor to the reality we are currently experiencing. It has taken a decade for the community to begin the task of self-awareness and self-identification. We are now undertaking the development of an alternative model of social work that is conceptualised, implemented and controlled by persons with haemophilia and their families.

This new vision must be based on cooperation and partnership. We seek a cooperative partnership with medical/social professionals that are working in this community. One where we honour each others respective contributions to the well being of the whole community. Together we can begin to heal ourselves while developing and implementing structures and programs that directly speak to the needs and aspirations of our brothers, sisters, mothers and fathers.

With the kind permission of Corey Dubin
Sci Med Aids, coyoteradio@igc.apc.org, InterNet

MEDICAL NEWS *(cont. from page two)*

AMSTERDAM STUDY

(Journal of Infectious Diseases 1994;169:1236-43) In a study of long-term asymptomatics, the researchers in Amsterdam followed 61 HIV-positive men who remained asymptomatic for at least seven years and compared them with 142 men who progressed to AIDS. Long-term asymptomatic HIV infection was associated with high levels of antibodies to HIV core proteins and the absence of hepatitis B antibodies. No association with unsafe sex practices and recreational drug use was found. Additionally, a test given to measure levels of psychological coping found no association between such skills and slower disease progression.

Note: Life styles have recently been shown to have an affect upon the symptoms of those connected with HIV. (see *Controversy over poppers and Kaposi's sarcoma*, AIDS Treatment update, 20.)

THE USE OF CD4 COUNTS

British Medical Journal *Use of CD4 lymphocyte count to predict long term survival free of AIDS after HIV infection*, Andrew Phillips et al, 309, 309-13.

This paper by Andrew Phillips et al looks at a statistical model of predicting AIDS by extending the levels of CD4 counts from the date of infection to 23 years after seroconversion. It was done at the Royal Free Hospital with 111 people with haemophilia infected with HIV. From 1989, prophylaxis was given to 93 patients when their CD4 count fell below 200 x10⁶/l (13 had already been on the Concorde Trial). It comprised 57 treated with zidovudine (AZT), 40 with prophylaxis, against *Pneumocystis carinii* and 36 with fluconazole. As this was a statistical survey, AIDS was defined in the people as any CD4 count below 50 x10⁶/l. These CD4 markers were used to determine the start of AIDS.

"It is supposed to be a professional secret, but I'll tell you anyway. We doctors do nothing - we only help and encourage the doctor within."

Albert Schweitzer

THE CHALLENGE OF THE FUTURE

THE CONFERENCE OF THE BIRCHGROVE GROUP TO BE HELD AT THE
PICCADILLY HOTEL, MANCHESTER ON THE 26TH & 27TH NOV 94

The theme of the weekend is the Challenge of the Future, we believe that this will be an opportunity for people to meet and look at the important issues that we all share and are concerned about. We are also keen that the event should be informal and relaxed, with chances for people to enjoy themselves socially as well as to be involved in more serious issues and discussions.

During the weekend there will be several opportunities for people to meet and talk. There will be a range of discussion groups and people will be able to choose two topics which they are particularly interested in, and there will be a structured discussion involving everyone and focusing on the repercussions of HIV on the haemophilia community. There will also be a brief meeting to ensure the ongoing direction of the Birchgrove Group.

Throughout the weekend people will be linked with a "home group", which will offer a space for people to express their opinions and provide feedback about the subjects that are under discussion during the weekend. We hope that people will participate in and help to decide the direction of the weekend, and that people will very much take the opportunity to make this conference their own.

Founded in Spring 1987, the Birchgrove Group is now widely experienced in initiating, organising, and participating in mutual support for people with haemophilia and HIV. As a group we are rich, in the experiences of living, of loving, and of losing. Our determination to survive has carried us through extraordinary times - both good and bad.

"It is hard to impart my feelings, but no one would have believed that a weekend could change someone's life so dramatically and as much as the one you have just held did. It was an experience that I shall remember for the rest of my life."

A positive haemophiliac

"As a founder member, the benefits I have gained over the years are too many to mention. I really think the group has helped me to stay so healthy so long."

A positive haemophiliac

"The contagious infection of well-being that the group generates has given my husband a new-found energy and the will to fight this virus and win."

Wife of a positive haemophiliac

DISCUSSION GROUPS

Further details on these discussion groups will be available at the conference.

TREATMENT AS A CONCERN

A discussion reviewing the current medical approach to treating HIV, Hepatitis C and Haemophilia.

COMPLIMENTARY THERAPY

Exploring the partnership that complimentary therapies can have with traditional medical methods of treatment.

DISABLED, WHO ME?

Looking at the relationship that we all have with the image of disability.

CLOSED GROUPS

Sharing experiences to explore the situations that we all are facing.

SPEAKING OUT

Forced to keep silent on issues that are central to our lives. How do we make our voice heard?

TELLING OUR STORY

A chance to contribute to a project that will record the recent history of our community.

SHOULD LIFE BE FAIR?

Looking at our rights to an equal position in society.

I am interested in attending the Birchgrove Conference, at the Piccadilly Hotel, Manchester on the 26th & 27th of November 1994.

Please send me further information about the Birchgrove Group. I wish to attend the conference "The Challenge of the Future".

Name:

Address:

.....Postcode:

I will require: Single Room/s Twin Room/s Double Room/s Family Room/s (all rooms are en-suite with bath/shower)

Special requirements (vegetarian/wheelchair/other) :

I enclose a cheque for £ Finalised details will be sent as soon as they are available.

FOR FURTHER INFORMATION WRITE TO: THE BIRCHGROVE GROUP • PO BOX 313 • CANTERBURY • KENT CT1 1GL
OR TELEPHONE: (0345) 697231 LO•COST